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Abandonment at the end of life from patient and clinician perspectives:

Loss of continuity and lack of closure

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Abstract

Background—Surveys and anecdotes suggest that patients and family members sometimes feel abandoned by their physicians at the transition to end-of-life care. To our knowledge, no prior studies describe abandonment prospectively.

Methods—We conducted a longitudinal, qualitative study of patients, family caregivers, physicians and nurses using a community-based sample. Using a purposive recruitment strategy, we identified 31 physicians, who identified 55 patients with incurable cancer or advanced chronic obstructive pulmonary disease (COPD), 36 family caregivers, and 25 nurses. Eligible patients met the prognostic criterion that their physician ‘would not be surprised’ if death occurred within a year. Qualitative semi-structured interviews were performed at enrollment, 4–6 months and 12 months, and were audiotaped, transcribed and coded by an interdisciplinary team. When asked to talk about hope and prognostic information, participants spontaneously raised concerns about abandonment, and we incorporated this topic into our interview guide.

Results—Two themes were identified: (1) before death, abandonment worries related to loss of continuity between patient and physician; (2) at the time of death or after, feelings of abandonment resulted from lack of closure for patients and families. Physicians reported lack of closure but did not discuss this as abandonment.

Conclusion—The professional value of nonabandonment at the end of life consists of two different elements: (1) providing continuity, of both expertise and the patient-clinician relationship; and (2) facilitating closure of an important therapeutic relationship. Framing this professional value as continuity and closure could promote the development of interventions to improve this aspect of end-of-life care.

INTRODUCTION

Expert guidelines on caring for patients at the end of life emphasize the importance of not allowing a patient to feel abandoned, especially when the care plan includes withdrawal of disease-modifying treatment.^{1–5} Nonabandonment has been cited as a primary tenet of medicine and a key value in professionalism.^{6, 7} However, limited empirical data describe how physicians put this value into practice. One study of intensive care unit family conferences observed that clinicians missed opportunities to respond to family concerns

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about nonabandonment,⁸ although when present, expressions of nonabandonment correlated with higher family satisfaction.⁹

Despite the professed importance of nonabandonment to end of life care, surveys show that patients and families still experience abandonment around the time of death.^{10–12} Anecdotal descriptions provide vivid first-person accounts,^{13, 14} but medical literature does not explain the discrepancy between physicians' stated professional values, and patients' and families' experiences of abandonment.

We found that patients with incurable cancer and advanced COPD who were asked to talk about hope and their views of the future independently brought up the subject of abandonment. We then observed abandonment prospectively in this longitudinal study from the perspectives of patients, their family caregivers, physicians, and nurses.

METHODS

Design

Data for this analysis was drawn from a qualitative study that examined how patients, family members, physicians, and nurses talk about hope in the context of providing or receiving information about a life-limiting illness. Details have been reported previously.^{15, 16}

Participant recruitment

Physician Participants—We designed a recruitment strategy to sample oncologists, pulmonologists and general internists with a spectrum of attitudes towards palliative care. To identify potential participants, we selected an expert panel of nine physicians from the same specialties who were “thought leaders,” and asked them to identify physicians they believed had good communication skills and who were in one of the following three categories: physicians who focus on curative or life-prolonging treatment, those who focus on palliative care, or those “in the middle” of these two categories. We then randomly selected physicians from each category. Eligibility requirements included: 1) $\geq 50\%$ time spent in clinical practice; and 2) ability to identify at least four eligible patients.

Patient Participants—Enrolled physicians identified potential patient participants based on: 1) a diagnosis of advanced cancer (metastatic solid tumor or non-operable lung cancer) or severe COPD (defined as an FEV1 $< 35\%$ predicted and oxygen-dependent); and 2) the physician's assessment that she “would not be surprised if the patient died from any cause in the next year.”¹⁷

Family Member and Nurse Participants—Patients identified a family caregiver or close friend who was “involved in their medical care,” and a nurse who was “involved in discussing their medical care” who might be willing to participate.

Data collection

Interviews were conducted by two interviewers (JY, EM) who received at least 20 hours of training from qualitative researchers (BM, AB). Respondents were interviewed in the following order: patient, family member, physician, nurse. Follow-up interviews with patients were conducted at two points: 1) 4–6 months following study entry; and 2) 12 months after study entry. Interviews were recorded using digital recorders and transcribed verbatim.

Qualitative Analyses

We used a limited application of grounded theory to analyze the data.^{18, 19} Investigators were grouped into analysis pairs to review transcripts, with each pair including a clinician investigator, and coded transcripts using open, axial and selective coding. The entire research team met weekly to analyze interviews as data were collected over a 27 month period. For this analysis, we utilized the codes ‘hospice,’ ‘end of life,’ and ‘no more treatment’, and ‘abandonment’ (a code added 2 months after the first code list was established). The probes that we used to inquire about nonabandonment specifically are in Table 1.

Trustworthiness was established by: 1) initial review of the coding scheme by the entire multidisciplinary team; 2) review by all investigators of initial coding of all transcripts for the first 10 sets of patient, family, physician and nurse transcripts, and revision of coding to achieve consensus; and 3) coding of 50% of the remaining transcripts by two investigators who met to reconcile differences. Interviews were concluded when saturation was reached for the study’s primary focus on hope and information needs; the investigators also concurred that abandonment topics met standards for theoretical saturation.

RESULTS

Participants

Of the 129 physicians who were identified by the expert panel, 84 physicians met eligibility criteria and 31 participated in the study for a participation rate of 37% (31/84). Non-participants were more likely to be oncologists, the the most common reasons for non-participation were ‘too busy’ or ‘already involved in research.’ (Table 2) Participating physicians identified 67 eligible patients and 55 of these patients were willing to participate, for a participation rate of 82% (55/67). (Table 3) Of the 55 enrolled patients, 42 identified a family member or friend and 36 of these individuals consented to participate (86%, 36/42). (Table 3) All 25 nurses identified either by patients (n=16) or physicians (n=9) participated (100%). Not all patients could name an outpatient nurse they knew well, which reflects the structure of enrolled medical practices. These participants provided over 220 hours of interviews.

Physicians represented Pulmonary/critical care, Medical oncology and General Internal Medicine in similar proportions. Both physicians and nurses were mostly white (physicians, 90%; nurses, 80%) and highly experienced (physicians, mean of 21 years in practice; nurses, mean of 19 years) and the majority had some training in end-of-life care (physicians, 61%; nurses, 64%) (Table 1) Patients and families were predominantly white (patients, 78%; families, 81%), older (patients, 67.3 years; families, 60.3), and college educated (patients, 62%; families 72%. (Table 2). The patients’ diagnoses were split between cancer and COPD, and 38% of the patients died during the 6 months (mean) they were followed for this study.

Themes

We identified two themes describing abandonment of patients and their families: (1) before death, abandonment worries related to loss of continuity between patient and physician; (2) at the time of death or after, abandonment experiences related to lack of closure for patients and families. These themes are described in detail below.

1. Before death, abandonment worries related to loss of continuity

Patients and Families: Patients described two kinds of continuity losses. The first kind of loss was losing access to their physician’s medical expertise. For example, one patient said,

“I feel I need more help now, than I did...and by help I mean I need to be able to depend on my doctor, and I guess I want her to know that ‘If I call you next week, doctor, will you see me right away?’” Another patient, anticipating hospice, said “You can’t seek your regular treatment...your doctor is out of it.” While this may represent a misconception about hospice, it also underscores the value patients place on their primary physician’s expertise. A patient voiced a concern that near death “someone else would take over, who doesn’t have a lot of history with [the dying] person....I think that one could feel relatively abandoned.”

The second kind of continuity loss involved the patient-clinician relationship, distinct from the medical expertise. One patient noted, “I think that it’s important that you still have that contact with them even though there isn’t anything they can do to make you better,” said one patient, who continued “I mean, what are they going to do? There isn’t anything they can do. And I realize that, but they can hold my hand, so to speak, to the very end.” A nurse recalled how this abandonment fear surfaced with a sense of “desperation” over an unplanned hospital admission: “[The patient asked] Will you go with me? Will you come out and see me?”

Families also perceived value in continuity, in ways similar to patients. For example, one family member anticipating a transition to hospice said “the way they presented it...they’re just here to make you comfortable until you die. But you can’t seek your regular treatment from your doctor. Your doctor is out of it. And that’s not what we want” Aside from whether the family understood hospice accurately, the family member’s concern about continuity is clear. Another family member talked about the importance of the doctor “wanting to hang in there and fight or try things”, saying that “when your provider gives up, why should you care any more?”

Physicians and nurses: Physicians were conscious of the possibility that patients would feel abandoned, especially at the point where disease-modifying therapy was no longer available. One physician described his approach to explicitly address abandonment: “And what we need to do, now, is re-focus our efforts and treat your symptoms. That doesn’t mean we’re going to abandon you.” Oncologists were particularly aware that patients often equated chemotherapy with continuity. One oncologist, anticipating a “difficult” conversation with a study patient, said “she’s going to look at stopping chemotherapy as abandonment.” and said at another point in the interview “the trap we fall into is, ‘ok we’re done. No more chemotherapy.’” Another oncologist said, “I don’t want them to feel like ‘oh, you’re on hospice, we’re done with you.’”

Even aside from chemotherapy, physicians were aware that patients are sensitive to the physician’s willingness to continue thinking and working on their behalf. One physician described “abandonment” as the patient saying: “Well aren’t you going to try for me any more, doctor?” Nurses felt similarly to physicians in both noting continuity concerns and naming abandonment. For example, a nurse observed that “why hospice is such a bad thing, is, it comes on the heels of ‘Ok, I’ve been abandoned essentially by my physician.’” Another nurse described a patient saying that “my doctor said there was nothing more he could do” which she felt was “a huge abandonment thing”.

Physicians actively sought to “avoid the abandonment issue” with reassurance and continuity strategies. As one physician put it, “what patients need is to know that you care about them. That you care about their future and that you’re there for them.” Another physician said “I want patients to know that, when the going gets tough, I don’t just bow out.” A physician described his strategy for continuity: “Keeping them coming in is important. I think they feel connected and they don’t feel like you’ve dropped them. And if

you drop them, that means, you're only interested in treatment and you're not interested in me".

2. At the time of death or after, feelings of abandonment resulted from lack of closure for patients and families

Patients and families: While patients and families worried about abandonment spoke of loss of continuity near the end of life, the actual experience of feeling abandoned included another dimension: lack of closure with their physician. A patient recalled that the doctor was "very matter of fact — this is what you have and this is what we need to do." And I wasn't ready for it. I just felt, "how cold" ...I'd been going to him for quite a while. I mean he was a nice guy and everything but I just felt so alone." A family member recalled: "The last few days, I was like, "Where's [the doctor]?" I thought maybe he would come over...and see him [participant's husband], but he did not. So that kind of shocked me a little bit. He left. I mean, he just disappeared....we never saw him."

The lack of closure after death came as a shock for others. Another family member noted in an interview prior to her husband's death that "Dr. [name] is really good...I don't feel that he's given up on him [participant's husband]...I haven't felt like we've reached a point where, ok, there's nothing we can do." Yet after her husband's death, she said "honestly, the one thing that that really bothered me is that fact that Dr. X never called" after her husband was no longer able to come in to the office, and was on hospice. "To me, it was almost like a slap in the face. I mean, I realize that the doctor is busy. He's got other patients. [crying] But he *knew* R. and me. And even though I knew that R was going to die, it wasn't easy to deal with, and it would've been nice just to hear from him, even if all he said was, "'I'm sorry for your loss.'"

The positive effect of closure was evident for one family member in our sample, who received a phone call from the physician after the patient's death. The family member said "I think it was really important that he [the physician] did call....It just showed me that he cared and that [5 second silence] she just wasn't a...just wasn't a patient ...that he treated and then she didn't make it, so, "Oh well". This family member experienced the physician's phone call as the completion of the therapeutic relationship.

Physicians: Physicians reflected on the end of their relationships with patients and families, but framed the experience as lack of closure. One physician said "I think it's probably more important for them [the family], than it is for me, in terms of what I recognize, but maybe there are things that I don't recognize, psychologically...it probably would be good for me to have better closure." Another physician described the experience this way: "The hard part for me is that I really lose track of what's happening. And I have an underlying guilt that somehow, I should still be more involved....because we develop these really deep relationships, up until the point the treatment stops. And then, I know there's just like this vacuum that's created when all of a sudden they're not seeing me any more."

Physicians often did not see closure as a reason to see a patient as death approached: "It seemed almost like she was coming into visit rather than to actually get any care." Or, "I have patients that come to see me and I...don't really know why they're here....I tell them, 'I don't need to see you.'" Another physician described the issue this way: "I still remember that the week before he died, he told me he wanted to see me every week.... and I was thinking to myself, 'Oh God, my schedule's overflowing with people who actually need me to care for them and he wants a social visit.'"

After death, physicians were sometimes unaware that family members experienced this lack of closure as abandonment. One physician said, "I was actually not here [i.e., out of town]

when he died. And then I thought, ‘Oh, I should really call B [patient’s spouse]’ And then, didn’t, because I was just too busy. And then, ...by the time I got around to remembering, I felt guilty that I hadn’t called her earlier and I didn’t know if it was appropriate...maybe it would just stir up emotional stuff if I did call...so I don’t know.” Later in the interview, the physician said, “I don’t know in actuality, that things would be any better or any different, if I did keep in touch.”

Physicians described logistical and personal barriers to closure. One physician framed the barrier as logistical: “There are only so many hours in the day and I have probably, at any one time 10 to 20 patients on hospice. And if I started calling them up, there would be this problem and that problem and I would have to get in the middle of it. And quite frankly, it’s care that’s not reimbursed.” Another physician framed the barrier as personal. When asked if he said goodbye, one physician said “when I know it’s the last time I’m going to see someone, in the office, I...I try to do that. But it’s a tough go, sometimes. I think that I’m not very good at that. I have a tough time, ‘cause I don’t...sometimes I do cry, but I try not to. It’s too disruptive to my day...I sometimes am afraid that I’m going break down, so I tend to gloss it over.”

DISCUSSION

In this study, we found that the professional value of nonabandonment at the end of life actually consists of two different elements: (1) providing continuity, of both expertise and the patient-clinician relationship; and (2) facilitating closure of an important therapeutic relationship. At first glance, continuity and closure may seem mutually exclusive, but these elements reflect different needs occurring at different times in the dying process. Early on, patients and family members fear that their physician, whose expertise and caring they have come to depend on, will become unavailable. Physicians are aware of this fear, and attempt to address it with reassurance or continuity strategies. Yet, as death approaches, some patients and families may feel abandoned nonetheless because they lose the continuity of their physician’s expertise or their relationship with that physician. Near death or afterwards, they may also experience a lack of closure of that relationship. Most of these physicians are not consciously aware of having abandoned their patients. Instead, they report lack of closure, or a feeling of unfinished business.

This study builds on prior work on nonabandonment and ties together other existing work on physician practices at the end of life. Using a bioethical framework, Quill and Cassel defined nonabandonment as “open-ended, long-term, caring commitment to joint problem-solving”.⁶ Certainly that definition, echoed in the Institute of Medicine’s call for ‘continuous healing relationships’,²⁰ echoes the continuity that our participants discussed. Our study provides empirical verification of continuity in two dimensions: the perceived need for access to physician expertise, as well as the importance of continuity in a therapeutic relationship. In addition, our study adds another dimension to non-abandonment: the need for closure of the patient-family-clinician relationship near or after the patient’s death. This finding ties non-abandonment to a small literature that describes expert practices for physicians experiencing the loss of an important relationship with a patient. These practices include personal reflection,²¹ saying goodbye,²² writing a condolence letter,²³ and attending a funeral.²⁴ Our study suggests that these practices could contribute to nonabandonment.

Little other empirical study of nonabandonment exists. A prior study of expressions of abandonment during ICU family conferences found that families expressed concerns about abandonment of the patient in several different ways including ensuring the patient’s suffering is eased, ensuring the patient’s end-of-life preferences are respected, and “letting go.”²⁵ To our knowledge, our study is the only empirical study that provides a prospective

view of abandonment and non-abandonment using longitudinal interviews that began at the time the patient had advanced disease, and followed patients and families through death and into the beginning of bereavement.

The significance of our study is that it provides empirical grounding for a central professional value. We note that Quill and Cassel favored the use of the term ‘nonabandonment’ because alternatives did not ‘capture the responsibility for continuity and joint problem solving in the face of uncertainty’.⁶ As a bioethical framework, we respect their reasoning. Our empirical findings enrich and extend these concepts in ways that we did not expect. Specifically our findings identify aspects of nonabandonment —continuity and closure — that can be acted upon.(Table 4) Reducing system barriers to continuity, for example with non-hospice palliative care services, may foster nonabandonment. Physician or interdisciplinary team communication involving nurses and other clinicians that facilitates continuity and closure may improve patient and family experience. Finally, physicians can develop reflective skills that enable them to deal with loss and grief.

This study has limitations worth noting. First, the generalizability of our findings is limited for several reasons. The study occurred in one state, and involved older patients with one of two life-limiting diagnoses who were treated mostly as outpatients. In addition, most of the patients had a family or friend caregiver, were living at home and had a pre-existing relationship with a physician. Furthermore, none of our patients was seen by a palliative care consultation service, although some of the patients who died during study follow-up were seen by hospice before death. These are all characteristics that may limit generalizability to other groups of patients. Second, because the study was designed to understand patient-physician communication, we were unable to investigate the issue of closure for patient-nurse relationships. Because the vast majority of the physicians were men and nearly all the nurses are women, we are unable to comment on gender effects. Finally, our study was not originally designed to study nonabandonment, so could have missed findings if the study had focused specifically on this issue. On the other hand, asking participants to consent to a study about nonabandonment may have resulted in bias resulting from selective participation of patients willing to discuss the topic.

In summary, we found that the professional value of nonabandonment at the end of life consists of (1) providing continuity of expertise and a therapeutic relationship, and (2) facilitating closure of that therapeutic relationship. Our aim in establishing an empirical frame for nonabandonment was to enable the development of interventions designed to improve this aspect of end-of-life care. Future studies are needed to determine whether intervention with clinicians, patients, or family members can prevent or address abandonment.

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Table 1

Questions used to investigate nonabandonment

For patients and families

- What do you need from [doctor], now that there aren't any treatments available?
- What is different for you and your relationship to [doctor] now that you aren't receiving treatment?
- Did your relationship with the doctor and other clinicians change once on the patient was on hospice or not receiving [disease-modifying] treatment? How did the family member (and patient) experience this?
- Did anyone contact family member after the patient died? (When [doctor] called you after [patient] passed away, what did that mean to you?) (When you didn't hear from [doctor] after [patient] died, what did that mean to you?)

For physicians

- What strategies do you use in transitioning patients from active treatment?
- What is different for you and your relationship to [patient] now that they are no longer in treatment? What is important now?
- Did your role or interactions with [patient] shift since we last talked? (if a change in patient status had occurred)
- One thing we've been looking at is the idea of how or if doctors say goodbye to patients. What is your experience with that?
- Do you have contact with family members after a patient's death – why this is important (if it is)? Are there barriers to doing this?
- [When MD said they send a card or call after patient dies] Why is it important for you to do that?

Note: the complete interview guide is available upon request from the authors.

Table 2

Characteristics of study clinicians

	Physicians (n=31)	Nurses (n=25)
Age, mean years (sd)	48.7 (7.9)	46.6 (8.6)
Female, n (%)	11 (35.5)	23 (92.0)
Ethnicity, n (%)*		
Caucasian	28 (90.3)	20 (80.0)
African American	0	2 (8.0)
Asian	2 (6.5)	2 (8.0)
Hispanic or Latino	1 (3.2)	1 (4.0)
>1 ethnic identity	0	0
Physician specialty, n (%)		
Pulmonary	11 (35.5)	NA
Oncology	12 (38.7)	
Internal Medicine	8 (25.8)	
Nurse Education, n (%)		
>=4 year degree	NA	17 (68.0)
Physicians with academic affiliation, n (%)	15 (48.4)	NA
Clinicians without formal training in end-of-life care, n (%)	19 (61.3)	19 (76.0)
Years in practice, mean (sd)	21.0 (7.7)	19.3 (8.9)

Abbreviations are as follows: sd = standard deviation; MD = medical doctor; RN = registered nurse.

Table 3

Characteristics of patients and family members

	Patients (n=55)	Family or friend caregivers (n=36)
Age, mean (sd)	67.3 (11.4)	60.3 (15.8)
Female, n (%)	33 (60%)	18 (50%)
Ethnicity, n (%)		
Caucasian	43 (78.2)	29 (80.6)
African American	9 (16.4)	5 (13.9)
Asian	2 (3.6)	2 (5.6)
Hispanic or Latino	0	0
>1 ethnic identity	1 (1.8)	0
Diagnosis, n (%)		
COPD	24 (43.6)	NA
Cancer	30 (54.5)	
COPD and cancer	1 (1.8)	
Hospice care at some point during study, n (%)	9 (16.4)	NA
Died during study, n (%)		
COPD	5 (9.1)	NA
Cancer	15 (27.3)	
COPD and cancer	1 (1.8)	
Length of relationship with physician, median years (IQR)	2.0 (0.83, 6.00)	NA
Education, n (%)		
<= High school	21 (38.2)	10 (27.8)
<= College	25 (45.4)	20 (55.5)
> College	9 (16.4)	6 (16.7)
Living setting, n (%)		
Private home	48 (87.3)	NA
Assisted living	3 (5.5)	
Skilled nursing/ long term care	4 (7.3)	
Family's relationship to patient, n (%)		
Spouse/partner	NA	20 (55.6)
Relative (adult child, sibling, in-law)		12 (33.4)
Friend		4 (11.1)

Abbreviations are as follows: sd = standard deviation; COPD = chronic obstructive pulmonary disease; IQR = interquartile range

Table 4

Participant descriptions of continuity and closure: How physicians and nurses can ensure that patients and families do not feel abandoned

	Continuity	Closure
<i>Before death</i>	<ul style="list-style-type: none"> Address concerns about continuity proactively, including assurances that the physician and nurse will continue to be available Maintain contact with patient and family as death approaches, often by phone 	<ul style="list-style-type: none"> Anticipate and acknowledge the probable last visit with a patient
<i>After death</i>	(after death, the work of nonabandonment is in closure)	<ul style="list-style-type: none"> Call the family member after death Write a bereavement letter