Title

"It's Case by Case, and It's a Struggle": A Qualitative Study of Hospice Practices, Perspectives, and Ethical Dilemmas When Caring for Hospice Enrollees with Full-Code Status or Intensive Treatment Preferences

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"It's Case by Case, and It's a Struggle": A Qualitative Study of Hospice Practices, Perspectives, and Ethical Dilemmas When Caring for Hospice Enrollees with Full-Code Status or Intensive Treatment Preferences

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Abstract

Objective: Characterize hospice staff practices and perspectives on discussing end-of-life care preferences with patients/families, including those desiring intensive treatment and/or full code.

Background: Patients in the United States can elect hospice while remaining full code or seeking intensive interventions, for example, blood transfusions, or chemotherapy. These preferences conflict with professional norms, hospice philosophy, and Medicare hospice payment policies. Little is known about how hospice staff manage patient/family preferences for full-code status and intensive treatments.

Methods: We recruited employees of four nonprofit US hospices with varying clinical and hospice experience for semi-structured, in-depth interviews. Open-ended questions explored participants' practices and perceptions of discussing end-of-life care preferences in hospice, with specific probes about intensive treatment or remaining full code. Interdisciplinary researchers coded and analyzed data using the constant comparative method.

Results: Participants included 25% executive leaders, 14% quality improvement administrative staff, 61% clinicians (23 nurses, 21 social workers, 7 physicians, and 2 chaplains). Participants reported challenges in engaging patients/families about end-of-life care preferences. Preferences for intensive treatment or full-code status presented an ethical dilemma for some participants. Participants described strategies to navigate such preferences, including educating about treatment options, and expressed diverse reactions, including accepting or attempting to shift enrollee preferences.

Discussion: This study illuminates a rarely studied aspect of hospice care: how hospice staff engage with enrollees choosing full code and/or intensive treatments. Such patient preferences can produce ethical dilemmas for hospice staff. Enhanced communication training and guidelines, updated organizational and federal policies, and ethics consult services may mitigate these dilemmas.

Keywords: advance care planning; bioethics; ethics; hospice; hospice and palliative care nursing; mortality; palliative care; prolongation of life; resuscitation orders

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Introduction

IN HOSPICES across the United States, a substantial proportion of enrollees elect full code or intensive medical interventions (e.g., blood transfusions, chemotherapy, total parenteral nutrition [TPN]). Estimates of the prevalence of non-do not resuscitate (DNR) status among recipients of the Medicare Hospice Benefit (MHB) range from 13% to 20%.[1–3] One study estimated that 20% of patients discharged live from hospice do so specifically to resume disease-directed treatment.[4] While speculative, this suggests up to 200,000 of the ~1.5 million Medicare beneficiaries receiving hospice annually may have full code or intensive treatment preferences.[5]

The provision of intensive treatment in hospice arises from professional and federal efforts to serve diverse enrollee preferences and disease types[6–9] and accords with an essential hospice tenet (preference-aligned care). Nevertheless, many consider CPR and intensive treatment as deviations from hospice's historic focus on comfort care.[10] Hospice organizations and clinicians have adjusted their practices with little policy guidance amidst increasing payment restrictions.[1,11–14] Permitting full code and intensive treatments may therefore have resulted in clinical, organizational, financial, and ethical challenges[15] for hospice employees.

Little research explores how hospice clinicians and staff discuss end-of-life preferences or care for patients/families who remain full code or seek intensive interventions. This article reports findings from a qualitative study of hospice employees regarding their practices of engaging patients/families in these discussions.

Materials and Methods

Design

We conducted a qualitative, descriptive, multisite study[16] of how clinicians elicit patient/family goals and values for hospice care and changes in these practices over time. Methods, summarized below in accordance wiht SRQR guidelines, have been described in detail elsewhere.[17] Feedback from a community advisory group of nonparticipating hospice stakeholders and methodologic experts within the Palliative Care Research Cooperative (PCRC)[18] informed study design and interview guides. The University of California San Francisco IRB reviewed this study and determined it exempt.

Participants

Sites. Nonprofit community-based PCRC-affiliated hospices were eligible. Sites were selected using a criterion sampling strategy[20,21] based on geographic diversity and nonprofit status. The first four recruited sites agreed to participate; each received $500 after data collection. *Individuals:* Seventy-one individuals were recommended for recruitment based on criterion sampling.[19,20] Eligible hospice staff were clinicians, leaders, and quality improvement experts. Data collection concluded at a site when at least 12 individuals had been interviewed and the sample reflected a range of clinical experience, hospice experience, and positions. Fifty-one employees (72%), evenly split across sites, participated (4 declined and 16 did not respond): 61% were clinicians, 25% executive leaders, and 14% administrative staff. Participants with clinical backgrounds included 23

nurses (RN), 21 social workers (SW), 7 physicians (MD), and 2 chaplains; two had multiple degrees/disciplines. Eighty-six percent were non-Latinx white and 80% were female.

Data collection

Data collection occurred in 2016. The interviewer (K.L.H.) had doctoral-level training in qualitative research and familiarity with hospice from prior employment in nonprofit hospice leadership. K.L.H. visited each site and conducted semistructured in-depth interviews.[19] All participants consented verbally. Interview domains emanated from the Theory of Domains Framework[21–23] to understand stakeholder behavior. Questions addressed: (1) capability, opportunity, and motivation to facilitate end-of-life care conversations; and (2) professional opinions about end-of-life care conversations and changes in practice over time. Based on early themes, later interviews probed about intensive treatment and full-code status (e.g., whether approaches to discussions have changed to accommodate patients' ''diverse preferences, like being full code''). Interviews were recorded, redacted, and notes/transcripts returned to participants for clarification; participants made no changes. Mean interview length was 49 minutes.

Data analysis

The team employed the constant comparative method,[24] an approach based on iterative comparisons within and between analytic cases that is well-suited to investigate and develop theories about complex phenomena. Members of the interdisciplinary research team independently reviewed the data and identified elements relevant to end-of-life care conversations. They next created preliminary codes, evaluated code adequacy in 25% of the data, and further refined the code set. One investigator then coded the full dataset in ATLAS.ti version 8.[25] Data relevant to code status or intensive treatment were coded separately unless both terms were mentioned explicitly by participants, in which case those data were double coded. Ambiguous cases were resolved through discussion. The team iteratively reviewed and discussed the coded data to identify key concepts and patterns; they evaluated and refined findings through discussion, analytic memoing,[26] and comparisons across and within respondent type.[20] The team documented an audit trail of methodologic and analytic decisions. Interview data citations below refer to ''s,'' data collection site number; ''p,'' participant number; and participant role and/or discipline, for example, leader.

Results

Across all four sites, participating hospice staff described their organizational context and practices for discussing end-of-life care preferences with patients/families. All sites were founded in the 1970's, had free-standing inpatient units, employed formal processes to document preferences on admission, trained staff in advanced care planning conversations, and accepted full-code patients. Three themes emerged regarding staff practices and attitudes. First, participants encounter challenges when engaging in these conversations, including supporting patients who are full code or prefer intensive treatment. Second, participants use specific

strategies to engage patients/families with these preferences. Third, participants describe varying reactions to preferences for intensive treatment or remaining full code. Although these themes often overlapped in practice, we describe them as conceptually distinct phenomena here.

Challenges encountered during end-of-life care conversations in hospice and resulting ethical dilemmas

Participants frequently referenced challenges inherent to discussions about end-of-life preferences (Table 1). Many participants emphasized concern about upsetting patients/families by initiating discussion of end-of-life care prefer-

ences too quickly, too often, or at the wrong time, and thereby unintentionally "squelch[ing] somebody's hope" (site 2, participant 33, role as QI administrator with RN training). Similar hesitation stemmed from participants' own discomfort discussing death and fear of affirming the misconception that hospice is "the death squad" (s3-p9-clinician-SW). Participants also acknowledged that patients/families were often unprepared for these conversations despite being on hospice, and were reticent to discuss death and dying: "As a new nurse and with my ideas of hospice, I was really looking forward to talking about death… By and large, my experience has been that most patients and certainly some family members are not interested… It's too intimate, too close, too hot" (s4-p43-clinician-RN).

TABLE 1. CHALLENGES INHERENT TO DISCUSSING END-OF-LIFE CARE
PREFERENCES IN HOSPICE AND RESULTING ETHICAL DILEMMAS

Factors contributing to patient/family avoidance of conversations about end-of-life care preferences	**Inadequately prepared by community physicians:** Sometimes, when we get patients, believe it or not, the doctors have not been completely up front with them about their prognosis… Maybe they think the patients understand when they're referred to hospice that that means they have six months or less, but sometimes, people are kind of surprised by that. It doesn't happen often, but it does happen sometimes. So I think those tough conversations need to be started in their doctor's office sometimes a little bit more clearly than they are. (s1-p19-clinician-RN)
	Personal discomfort with discussing death: I feel like it's… that "if I talk about it, it will come true" kind of mentality that we seem to have here in [redacted - geographic area], and if we don't talk about things, that's our way of coping. (s2-p36-clinician-RN)
	Patient/family disagreement about treatment: You could kind of pick up on the tension in a family. If they felt okay [about discussing wishes], we would advise them, "You need to do these things while you're still able." But if you walked in and saw a family where the dynamics were really difficult, that there might be somebody who comes out of town at the last minute and wants this done, that done, we would really strongly encourage that they take care of that advance care planning so that their wishes were honored. (s1-p15-QI-SW)
	Cultural aversion: We also culturally don't go there [*i.e.* talk about end-of-life care preferences]. So we don't have even the language necessarily, sadly, to have these conversations in an [effective manner]. (s4-p43-clinician-RN)
	Misconceptions about hospice: A lot of people in the community still think we have to be a do not resuscitate in order to have hospice. And so, educating the community that they don't have to be DNR, I think that is probably a strongly held misperception, that you have to be a DNR to be on hospice. (s1-p19-clinician-RN)
Clinician concern about upsetting patients	I think each of us tries to judge accordingly. Is this a good time? Are they open to this conversation? How much more can I ask or inquire? We don't want to push… I think the other barrier is emotionally, people are not always prepared to do it. (S3-p10-clinician-sw)
Clinicians' discomfort discussing death	[Barriers to having conversations include] their [clinicians'] own personal comfort level. I really feel like you have to be comfortable. Not that you're like, "Oh, I feel so comfortable about dying," but you have to know what you think, and… you have to believe that people have the right to choose. (s2-p36-clinician-RN)
Patient preferences for intensive treatment and/or remaining full code	The other thing that I think has really impacted hospice is there are more complex treatments, there is more technology, there's a lot more people who have LVADs [left ventricular assist devices], there's a lot of people who maybe on dialysis, there's a lot of people who are on different kind of therapies that they may not be equipped to deal with, with hospice. So I think that's challenging the industry as well. So, again, I think it takes a good skill-set to be able to navigate that with patients and families. (s1-p24-leader-MD)
Ethical dilemma between respecting patient/family choices, avoiding harm, and alleviating suffering	It's a moral dilemma for them [hospice staff]. So every couple years—it just went to ethics about two years ago. There were staff that wanted to say they couldn't come into the [inpatient] unit if they weren't a DNR, and between the ethics committee's suggestions and my own it's like "No, because that's a lot of where the deep work of hospice is done." If you say no then that person probably is going to 911 and end up dying on a vent in a unit hooked up to everything versus if we get them in there and we start the conversations they might change their mind what their end of life looks like. (S3-p2-leader-APN)

Patient/family preferences for full-code status or intensive treatment presented a significant challenge. One nurse reflected, ''I think the DNR and full code is the hardest thing for me… a lot of patients feel like if they sign that they're giving up'' (s3-p11-clinician-RN). Intensive treatments discussed by participants included: TPN, blood transfusions, intravenous fluids and antibiotics, chemotherapy, radiation, and left ventricular assist devices. One participant said that clinicians have to consider whether these treatments ''are enhancing [patients'] quality of life or just prolonging basically the inevitable'' (s3-p12-clinician-SW). Another emphasized the difficulty of making such a determination: ''There's people where radiation for pain makes sense to improve their quality of life, and it's not extending their life… So we do cover those things. But again, it's case by case, and it's a struggle'' (s2-p27-leader-MD). Participants described that patients and families sometimes disagreed about which intensive treatments were appropriate. Among patients/families who remained full code, a subset did not want CPR but would not consent to a DNR. One clinician noted that, ''they [patients/families] just can't seem to bring themselves to sign that paper'' (s3-p14-clinician-SW).

Some participants were challenged with ethical dilemmas when engaging with enrollee preferences for intensive treatment or being full code. Participants noted tension between three goals: respecting patient/family choices, avoiding harm, and alleviating suffering. A social worker explained, ''I think hospice will always, it seems, have a vested interest in wanting to see DNRs in homes… Our goal is to never sway someone, but I think that we would always hope, knowing that this person is going to take a last breath with us, that they would not want CPR performed. But again, if it is their wish to do so, we will honor that'' (s1-p15-QI-SW). To some participants, upholding one ethical obligation (e.g., respecting patient/family wishes for intensive treatment) would violate another (e.g., avoiding harm). This caused some clinicians distress: ''Our clinicians struggle the most when families and patients make decisions that [providers] can see are physically hurting them: doing tube feedings or PEGs [percutaneous endoscopic gastrostomy tubes] or IVs or TPN—things that the burden is more than the benefit'' (S3-p2-leader-APN). Others anticipated distress: ''It's never happened to me, and I would never want it to, but I would hate to get called out to a house and end up having to perform CPR on a patient that's dying and frail… I mean, that would be traumatic'' (s2-p35-clinician-RN).

Strategies to discuss end-of-life preferences, including intensive treatment or remaining full code

Across all sites, participants reported ''meeting patients where they are'' as their general approach to discussing end-of-life preferences: ''We try to meet them where they're at, compromise a little bit, find a middle ground, you know, in terms of interventions that wouldn't be harmful and may be beneficial'' (s3-p1-leader-MD). Additional general strategies included receiving training in advance care planning and communication, building rapport and trust, assessing patient understanding, communicating honestly, and relying on interdisciplinary teamwork (Table 2).

Participants also described specific strategies to engage patients/families who prefer intensive treatment or full-code status (Table 3). The first such strategy involved educating about treatment options, including clarifying misconceptions

TABLE 2. GENERAL STRATEGIES TO DISCUSS END-OF-LIFE CARE PREFERENCES IN HOSPICE

Meeting patients where they are	I may have been through this 25, 100 times, and I might already know the outcome before they ever get to it, but we have to always default back to where they are and know that we've got to walk this walk with them instead of 100 miles ahead where we already are because we've seen it happen over and over and over. (s1-p15-QI-SW)
Receiving training in advance care planning and communication	Physicians, PAs, [and] nurse practitioners all attend our [redacted—course name]. And a big part of that course is communication skills, and how do we talk about hospice, how do we talk about code status, how do we talk about advance care planning, how do we talk about discontinuation of aggressive treatment? (s1-p21-clinician-MD)
Building rapport and trust	We have to gain their trust and build a rapport. So once they start trusting you… and you collaborate with their physician, who they've had for years, they start making decisions. They start coming around. (S3-p14-clinician-sw)
Assessing patient understanding	I really like to start with what do people understand about their illness, and do they understand that it is a progressive illness… what is their quality of life now, is that acceptable to them, are there ways that they would want their quality of life improved. (s2-p31-clinician-SW-RN)
Communicating honestly	We really work hard to establish open and honest communication. I tell them from the very beginning, ''I cannot always tell you what you want to hear, but I will never lie to you. I promise to always tell you the truth.'' (s1-p20-clinician-SW)
Relying on interdisciplinary teamwork	I find that that works best because then you can kind of work together to tease things out and there's different perspectives, different ideas, different personalities, people respond differently, too, so I like to do joint visits with my social workers and have those discussions together. If I were to approach a conversation like that with a patient and they weren't receptive to it, I might say, ''Can you give this a try? I'm not getting anywhere.'' (s2-p35-clinician-RN)

TABLE 3. SPECIFIC STRATEGIES TO ENGAGE PATIENTS/FAMILIES WHO PREFER INTENSIVE
TREATMENT OR REMAINING FULL CODE

Educating about treatment options	**Clarifying misconceptions about DNR orders:** DNR doesn't mean "do nothing." It doesn't mean that we don't treat you or care about you or treat infections. That's one of the things we hear a lot, is people think that it means that you won't give me antibiotics, or if I fall and break something you won't send me to the hospital, and what it really means is we have a conversation about that. (s1-p17-leader) **Educating about likely outcomes of intensive treatment:** People get also very freaked out about the whole nutrition/hydration thing. "Are we starving her to death?" … Just talking about, "Research has shown that dehydration is not uncomfortable…" [Families have] never really heard that before, and that hydration often can be uncomfortable and that [with parenteral nutrition] we're putting food into a tissue that can't bear the burden. (s2-p36-clinician-RN) **Educating about likely outcomes of CPR:** We know that that patient has come to us because he or she is dying, and at the end of the day when they take their last breath the thought of them having something happen that they don't want to happen just is a haunting feeling… We would love for people to truly be educated on that DNR, what it means to have CPR done, and [the outcome of that is] not what you want. (s1-p15-QI-SW)
Using graphic language to describe intensive treatment and CPR	**Employing graphic language:** I talk a lot about what it looks like in a code situation and the fact that in my experience, not many people come out the other side the same and then again, that disease process is still going to be there. So I've had several people tell me, "Well when you put it that way, of course I don't want to do that," you know what I mean, so it's kind of like I'm pretty brutally honest about rib fractures, lung punctures, lacerated livers, I've seen them all in my experience. (s4-p40-clinician-RN) **Rejecting graphic language:** Approaching it [end-of-life care conversations] with a lot of compassion, empathy and listening and clarifying [the] conversation [works well]. It seems like to the flip side of that, we sometimes would be told, "Well, they haven't signed the DNR. Do they realize what's going to happen? That there's going to be chest compressions and broken bones," and that said in that way never seems to work, really. (s4-p45-clinician-CP)
Leveraging physicians' perceived authority	They call me [a physician] the patient whisperer. So, they kind of call me in when things have really stymied down… I see the really difficult cases, so to speak. The ones where patients want to continue to get G tube feedings or IV fluids or continue stuff that's high intervention or want to be full code despite the fact that they're about to die tomorrow. (s4-p44-clinican-MD)
Regularly revisiting conversations with full-code patients but not those who signed a DNR	**Without DNR:** If I were in a home and I talked with the family and they were adamant that they did not want to discuss the DNR, I would typically leave it at that point, because if they're not in an okay place I'm not going to push that with them. And my experience was that typically, later on it was okay to broach that topic again, but the team would keep that top of mind with that patient, because those who don't have DNRs we always cringe a little in knowing what we've seen as the outcome when that happens. (s1-p15-QI-SW) **With DNR:** Certainly, if they are already a DNR … I really don't bring it up except maybe as an initial asking about their preferences… they're sort of already aligned with their goals of care, hospice goals of care, then we may not revisit that particular issue. (s4-p48-clinician-SW)
Relying on organizational structures	**Interdisciplinary team meetings:** [Nurses] send a list to the team. Who is a full code on this team? They talk about it in IDT. They help facilitate IDT. They pull up and put up the care plan right there electronically so that the team can see, and we address issues right away. (s2-p29-leader-RN) **Policies limiting CPR:** We don't have the crash carts here. We don't have ventilators. We're not going to be doing those aggressive measures. So the majority of patients need to be a DNR to come over to the [inpatient unit], but we don't exclude patients that want to be a full code. They just have to understand we won't provide CPR. We won't do anything. (S3-p12-clinician-SW)

about DNR orders: "If you get a UTI, we're going to treat you. If you get pneumonia, if you elect it, we will treat you… People confuse do not resuscitate with do not treat" (s1-p20-clinician-SW). Some participants sought to inform patients/families about the likely outcomes of intensive treatment and CPR: "You have to educate the family that you really don't do just a few compressions, and you just don't put them on a ventilator for two hours… [You] discuss the disease progression and the outcome of emergency measures" (s3-p13-

clinician-RN). Often such education was without agenda; other times, clinicians aimed to convince patients/families to adopt DNR status.

This was evidenced in a second strategy employed by a subset of participants: using graphic language to describe CPR and intensive treatments. One clinician explained, "Discussions get very, very blunt with folks because they don't always understand that word resuscitation. And we use terms such as, 'someone will pound on your chest when your

heart stops''' (s2-p34-leader-RN). Other participants disagreed about the efficacy of this approach.

Additionally, participants reported leveraging physicians' perceived authority if conversations about being full code stalled: ''we'll have our doctor help… They seem to have a little bit more influence'' (s1-p23-clinician-sw). Another strategy involved revisiting end-of-life care conversations ''quite frequently'' with full code patients/families, but not with those who had signed a DNR (s3-p13-clinician-RN). A nurse explained, ''We have an obligation to give them the information… and help them see why it doesn't make any sense [to continue treatment]. The ultimate choice is theirs, but… we should be revisiting that, and the frequency depends on what the treatment choice is'' (s3-p5-QI-NP).

Finally, where available, hospice staff relied on organizational structures to navigate patient/family preferences for intensive treatment or remaining full code. These structures included interdisciplinary team meetings, ethics committees, and organizational policies (e.g., prohibiting hospice clinicians from calling 911 or requiring DNR orders for admission to an inpatient hospice unit). One participant described, ''It's in our brochure, our entrance guide to the [inpatient unit]… 'You have the right at any time to change your mind and want to be resuscitated and have 911, and you can come in without a DNR, but we will not provide that service on-site''' (s3-p2-leader-APN). However, such organizational policies and structures varied across sites.

Reactions to patient/family preferences for intensive treatment or remaining full code

Preferences for receiving intensive treatment or being full code while on hospice elicited three reactions from participants: (1) accepting preferences; (2) attempting to shift preferences; and (3) hoping that preferences would change (Fig. 1).

First, many participants described accepting patient/family preferences: ''If somebody wants everything, you have to uphold that… that's not for us to determine'' (s2-p36-clinician-RN). Some participants accepted these preferences to allow [patients/families] ''the humility of their own process, whatever that might look like'' (s1-p15-QI-SW). Others spoke to the importance of delivering preference-aligned care to avoid ''severing'' the patient/clinician relationship (s3-p9-clinician-SW).

Second, some participants explicitly desired to shift patient/family preferences away from intensive treatment or full-code status. One participant framed this effort as preventing anticipated harms: ''a lot of times, it's convincing families that… high flow rate IV fluids… are not conducive

to comfortable dying'' (s3-p1-leader-MD). Another suggested that intensive treatments and CPR are inappropriate in hospice: ''If you're on hospice, the understanding is that this is a time when you don't want aggressive treatment… Sometimes we have to help the family make that transition to realize that really what we want is comfort, that medicine is done'' (s2-p28-clinician-SW). One participant characterized shifting preferences as a professional duty: ''Our staff do back off a little too easily from having conversations… You do have an obligation as a professional… to help people move along even if they don't want to when it's very clear what's going to happen'' (s3-p5-QI-NP).

A third reaction involved hoping that patients/families would change their preferences. This more subtle position represented neither complete acceptance nor active efforts to change patients'/families' minds. One participant explained, ''We really hope when people come on as a full code, that we are able to at some point help them see the light'' (s4-p40-clinician-RN). Others described tension between hoping to keep patients out of the hospital and honoring patient/family preferences for intensive treatment or full-code status.

Discussion

In this study, participants reported challenges in discussing end-of-life care preferences in hospice, including patient/family preferences for intensive treatment and remaining full code. Participants sought to balance respecting patient/family wishes, avoiding harm, and alleviating suffering. Yet, their accounts—which raised similar concerns across sites—revealed tension between these goals, ethical dilemmas, and sometimes moral distress. Our data demonstrate conflict between three components of the hospice philosophy: (1) honoring patient/family wishes for CPR and/or intensive treatments (respect for persons), (2) promoting comfort-focused care in line with the hospice philosophy (beneficence), and (3) avoiding harm and relieving suffering by mitigating negative consequences of CPR or intensive treatments (nonmaleficence).

Our data suggest that this clinical ethical dilemma may stem from changes in US hospice policy and culture over time.[11] While the MHB requires enrollees to forgo ''curative'' treatment to elect hospice care,[7,27] the shifting evidence regarding what can be palliative (e.g., radiation and dialysis, formerly primarily perceived as curative but now recognized to alleviate distressing symptoms) blurs what may be hospice appropriate. Evolving economic incentives (i.e., capitated rates that must cover all costs associated with terminal prognosis[28]) further impact how
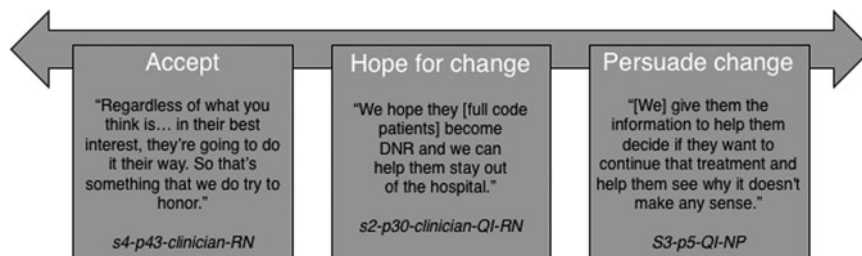
FIG. 1. Reactions to patient/family preferences for intensive treatment or remaining full code.

organizations advise clinicians to consider expensive treatment preferences. Although the Patient-Self Determination Act[12] prohibits discrimination based on directives,[1] many participants described DNR as the unspoken preference of hospice clinicians. Yet, patients and families may associate DNR status with abandonment and death, versus aligning CPR with treatment and life, creating a fundamentally false choice.[29] This is complicated by the way that contemporary US medical culture positions intensive treatment as the "default" at the end of life,[30] and that hospital culture and policies influence physician trainees' recommendations about DNR orders.[31,32] Our results suggest that such cultural trends may be infiltrating hospice, despite its philosophical origin as a counter-culture backlash against intensive end-of-life care.[7]

Our findings have clinical implications for hospice clinicians and referring providers. Lack of policy guidance about whether hospices must or may accept potential enrollees preferring full code and intensive treatments may contribute to confusion and cause eligibility[33] and care inconsistencies across organizations.[34,35] Electing full code while on hospice could suggest poor communication concerning the scope of hospice care and the likely inefficacy of CPR once hospice eligible.[1] Improved communication before, during, and after hospice referral could help inform patients', families', and hospice providers' expectations for care.

Hospice stakeholders need additional information and training about supporting patients, families, and clinicians in discussions of preferences. First, we need to understand how preferences for full code or intensive treatments impact hospice patients/families. Limited studies suggest that younger patients, those without advance directives, and patients of color—particularly African Americans[36]—are more likely to revoke their hospice benefit to pursue life-prolonging treatment[4] or to be discharged alive after enrolling in hospice as full code.[1] Research is needed to inform models of care that equitably support high-quality end-of-life care for all people. Additionally, we need a comprehensive evaluation of how intensive treatment and CPR in hospice may impact moral distress or burnout among clinicians[37] and how economic forces—including the entry of for-profit hospices into the US market[38]—may shape these issues.

Strengths and limitations

This study has several strengths. Experienced researchers employed a method appropriate to explore and characterize an underresearched phenomenon. Study design and data analysis were crafted by individuals with substantial knowledge of hospice and palliative care, hospice policy, preference-aligned end-of-life care, and bioethics. Numerous approaches enhanced rigor and trustworthiness (community advisory group, member checking, audit trail, double-coding). This study presents one of the first descriptions of how hospice stakeholders approach and react to preferences for full code or intensive treatments.

The study also has limitations. Our findings may differ from for-profit, rural, or international hospices. Additionally, intensive treatment and remaining full code were one of multiple topics addressed. The research team did not uniformly probe whether participants' use of aggressive treatments included CPR when participants did not specify. Future studies may discover additional nuance, particularly around differences between full code as compared with intensive treatment preferences.

Conclusion

This study offers insight about challenges of discussing end-of-life preferences, including intensive treatment or full-code status, in hospice. Participants depicted ethical dilemmas between respecting patient/family wishes, avoiding harm, and alleviating suffering, which enhanced the difficulty of providing preference-aligned care. Hospice clinicians currently engage with this dilemma on an individual, *ad hoc* basis. Additional ethics training and organizational structures may be helpful, but they cannot resolve systemic conflicts between hospice philosophy and current payment and policy structures. Our findings help clarify contemporary hospice practice, inform future scholarship, and identify opportunities to better support hospice clinicians and organizations.

Authors' Contributions

G.D.: contributed to analysis and interpretation of the data, drafting of the article, and critical revision of the article for important intellectual content. S.B.G.: contributed to analysis and interpretation of the data, drafting of the article and critical revision of the article for important intellectual content; and study supervision. L.J.H.: contributed to interpretation of the data and critical revision of the article for important intellectual content. N.T.: contributed to analysis of the data and critical revision of the article for important intellectual content. K.M.: contributed to analysis of the data and critical revision of the article for important intellectual content. R.L.S.: contributed to study concept and design; interpretation of the data; and critical revision of the article for important intellectual content. C.S.R.: contributed to study concept and design; interpretation of the data; and critical revision of the article for important intellectual content. K.L.H.: secured funding; led study concept and design; collected data; and contributed to analysis and interpretation of the data, drafting of the article and critical revision of the article for important intellectual content, and study supervision.

Research Ethics and Patient Consent

The University of California San Francisco IRB reviewed this study and determined it exempt. All study participants verbally affirmed informed consent.

Data Management and Sharing

Study data will be made available on the Qualitative Data Registry (QDR; https://data.qdr.syr.edu). The sponsor of this study (PCRC) is currently developing guidance

on preparing data for deposit. Interested parties who wish to inquire about data access before it is available from QDR may contact the corresponding author directly.

Author Disclosure Statement

No competing financial interests exist.

Supplementary Material

Supplementary Data
SRQR Guidelines

References

1. Ankuda CK, Fonger E, O'Neil T: Electing full code in hospice: Patient characteristics and live discharge rates. J Palliat Med 2018;21:297–301.
2. Caffrey C, Sengupta M, Moss A, et al.: Home health care and discharged hospice care patients: United States, 2000 and 2007. Natl Health Stat Report 2011:1–27.
3. Resnick HE, Hickman S, Foster GL: Documentation of advance directives among home health and hospice patients: United States, 2007. Am J Hosp Palliat Care 2012; 29:26–35.
4. Russell D, Diamond EL, Lauder B, et al.: Frequency and risk factors for live discharge from hospice. J Am Geriatr Soc 2017;65:1726–1732.
5. National Hospice and Palliative Care Organization: NHPCO Facts and Figures: Hospice Care in America. https:// www.nhpco.org/wp-content/uploads/2019/07/2018_NHPCO_ Facts_Figures.pdf. 2018. (Last accessed July 8, 2020).
6. Buck J: ''From Rites to Rights of Passage'': Ideals, politics, and the evolution of the American Hospice Movement. In: Kirk TW, Jennings B (eds): *Hospice Ethics: Policy and Practice in Palliative Care*. New York, NY: Oxford University Press, 2014, pp. 13–34.
7. Mor V, Teno JM: Regulating and paying for hospice and palliative care: Reflections on the Medicare Hospice Benefit. J Health Polit Policy Law 2016;41:697–716.
8. Carlson MD, Barry C, Schlesinger M, et al.: Quality of palliative care at US hospices: Results of a national survey. Med Care 2011;49:803–809.
9. Carlson MD, Morrison RS, Bradley EH: Improving access to hospice care: Informing the debate. J Palliat Med 2008; 11:438–443.
10. Friedman T: Inpatient hospice care: Organizational and ethical considerations. In: Kirk TW, Jennings B (eds): *Hospice Ethics: Policy and Practice in Palliative Care*. New York, NY: Oxford University Press, 2014, pp. 163–180.
11. Harrison KL, Connor SR: First Medicare demonstration of concurrent provision of curative and hospice services for end-of-life care. Am J Public Health 2016;106:1405–1408.
12. Patient Self Determination Act: H.R.4449, 101st Congress (1990).
13. Aldridge MD, Bradley EH: Epidemiology and patterns of care at the end of life: rising complexity, shifts in care patterns and sites of death. Health Aff (Millwood) 2017;36: 1175–1183.
14. Thorns AR, Ellershaw JE: A survey of nursing and medical staff views on the use of cardiopulmonary resuscitation in the hospice. Palliat Med 1999;13:225–232.
15. Beauchamp TL, Childress JF: Moral norms. In: *Principles of Biomedical Ethics, 8th ed.* New York, NY: Oxford University Press, 2019, pp. 1–29.
16. Rendle KA, Abramson CM, Garrett SB, et al.: Beyond exploratory: A tailored framework for designing and assessing qualitative health research. BMJ Open 2019;9:e030123.
17. Harrison K, Allison T, Garrett S, et al.: Hospice staff perspectives on caring for people with dementia: A multi-site, multi-stakeholder study. J Palliat Med 2020;23:1013–1020.
18. Ritchie CL, Pollak KI, Kehl KA, et al.: Better together: The making and maturation of the Palliative Care Research Cooperative Group. J Palliat Med 2017;20:584–591.
19. Creswell J: *Qualitative Inquiry and Research Design: Choosing among Five Approaches, 2nd ed.* Thousand Oaks, CA: Sage Publications, 2006.
20. Miles M, Huberman A: *Qualitative Data Analysis: An Expanded Sourcebook, 2nd ed.* Thousand Oaks, CA: Sage Publications, Inc., 1994.
21. Michie S, Johnston M, Abraham C, et al.: Making psychological theory useful for implementing evidence based practice: A consensus approach. Qual Saf Health Care 2005;14:26–33.
22. Michie S, van Stralen MM, West R: The behaviour change wheel: A new method for characterising and designing behaviour change interventions. Implement Sci 2011;6:42.
23. Michie S, Atkins L, West R: *The Behaviour Change Wheel Book—A Guide To Designing Interventions*. Great Britain: Silverback Publishing, 2014.
24. Boeije H: A purposeful approach to the constant comparative method in the analysis of qualitative interviews. Qual Quant 2002;36:391–409.
25. ATLAS.Ti [Computer Program]. Scientific Software Development GmbH, Version 8, 2010.

26. Yin RK: *Case Study Research: Design and Methods, 4th ed.* Thousand Oaks, CA: Sage Publications, Inc., 2009.

27. Centers for Medicare & Medicaid, Department of Health and Human Services: Code of Federal Regulations PART 418—HOSPICE CARE [Internet]. 418 October 1, 2018. https://www.govinfo.gov/content/pkg/CFR-2018-title42-vol3/xml/CFR-2018-title42-vol3-part418.xml (Last accessed July 8, 2020).

28. FY 2018 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements: In: Services CfMaM, ed. https://www.federalregister.gov/documents/2017/05/03/2017-08563/medicare-program-fy-2018-hospice-wage-index-and-payment-rate-update-and-hospice-quality-reporting (Last accessed July 8, 2020).

29. Gillick MR: Cardiopulmonary resuscitation in hospice. In: Kirk TW, Jennings B (eds): *Hospice Ethics: Policy and Practice in Palliative Care*. New York, NY: Oxford University Press, 2014, pp. 209–222.

30. Dzeng E, Dohan D, Curtis JR, et al.: Homing in on the social: System-level influences on overly aggressive treatments at the end of life. J Pain Symptom Manage 2018;55: 282–289 e281.

31. Dzeng E, Colaianni A, Roland M, et al.: Influence of institutional culture and policies on do-not-resuscitate decision making at the end of life. JAMA Intern Med 2015;175: 812–819.

32. Cardona-Morrell M, Kim J, Turner RM, et al.: Non-beneficial treatments in hospital at the end of life: A systematic review on extent of the problem. Int J Qual Health Care 2016;28:456–469.

33. Vig EK, Starks H, Taylor JS, et al.: Why don't patients enroll in hospice? Can we do anything about it? J Gen Intern Med 2010;25:1009–1019.

34. Carlson MD, Morrison RS, Holford TR, Bradley EH: Hospice care: What services do patients and their families receive? Health Serv Res 2007;42:1672–1690.

35. Aldridge Carlson MD, Barry CL, Cherlin EJ, et al.: Hospices' enrollment policies may contribute to underuse of hospice care in the United States. Health Aff (Millwood) 2012;31:2690–2698.

36. Johnson KS, Kuchibhatla M, Tanis D, Tulsky JA: Racial differences in hospice revocation to pursue aggressive care. Arch Intern Med 2008;168:218–224.

37. Harrison KL, Dzeng E, Ritchie CS, et al.: Addressing palliative care clinician burnout in organizations: A workforce necessity, an ethical imperative. J Pain Symptom Manage 2017;53:1091–1096.

38. Aldridge MD, Schlesinger M, Barry CL, et al.: National hospice survey results: For-profit status, community engagement, and service. JAMA Intern Med 2014;174:500–506.

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