

**Original Article**

# Transforming Doctor-Patient Relationships to Promote Patient-Centered Care: Lessons from Palliative Care

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**Abstract**

*Palliative care was studied for its potential to yield lessons for transforming doctor-patient relationships to promote patient-centered care. Examination of patient and provider experiences of the transition from curative to palliative care promises valuable insights about establishing and maintaining trust as the goals of care shift and about addressing a broad spectrum of patient needs. The study was guided by a conceptual framework grounded in existing models to address five dimensions of doctor-patient relationships: range of needs addressed, source of authority, maintenance of trust, emotional involvement, and expression of authenticity. Data collection included observation of the care of 40 patients in the inpatient hospice unit and at home, interviews with patients and family members, and in-depth interviews with 22 physicians and two nurses providing end-of-life care. Standard qualitative procedures were used to analyze the data, incorporating techniques for maximizing the validity of the results and broadening their relevance to other contexts. Findings provide evidence for challenging prominent assumptions about possibilities for doctor-patient relationships: questioning the merits of the prohibition on emotional involvement, dependence on protocols for handling difficult communication issues, unqualified reliance on consumer empowerment to assure that care is responsive to patients' needs, and adoption of narrowly defined boundaries between medical and social service systems in caring for patients. Medical education can play a role in preparing doctors to assume new roles by openly addressing management of emotions in routine clinical work, incorporating personal awareness training, facilitating reflection on interactions with patients through use of standardized patients and videotapes, and expanding capacity to effectively address a broad range of needs through teamwork training. *J Pain Symptom Manage* 2007;33:40–57. © 2007 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

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**Introduction**

The Institute of Medicine (IOM), in the landmark report, *Crossing the Quality Chasm*, blamed major deficiencies in the prevailing quality of care on lack of responsiveness to the needs of patients. Their prescription for change was embodied in 10 guidelines for re-engineering health care.<sup>1</sup> While they did not explicitly address doctor-patient relationships, implementation of five of the IOM's guidelines would require alterations in the basic nature of the relationship: customize care based on patient needs and values, anticipate patient needs, regard the patient as a source of control, share knowledge and information, and facilitate patient participation in decision making. Recognizing the centrality of the doctor-patient relationship in achieving change, this research studies variations in the fundamental structure of the relationship and explores the implications for promoting patient-centered care.

Research on patients' perspectives on health care suggests that, in addition to accessible and affordable services, they value respect, good communication, concern and advocacy for their well-being, and up-to-date medical knowledge.<sup>2-5</sup> These studies document perceived deficiencies in interpersonal dimensions of their care,<sup>6-9</sup> which could be overcome by better relationships with their doctors. While there is vast social science literature on doctor-patient relationships, their wide-ranging forms in existing practice have not been studied with attention to the implications for medical education and health policy. Yet achieving effective health system change of the scope envisioned by the IOM requires that we learn from innovative medical practices, as proposed in this project, if we are to confront outmoded assumptions in devising new processes of care.

Design of the project was premised on the value of studying exemplars, that is, existing arrangements in medical practice that show promise in improving the match between patient needs and health care services, and

generating insights for broader application throughout the delivery system. Palliative care was selected as one of five substudies for the project, because it was anticipated that examination of patient and provider experiences of the transition from curative to palliative care would yield valuable lessons about communicating and maintaining trust as the goals of care shift. (The other four substudies are complementary medicine, selected because it relies upon disparate knowledge bases to address a broad range of patient needs; cancer self-help and advocacy because it offers new sources of support and shared authority among peers; group medical visits for chronic illness care because they draw upon mutual experience and learning among patients; and new communications curricula in medical education because they can prepare physicians to assume new roles with patients.) Also, end-of-life care offers a compelling context for assessing strategies for improving the compatibility of treatment decisions with patients' values and expectations. Effective care of patients at the end of life frequently requires attention to an expansive spectrum of needs, often entailing interventions whose scope extends beyond the confines of traditional medical practice. Decisions often require confronting the limits of medicine and reassessing the goals of care, and the relationship between patients and doctors may compel unprecedented emotional involvement and vulnerability among both parties. These features, heightened in palliative care but having broad relevance in health care delivery, further enhance the promise of studying end-of-life care for purposes of this project. While the research focuses on patients' relationships with their doctors, the findings are likely to have relevance to relationships with other health care providers as well.

A qualitative-inductive methodology was applied to this study. The research design was guided by a conceptual framework grounded in existing models of doctor-patient relationships, as outlined below.

### *Conceptual Framework*

Sociologists, political philosophers, and ethicists have made important conceptual contributions to understanding doctor-patient relationships. To varying degrees, they acknowledge inherent tensions arising from the disparate circumstances through which doctors and patients come to interact: Doctors bring to the relationship esoteric knowledge accumulated through years of training, while patients bring intimate stories and intensely personal concerns. Doctors' involvement may be limited to an illness episode, while the course of treatment may have a lasting impact on the patient's life. Controls on doctors' behavior are institutionalized codes, laws, and regulations, while patients are guided by norms and values. Perhaps most striking, an illness episode for doctors is a routine part of their workday, while for patients it is a unique, often traumatic event.

Perspectives on doctor-patient relationships can be categorized in three models, distinguished primarily by the way in which they treat these tensions and regard their potential resolution: *Functionalist models* posit inherent difficulties in bringing together patients who are vulnerable and uninformed, and physicians whose depth of knowledge insulates them from routine bureaucratic controls; they stipulate constraints on the behaviors of doctors and patients to assure establishment of workable relationships under these conditions; *patient-centered models* treat as inevitable the conflicts that arise from the unequal footing of doctors and patients; they view patient autonomy and consumer choice as essential mechanisms in achieving an outcome that assures the well-being of patients; and *relationship-centered models* also foresee inherent differences in outlooks between doctors and patients but regard collaboration as the means of bridging such differences rather than safeguards assured by the professional obligations of providers or the autonomous rights of patients.

Five analytic dimensions figure in these models and merit attention in studying doctor-patient relationships: range of patient needs addressed (the scope of the intended impact of interventions on patients' lives), source of authority (the basis of the doctor's influence on patient's behavior), trust (how trust is

secured and maintained among doctors and patients), emotional involvement (benefits and costs of affective involvement of doctors in the lives of their patients), and authenticity (extent to which doctors and patients respond genuinely to each other as individuals). Table 1 summarizes what each of the three theoretical models has to say about each of these five dimensions.

Functionalist models prescribe constraints on providers because medical practice, relying as it does on a high level of expertise, cannot be subjected to the usual bureaucratic controls of the workplace. Balancing their unprecedented autonomy in carrying out their work, physicians are committed to confining their use of authority to areas relevant to their expertise, treating all patients alike regardless of self-interest, and avoiding emotional involvement with patients, which may impair their clinical judgment.<sup>10</sup> Patient-centered models, similar to the functionalist model, recognize asymmetries in the status of doctors and patients,<sup>11</sup> but view their resolution in negotiation between providers and consumers rather than prescribed rules of behavior. The responsibility of the doctor extends to advising the patient on the best course of treatment or management in view of established evidence; the patient is responsible for gathering advice, weighing that evidence, assessing the compatibility of options with their values, and making a decision about what course to follow. Relationship-centered models do not view doctors and patients as types or roles,<sup>12,13</sup> whose disparate positions compel negotiation; rather, they conceive of them as distinctive and unique human beings whose relationship binds them in a common purpose and becomes a healing force in itself (Table 1).

Each model offers a distinctive view of the basis for the physician's commitment to the patient and safeguards against abandonment. The functionalist model regards commitment as a prescriptive duty, recognized as a central professional value: the obligation to treat all patients alike, regardless of self-interest.<sup>10</sup> Commitment, in the patient-centered perspective, is grounded in a contractual relationship, guided by respect for rights, consent, and consumer choice.<sup>14</sup> The relationship-centered model, like the functionalist perspective,

Table 1  
**Perspectives of Three Theoretical Models on Five Dimensions of Doctor-Patient Relationships**

Dimensions	Models		
	Functionalist Models	Patient-Centered Models	Relationship-Centered Models
	<i>Regard illness as a potentially destabilizing force in society, requiring constraints on doctors and patients.<sup>10</sup></i>	<i>Acknowledge rich distinctions that differentiate patient and provider perspectives,<sup>11</sup> and emphasize the importance of patient autonomy and consumer prerogative in addressing potential conflicts.<sup>14</sup></i>	<i>Acknowledge differing outlooks and unequal expertise among doctors and patients, and pose collaborative relationships and mutual understanding as means of bridging perspectives</i>
Needs (range of patient needs addressed by doctor)	Bounded by expertise: physicians define scope of practice	Decided by patients: honors patient autonomy	Fluid: collaboration resolves tension between expansive needs and limited resources
Source of authority (basis of doctor's influence on patient's behavior)	Based on position: "I am your doctor—given my years of training, I know what's best for you"	Based on expertise: "Here's why I advise you to do this."	Dictated by needs of the patient: "Let's figure this out together."
Trust (how is it secured and maintained)	Unconditional: a prerequisite for seeking care	Contractual: grounded in informed consent	Established through mutual understanding
Emotional involvement (of both parties)	To be avoided: may compromise clinical judgment	Irrelevant: threatens patient autonomy	Essential: critical to effective healing
Authenticity (genuine interaction as individuals)	Irrelevant: ban on emotional involvement precludes mutual identification	Irrelevant: quality of advice, not the persona of provider, is key	Central: genuine engagement defines the relationship

regards commitment as a calling; but, unlike a mandate imposed on physicians to safeguard the well-being of patients, it flows naturally from the common humanity that brings doctor and patient together in the healing process.

## **Methods**

A qualitative research strategy serves the goal of this research: to generate an empirically based vision of new possibilities for structuring doctor-patient relationships that show promise in promoting patient-centered care. Several aspects of this topic compel an inductive methodological approach. First, lack of prior research suggests the need for an exploratory, hypothesis-generating approach. Second, the importance of capturing insights unanticipated by the researcher is served by open-ended interviewing and firsthand observation as primary sources of data. Third, the intent to discriminate among conceptual models of behavior demands a high degree of validity afforded by the depth and density of data collection integral to qualitative research. The methodological procedures used here conform to prescribed standards of qualitative research,<sup>15–18</sup> including systematic sampling, an inductive data collection and analytic strategy, and concern for reliability and validity in analyzing data and reporting findings.

The primary research site, Continuum Hospice Care/The Jacob Perlow Hospice at Beth Israel Medical Center, New York, and its affiliated services, was selected because of its capacity to provide a full spectrum of end-of-life care. To expand the generalizability of the sample, supplementary observations and interviews were conducted at an inpatient unit of the same hospice program situated at another hospital serving a predominantly African American population. To enrich the analysis of issues arising in the transition to palliative care, observations of care and interviews with medical oncologists were conducted at a prominent cancer center in New York City.

Observations over the course of five months included patient-care rounds at the inpatient hospice units, home visits by palliative care physicians and nurses, interdisciplinary team meetings for developing care plans for inpatient and home care, and palliative care

consultations on the acute wards of the hospital. At the primary research site, the care of 40 patients on the inpatient service was observed, and interviews were conducted with patients and families in the context of daily rounds. Follow-up, one-hour interviews were conducted with eight patients subsequent to discharge. Patients were included if they were admitted for end-of-life care (i.e., not exclusively for pain management), they or a family member conversed easily in English, and they consented to participate. Extended interviews were conducted with 12 hospice-care providers (10 physicians and two nurses) and 12 medical oncologists. The sample of hospice providers included all of those who were centrally involved in the care of the patients observed over the course of the five months. Medical oncologists were selected for their clinical leadership, experience with end-of-life care, and variation among specialties. The data collection strategy was designed to enhance the credibility and internal validity of the findings by eliciting the perspectives of patients and providers (triangulation of perspectives<sup>19</sup> in the terminology of qualitative methodologists), integrating observations with interviews (triangulation of data<sup>20</sup>), and asking patients to comment on the salience of emerging themes during the follow-up interviews (facilitating member checking<sup>15,19,21</sup>). Observation of care focused chiefly on choices among treatment options and goals; interviews with providers addressed emotional involvement, establishment of trust, and clinical decision making; and interviews with patients concentrated on their expectations of physicians, establishment of trust, and care decision making. [Table 2](#) details the topics covered through each set of observations and interviews.

Interviews were structured to suit the inductive strategy of the research, with initial questions on dimensions of doctor-patient relationships phrased broadly—to elicit relatively unencumbered responses—followed by probes addressing specific issues suggested by the three theoretical perspectives. [Table 3](#) presents examples of a sequence of questions for providers on their emotional involvement with patients and another for patients on their expectations of their doctors.

Table 2  
Sources and Content of Data

Mode of Data Collection	Content
Observation	Identification of patient and family needs
Patient care	Discussion of treatment options and goals
Inpatient hospice rounds	Decisions regarding tests and procedures
Palliative care service	Emotional involvement and quality of communication
Home visits	Implementation of interdisciplinary care plan
Meetings	
Family meetings	
Interdisciplinary team	
Interviews with providers	Offering hospice/palliative care
Physicians	Care decision making
Palliative care	Posing palliative and curative options
Medical oncologists	Responding to patient/family questions about prognosis
Nurses	Emotional involvement with patients
Hospice/palliative care	Stress associated with role in end-of-life care
	Relationships among providers involved in end-of-life care
	Training of physicians for these roles
	Career choices
Interviews with patients	Decisions to seek hospice care
	Knowledge of hospice
	Considerations in making decision to seek hospice care
	Comfort with designation of life expectancy
	Treatment decision making
	Who has been involved
	Physician's contribution to decisions
	Factors that would optimize decision making
	What's most important in doctor-patient relationships
	Expertise
	Advice
	Choices
	Emotional support/understanding
	What's important in establishing trust in doctors

All of the interviews were audiotaped and fully transcribed, as were fieldnotes from the observations. In analyzing the data, Glaser and Strauss' approach to discovering grounded theory<sup>22</sup> governed identification of themes relevant to the dimensions selected for study—i.e., range of patient needs addressed, exercise of authority, basis for trust, emotional involvement, and possibilities for authenticity. For the interviews as well as fieldnotes, initial coding consisted of multiple readings of the transcripts to identify recurrent themes, coding the transcripts by themes, entering verbatim text into electronic files for each of the coded themes, subdividing categories of text to refine the concepts, seeking explanations for discrepancies, and examining how the themes relate to the dimensions of doctor-patient relationships selected for study as well as to the three theoretical perspectives on them.

Coding of transcripts entailed assigning themes to segments of text based on a line-by-line reading known as open coding.<sup>23</sup> Re-reading the coded text, categories were added to make fine distinctions reflecting as many shades of meaning as were evident in the data. Concepts were identified and elaborated, relying upon an approach known as the constant comparative method.<sup>22</sup> For example, for text coded as emotional involvement with patients, comparison of insights arising from varied sources (e.g., different patients, patients and providers, inpatient and home care) permitted examination of the circumstances in which issues and their broader consequences arose, and ultimately led to refining concepts through subdividing themes or combining them to identify overarching forces. To enhance the validity of findings, patients were asked in interviews about the importance of emerging themes. An independent expert in

Table 3  
Examples of Sequences of Questions in Interviews with Physicians and Patients

Topic and Function	Examples of Questions
<i>Physician questions on emotional involvement with patients</i>	
Broad question	Does provision of end-of-life care typically involve distinctive relationships with patients?
Probe	Does it generally entail intense emotional involvement with patients?
Probes re functionalist presumption re well-being of patients	<ul style="list-style-type: none"> <li>• Is there any truth in the cautionary warning that emotional involvement with patients may cloud clinical judgment and be detrimental to patients' well-being?</li> </ul>
Probes re personal strategies	<ul style="list-style-type: none"> <li>• Do you have personal strategies for setting boundaries around your emotional involvement with patients?</li> <li>• Are there liabilities in maintaining too much distance from patients?</li> </ul>
Probes re well-being of providers	<ul style="list-style-type: none"> <li>• Do you find the frequency of dealing with death taxing for you personally?</li> <li>• Has burnout been a factor for any of your colleagues? Or for fellows?</li> <li>• How can it be avoided?</li> </ul>
<i>Patient questions on expectations of doctors</i>	
Broad questions	Thinking about hospice care, what event best captures the nature of your relationship with doctors? What was particularly good about it? What was not?
Probes re:	To what extent do you rely on your doctor as...
Functionalist perspective	<ul style="list-style-type: none"> <li>• someone to place your trust in for clinical decisions for your illness</li> </ul>
Patient-centered model	<ul style="list-style-type: none"> <li>• someone whose consultation you seek for technical advice in planning your care</li> </ul>
Relationship-centered model	<ul style="list-style-type: none"> <li>• your partner or collaborator in dealing with your condition</li> <li>• someone who understands the meaning of your illness and participates in your experience of it</li> </ul>

qualitative analysis confirmed the soundness of the linkage between data and themes. To assess the salience of conclusions to providers, themes and associated text were shared at grand rounds and teaching sessions with medical residents, oncologists, and palliative-care providers who were asked to reflect on their interpretation. Theoretical saturation,<sup>15,17,22</sup> the qualitative analogue to statistical power, was established by confirming that analysis of transcripts of the most recent interviews and observations did not generate significant new themes.

## Results

Findings are organized to address the dimensions of doctor-patient relationships distilled from the three theoretical perspectives (Table 1) and to examine their implications for patient-centered care. Major themes are illustrated by verbatim quotations from the transcripts of the interviews. Unless otherwise attributed, quoted responses are those of physicians providing palliative care.

### *Range of Patient Needs Addressed*

Hospice and palliative care have emerged partly as a response to acknowledgment of unmet needs among patients nearing the end of

life. As illustrated in the observations reported in Tables 4 and 5, these needs are distinctive in their breadth, often requiring expertise from diverse fields to effectively address them; they often present issues whose resolution demands creative strategies to successfully negotiate the barriers imposed by organizational and financial requirements of an acute care-oriented system ill suited to palliative care; and they may obligate providers to bend clinical routines to meet the needs of patients or their families. The moral and technical complexity of issues that arise in addressing these needs may lead to their being overlooked earlier in the history of the illness or, if they do surface, to their being ignored by patients and family who find them overwhelming.

Satisfaction of such unmet needs generally eludes the prescriptive approaches of the first two models of doctor-patient relationships. The functionalist model, concerned about curbing excesses that may arise from unrealistic expectations of patients and unbridled enthusiasm of providers, is absolute: Doctors must scrupulously limit their sphere of influence to areas strictly relevant to their expertise. Similarly confining is the patient-centered perspective on legitimate territory for intervention: It is the patient's consumer prerogative to disclose needs and shape the agenda for a medical encounter. Vigilance in adhering

Table 4  
**Juggling Needs: Inpatient Hospice Observation**

A 73-year-old man with acute myelitic leukemia; diagnosed 3 months prior, transfusion-dependent, transferred to inpatient unit from another hospital; conversation between patient and clinical staff (*italics*).

*Why did you come?*

I came to the hospital to die; I have terminal leukemia.

*Are you in pain?*

Yes. I don't like painkillers because they constipate me; I have a high threshold for pain, but not too much. — The transfusions got to be too much; up at 6:00 a.m., got to the hospital at 8:00; had to wait for 11:00 for lab work and then another 3 hours for results; once I was there until 7:00 at night. The next day I don't feel well — bleeding from my nose into the back of my throat; the platelets don't kick in right away. Then it's time to start the cycle all over again.

*I don't want you to be stoic with pain, because we can control your bowels and if you wait too long for pain medication, then it's harder to control your pain.*

All I ask of you, when I have to go, make it as painless as possible.

*Has the hospice team come to your house, the nurse and everyone?*

They've been very good. [Mary] was very compassionate.

*Do you have any thoughts about returning home? You know, this is a short-term stay unit. Things are not going to be 100% controlled here, but we will do our best and then we discharge patients, to home if possible.*

I don't want to turn my apartment into a hospital room (tears up); my wife has lung CA, which is controlled, thank God. I have no quality days left — what are they going to do, transfuse me 5 days a week?

I don't want to be a burden on my wife; her first husband died at home. My daughter lives in New Jersey with 2 kids; they want me to hang around as long as I can, but what can I do? I can't fight it, it isn't going to get better. I want to spare everyone. The end should come quicker than later.

Clinicians, outside his door:

*How long is he likely to have?*

*—Probably 2 weeks or less, but sometimes a long time. His platelets are declining.*

*It's too bad he came in so early. We'll tell him what to expect, hopefully get him home, and then come back here to die.*

to this rule is essential to preserve patient autonomy. Observation of hospice care suggests that success in meeting the expansive and sometimes conflicting set of challenges is more effectively achieved through collaboration among providers, patients, and family members, most consistent with the relationship-centered model.

Effective end-of-life care requires coordinated input and actions from diverse disciplines, implemented across multiple settings (e.g., in the home, inpatient hospice, nursing home, and sometimes the emergency department and/or critical care unit of the hospital). To be effective in addressing patients' needs in this environment, it takes a team:

We rely heavily on the interdisciplinary team, which makes a plan of care for each patient — pastoral, social work, nursing, medicine, and bereavement. That (teamwork) helps me to deliver individualized care. I think maybe this is the strength of palliative care and hospice: It is to really tailor the care to the patient, with a multi-faceted view.

Integration of expertise was most evident in team meetings for patients on the inpatient unit, such as the woman with endometrial cancer (Table 5), as well as in development of care plans for patients at home.

Addressing patients' needs for maintaining their identities as their illnesses progress is central to the delivery of effective hospice care and requires sensitivity to their belief systems and models of health and illness. Provider capacity to respond, however, may be constrained by organizational and financial considerations, such as those complicating the care of the man with leukemia (Table 4). Providers may confront clinical routines that are insufficiently flexible to respect the individual needs of patients. Creative responses are evident in the following examples:

We were treating a Buddhist [whose] family was chanting and insisting on no pain medications, as he had to be lucid to cross over. At some point, I had to intervene because he was suffering too much. Similarly, they didn't want anyone to touch the body right



Table 5  
**Maintaining the Patient's Identity: Inpatient Hospice Observation**

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A 33-year-old woman with endometrial cancer, metastasized to her bones; expected to die in the inpatient unit. She was lucid but had trouble speaking, so she communicated nonverbally or through written notes. Conversation outside her room between family and clinical staff (italics).

*Hospice Nurse: She may be dying. I can't say with 100% confidence. But be prepared: Say what's in your heart. You can't appease her pain, but you can help her by listening to what she's saying.*

Mother: But we can't understand what she's saying.

*Listen in other ways; sit with her and try to feel it with her. Allow her to be with her pain. It's hard to face someone who you love who is in terrible pain.*

Sister: Is there something we should say? About it being okay to die?

*Say what feels right to you. Let her know in some way that you know she is dying. — When she's lucid, ask her what's going on with her. How does it feel emotionally?*

Sister: I'm concerned that she is holding on for others, not for herself. Her boyfriend is committed to taking her home. He's convinced that she'll go home and live on. He's driving me crazy.

*Well, she'll probably hold on as long as he does.*

[Next day]

*Physician: My goal is to try to maintain her for the 18th (the opening of a retrospective of her artwork).*

Mother: Can you?

*Well, the hospital may not like it, because one of us will have to accompany her, but we can put a wig on her, pump her up for a 5–10 minute appearance. I'd try to find out from her if she wants that.*

Mother: But what about the Foley [catheter]?

*We'll hide it, make it look like a purse.*

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after death – I had to pronounce him dead without putting a stethoscope to his chest.

I keep reminding the staff that this is the patient's last moment – and one that the family has to live with. So, we gave a miniscule amount of fluids to a man because his wife felt that otherwise they were starving him to death. Her son was sensitive to this, saying: “Yes, give him life support, but I know it's not needlessly prolonging [his life].”

Both of these examples involve bending established procedures: in the first instance, omitting an accepted practice in determining that the patient is dead; in the second, modifying a feeding protocol without subverting its overall purpose. In both cases, slight departures in practice made a difference in providing extra comfort to patient and family at critical stages of their care.

#### *Source of Authority*

In making clinical decisions, providers rarely relied strictly upon their status as experts in asserting authority. End-of-life planning was regarded as a multi-faceted process of reconciling myriad considerations and as such was deemed incompatible with the narrowness of this posture:

For addressing difficult issues, like instituting a Do Not Resuscitate order, you have to establish trust, and trust is based on

feelings. It's not like you are the cardiologist, you have the knowledge, you showed authority and [patients] think you are right. This is different.

Yet, several of these same providers pointed out that, in particular circumstances, it may be necessary to resort to authority based on status to suit the needs of patients and/or family members:

It depends on the situation. Sometimes, I am called on to be paternalistic. This is where people are having a lot of difficulty making a decision or feeling guilty about the decision that needs to be made. For example, for people who understand that a feeding tube would not be the best thing for their family member because – it's going to make them more uncomfortable, or whatever. They know but they're having a lot of guilt feelings 'cause other family members are saying, “Well, you're not going to let 'em starve, you know, you got to feed them.” In situations like that, I may be paternalistic and say, “I'm not going to feed your mother, and this is why.”

While these views refer to similar clinical situations, they suggest varied strategies that share in common their genesis in a deliberate consideration of distinctive aspects of the patients' situations. While the latter physician chose to impose a decision based upon her position,

her rationale for this behavior is consonant with the principles of the relationship-centered model. In both instances, assumption of a specific posture is based on consideration of the needs of the patient, not the personality of the provider. Neither of these views abides by the constraints assumed by the functionalist model; rather, they support a more fluid stance, in which the mode of exerting authority is mediated by a broader knowledge of the patient's and family members' experience of illness.

Several respondents expressed comfort with the patient-oriented, consumer model wherein authority is enacted through exchange of knowledge and physicians issue advice rather than orders.

I feel that we're information providers, more than anything else – the same way I wouldn't impose my religious beliefs on a patient, I wouldn't impose my medical beliefs either. Basically, my goal is to provide as much of an objective evaluation of the different modalities and choices that patients have.

Providers who embraced this perspective generally acknowledged the importance of maintaining balance in providing information, even if this requires offering evidence supporting treatment strategies that are at odds with each other:

And to be objective means that you have to sometimes say, "Look, this palliative chemo isn't going to cure you, it's probably not going to make you live any longer; maybe it's going to give you side effects; it might not. It might improve your quality of life, it might not. The choice is yours. The other option is not to take this medication, and we'll try and work on your symptoms and issues as they come up, and take it from there."

This approach demands symmetry; providers must be prepared to consider treatment information offered by patients, which is often extensive, as described by one medical oncologist:

Patients will usually come with printouts from 20 different trials. And I'm quite patient – but unfortunately I have to shoot down almost everything that people bring in. I have to say I can't remember someone who brought something to my attention

[for which they were] an appropriate candidate. But that's part of the process. It's part of empowerment – patients try to regain that power through knowledge.

Implementation of this mode of authority poses challenges. The burden of uncertainty that so often accompanies medical decision making may be passed on from physicians to patients:

Sometimes we don't know where we are along the course, the trajectory of the illness. We are not exactly sure where we stand. Are we really at that moment [for initiation of palliative care] – we don't want to miss any opportunity to deliver more aggressive care. [With] all the facts that we present to the patients, there's a lot of uncertainty. And sometimes we simply don't know which one is the good option. And then we throw it all at the patient. And then he has even a harder time than us.

Some physicians expressed concern that full delegation of authority to patients under these circumstances may constitute an abdication of provider responsibility, de facto abandonment. For providers, meaningful exchange of knowledge depends heavily upon their ability to explain the complexities inherent in various care options:

We talk about patient autonomy, which has all sorts of implications, but it takes a lot of experience to really get to a place where everybody understands what's going on, and decisions are made so that the patient really is the ultimate final person deciding with full knowledge of what is being done.

The majority of providers, though they may vary their posture from imposing a decision as experts to advising as consultants, appeared to ground their approach in the relationship-centered model; they tended to engage patients in an exploration of values and preferences, clarifying areas of concern, and relating them to care options. Exemplifying this approach, one respondent characterized the role of palliative care providers as:

Being very skilled listeners and communicators, being able to understand people's values and goals. So that means that most

of the time I don't do most of the talking. [It] means me being able to say, "Okay, so what I hear you saying is that your father is the type of man that if he couldn't be out there putting on the golf course, life wouldn't be worth living. Or, your father's the type of man that if we wheeled him on the golf course with a blanket over him, that would be okay. So if that's the case, then this may be the best option for you to consider."

In this manner, physicians attempt to enter the patient's world and help interpret the consequences of treatment options for someone living in that context. The culmination may be presentation of evidence for alternative options, delivery of an expert opinion as to the best course, or continued participation in a process of weighing values, preferences, evidence, and options.

#### *Development and Maintenance of Trust*

End-of-life care affords a heightened context for discerning essential prerequisites of trust, particularly as patients and their doctors consider a shift of emphasis from curative to palliative goals. Acknowledging the limits of medicine can be difficult for both parties and may provoke a reconsideration of the basis of the bond between them. There was a consensus among providers and patients that belief in the provider's technical competence is absolutely necessary to maintenance of trust in this situation, but not sufficient. Knowing that the physician cares is key:

You earn patients' trust by being able to present yourself as a knowledgeable physician, and also a caring physician. Patients appreciate and can quickly pick up basically if you're a physician that is actually interested in their case, and that I think goes a long way.

What I would look for in a physician myself [is] a human touch and that they truly care. They don't have to be Einstein, they don't have to know everything there is to know about a disease but they're lookin' out for you. (Medical Oncologist)

I rely on my oncologist, given his knowledge and number of years of doing this. Also

[important to developing trust is] the way the doctor approaches the patient: if there can be somewhat of a relaxed mood when speaking with a patient, and not being rushed. And, of course, a very sick person needs reassurance. (Patient)

Interviews as well as observations disclosed the development of a bond, indispensable to trust, based on the conviction that patients would not be abandoned, regardless of the unpleasantness of the illness or the uncertainties of the therapy. This connection was palpable upon entering the patient's room and was a recurrent emphasis in conversations about trust:

I think when patients are suffering, they have to know that the health professional can feel and acknowledge it, and even if they're not on their best behavior, the physician is there to walk with them through whatever the particular medical challenge is. I think that even if [patients] have a bad reaction to IV contrast dye or the medicine makes them really sick, if you have created that feeling that you are there because you want to help them and that you are accepting them as they are, they will trust you.

The importance of being there for the patient emotionally was coupled with the obligation to be there instrumentally; for example, to persevere in satisfying the patient's needs for information:

I think knowing that you will maintain your interest in the patient is really what inspires their trust. They gain confidence. The fact that a patient will ask a question and a doctor will call them back and answer their question seems to inspire a fair amount of trust. The other thing is knowing that all their issues will be addressed. (Medical Oncologist)

Several physicians called attention to the importance of making explicit a shared humanity that transcends differences in expertise and status that separate doctors and patients:

If you treat a patient as if they were a family member, then they will trust you. And I think if you approach someone with honesty and without arrogance that they will trust you. (Medical Oncologist)

I believe that there's a certain amount of disclosure that's necessary, a certain amount of humanity. We may try to hide behind that white coat, but we're just human beings. (Medical Oncologist)

Beyond technical competence, the building blocks of trust appear to be establishing an emotional bond and a basis for genuine interaction.

### *Emotional Involvement of Doctors with Patients*

Emotional involvement of physicians with their patients is suspect in one model, irrelevant to the second, and central to the third. Sharing emotions is viewed as a precursor to emotional identification; concerns about adverse consequences of such a bond frame the disparate positions of the three models as follows: 1) the prospect that emotional involvement of physicians will cloud their clinical judgment to the detriment of the patient's well-being, 2) the possibility that emotional dependence of patients will undermine their autonomy and destabilize the consumer-provider relationship, and 3) the likelihood that emotional identification will generate intolerable stress on physicians and lead to an untenable work life.

The value of emotional display to patients was always evident in this study, in observations and interviews.

My doctor's show of emotion lets me know he's human and sees me as a fellow human being. That's very important to me. (Patient)

Emotional involvement served as a passport for entering the patient's world. Patients rarely voiced reservations. The equivocation evident in the following comment was an exception:

Hopefully [physicians in training can find] a way by which they can express their feelings and their empathy – but yet still be able to hold a certain degree of balance. They need to know how to hold feelings back. I would not want a medical person who sobs in my presence. That would be very unbecoming, but [I do want] someone who's sympathetic and understanding. (Patient)

Patients' reservations were generally confined to concern for the well-being of their physicians, not their own comfort. Among physicians, regard for patients' feelings as well as acknowledgment of their own vulnerability was evident, but endorsement of the importance of emotional engagement prevailed.

I laugh with my patients. I pray with them if that's a request that they have. I really couldn't see practicing medicine any other way. I don't cry with them – only... in the privacy of my own office because no patient needs to be burdened by seeing me cry. What they need from me is compassion and also strength and decisiveness and competency in medical care.

In no instance was emotional display or associated identification with patients acknowledged as a threat to clear-headed decision-making; rather, such personal involvement was viewed as inevitable in establishing effective relationships. Variation in physician behavior with respect to how they show their emotions appeared to be dictated more by the doctor's personality than by their perceptions of patients.

I've cried at the bedside, I cry in the clinic. Sometimes I can't cry 'cause I'm all cried out, and sometimes I'm just numb. But I think it maintains your humanity. And when patients see it or their families see it, they realize that you're not that person in the ivory tower, that you're a real person. (Medical Oncologist)

Such openness and expression has a corollary in the potential toll on doctors, as voiced by a long-time hospice physician:

If you are a good physician, I think you are always involved in a certain way with your patients, although you need something to protect yourself. You cannot be an open sore all the time while exposed [to] all those tough cases, because you won't be able to do your work.

How can doctors whose daily work lives are devoted to end-of-life care protect themselves?<sup>24</sup> According to the functionalist perspective on relationships, containing one's emotions is the only viable course for avoiding a slippery slope. In contrast, the responses of hospice

providers to this issue demonstrate a range of mechanisms for coping under these circumstances. The conviction that they did a good job despite the difficult terrain was offered as a source of comfort in interviews with eight physicians. Five mentioned internal rewards from the work in this context, and three cited the opportunity for personal growth and learning from patients. Familiar mechanisms for avoiding burnout included sharing feelings with colleagues and maintaining boundaries between professional and personal lives. Nevertheless, there was no denying that maintaining equilibrium—balancing the demands of clinical acuity, personal engagement, and emotional stability—is an active process demanding continuing introspection and adjustment.

It's not for everybody. (Laughs) You certainly have to have accepted that life is limited, have [done] some thinking about that. All your patients will die. I can't see how you can play a role in this field if you are angry at every patient that you will lose; obviously, it won't make sense. So I think you have to have some kind of reflection on life and dying. And be emotionally in balance.

But sometimes we can be off balance. Let's say when we have a week with 10 deaths, we wonder where we are, what kind of business we are in. And sometimes, I must tell you, even though we know that they will die, we say: "Did I do something wrong? Did I hasten death? Did I miss the point?"

### *Establishing Authenticity*

Related to emotional involvement, but less tangible, is development of an authentic mode of interacting with patients, reflecting a genuine appreciation of their individuality. Irrelevant in the first model of doctor-patient relationships and superfluous to the contractual arrangements central to the second, authenticity is the hallmark of the third, the relationship-centered model. According to this perspective, doctors and patients participate in relationships as distinct individuals rather than types, guided by a process of collaboration rather than by professional obligations of physicians or autonomous rights of patients. For physicians, this approach

requires more spontaneity and potential vulnerability than adherence to prescribed roles. The latter can be learned and practiced in training as standardized approaches, while the former requires a process of introspection and self-discovery.

If you use cliché words [with patients] they get irritated. They feel like you are treating them like material. And they get offended, and they don't trust you. If you act like you are detached from them, it may help to keep you protected, but you don't help them.

You have to understand what they feel. Then you can converse better with the patient and family, because they know that you understand.

Patients confirmed the importance of this quality to their comfort with doctors:

I like to feel [my doctor] is talking to me as though I were his brother. Not only because I expect to get the same advice, but also because I can feel the sincerity, like I'm a person in his life. We're two people relating to each other. (Patient)

Patient disclosure is essential to diagnosis and treatment and a prerequisite for seeking care. Physicians, who look for commonalities in such disclosures to establish diagnoses, are confronted with patients who seek confirmation that their doctors see beyond their diagnosis, that their individuality is respected. Physicians' self-disclosure can be central to assuring patients that they are understood as individuals—that the doctor cares about them, that they are not merely another case.

I find it helpful to share my own experiences with patients, to some extent. If I have some young people with a dying parent, I'm never hesitant to share what my experiences were when my father was dying – just to give [them] some common ground to relate to and show that you're a human as well.

This quote illustrates the importance of symmetry: The doctor, in permitting patients to see her as an individual, provides assurance to patients that, as a physician, she appreciates their uniqueness.

Authenticity is an elusive quality, and providers were asked about their capacity for expressing it.

You really have to be comfortable with yourself. That's the bottom line. If you have to use a script to do it, that's okay because it takes a while to be comfortable. I think we're always afraid of how somebody's going to react.

Fear of the unpredictability of patients' responses may, at least unconsciously, promote restrictive behavior on the part of physicians. Over time, according to several respondents, providers can become more comfortable with the self-disclosure associated with spontaneity and improvisation in interacting with patients. Structural differences in the roles of providers and patients introduce other barriers to authenticity.

When anything becomes institutionalized, it becomes difficult...to look at every patient as an individual within that system. I think there's something about the very intensity of the connection that really draws you. I'll just remind myself before I enter a room, no matter how hurried – I'll stop and say [to myself] "Just remember, it could be your child...grown old," and that helps me to see the person. [It] brings me...right into that moment and to heck with anything else.

This strategy calls attention to the challenges posed by the dramatic divergence in perspectives on the meaning of an illness episode: for the doctor, it is a routine part of the workday; for the patient, it is unique, often traumatic. For this provider, a conscious effort is required to maintain the individuality of patients in these circumstances and avoid reducing them to cases.

## Discussion

Study of hospice care offers a rich opportunity to critically assess aspects of the role of physicians in the doctor-patient relationship and yield insights into possibilities for promoting patient-centered care. Of particular interest here are lessons from end-of-life care that have broader application in health care delivery, their fit with prevailing models of doctor-

patient relationships, and the implications for medical education as a potential vehicle for change.

### *Lessons from Hospice Care*

Delivery of effective hospice care demonstrates the potential to serve an expansive scope of needs. Patients' needs at the end of life do not respect the boundaries of medical specialties or social service systems. Success in addressing such an array, as witnessed in the care plans developed at the sites observed for this study, entails overcoming several obstacles. First, hospice care requires too broad an expanse of expertise for one provider to master—not only medicine, but nursing, social work, pastoral counseling, ethics, and psychology. Second, needs are served in numerous settings, with home as the central one. Third, they are often entangled with complex social problems that do not respond to medical interventions. Finally, they are too numerous to address in the course of a normal workday. Serving these needs compels a team approach, increasingly recognized as vital across the health care delivery system,<sup>25</sup> but difficult to achieve. The effectiveness of hospice care in this light is particularly evident in delivery of home-based services. The variety of disciplines involved, as well as their appropriate integration in a care plan, are exemplary in realizing the promise of interdisciplinary care. Effective attention to patients' needs in these circumstances was further enhanced by sensitivity to individual belief systems, sophistication in addressing organizational and financial issues, and creativity in modifying clinical routines to harmonize with the particular expectations of patients and their families.

The manner of exercising authority in decision making sets the dynamic and tone for the physician's role. Hospice physicians were observed to modulate their strategy to suit each patient's situation. They were observed variably giving orders based on their status as experts (in accord with the functionalist model), serving as consultants to patients and responding to their decisions (consistent with the patient-centered approach), and collaborating with patients in a process of clarifying values and making choices (consonant with the relationship-centered model). Assumption of a specific posture was governed

mainly by the patient's needs, not the provider's personality. The mode of exerting authority was grounded in a broad knowledge of the patient's and family members' experience of illness.

While providers generally found the consumer-oriented approach appealing in supporting patient autonomy and self-determination, providing sufficient information to the patient to facilitate the consumer role was a daunting task. Transmission of comprehensive information is confounded by uncertainties deriving from unknowns in medical knowledge, burdens of communicating complexities surrounding what is known, and the enormity of the consequences of suboptimal decisions. Several physicians commented that delegating decision making to patients, in the face of these challenges, may be abandonment in some instances.

The experience of hospice providers illuminates the challenges in implementing a dynamic approach to exerting authority. First, to discern the needs of patients, which may differ from those of their families, physicians must have extensive knowledge of patients' lives and of the meaning of illness within that broader context. Access to this knowledge requires a practice organization that affords continuity in the relationship and associated development of rapport. Paralleling this organizational compatibility, implementation of this fluid approach requires an internal harmony: Physicians must be aware of and contend with elements of their own personalities that may limit adaptability of their behavior to suit patients' needs. Training can play a role in preparing doctors to address these challenges, as discussed below.

The relationship between hospice providers and their patients—as they consider a shift of emphasis from curative to palliative goals—was generally distinguished by a heightened trust that patients would not be abandoned, regardless of the unpleasantness of the illness or uncertainties of the therapy.<sup>26</sup> Sustaining this trust was development of an emotional bond and a basis for genuine interaction. Provider authenticity in interacting with patients provided assurance that patients were understood as individuals, that the doctor cared about them, that they were not merely another case.

Prohibitions against emotional involvement with patients are conveyed in medical training, based on the long-standing supposition that expression of emotion must be censored to safeguard the well-being of patients and to minimize the vulnerability of physicians. Provision of end-of-life care, however, demonstrates that emotional neutrality—the capacity for maintaining distance—is illusory. Emotional responses are ubiquitous; failure to acknowledge and address them may be problematic. It is conceivable, for example, that oncologists' feelings of guilt and sorrow about the prospect of giving up on their patients may delay reassessment of the appropriateness of aggressive treatment regimens and consideration of palliative rather than curative goals. In this manner, emotional involvement may impair clinical judgment. Rather than proscribing or denying such sentiments, attention to techniques for identifying and dealing with feelings about patients can be helpful to physicians in keeping the interests of patients paramount.<sup>27,28</sup>

Hospice providers evidenced a range of mechanisms for coping with the vulnerability associated with emotional identification with patients: appreciating the internal rewards of the work, embracing the conviction that they did a good job despite the challenges, and experiencing the opportunity for personal growth and learning from patients. Mechanisms for avoiding burnout included sharing feelings with colleagues and maintaining boundaries between professional and personal lives.

### *Rethinking Prevailing Models*

Findings on hospice care belie several of the assumptions of the functionalist and consumer models, demonstrating a more supple resolution of the tension between a constricted set of patient needs meriting attention, inherent in the former model, and a range of needs dictated strictly by consumer demand envisioned by the second. Functionalist theorizers pose rules to curb unbridled enthusiasm and unlimited demands: Physicians should confine their use of authority to areas relevant to their expertise. Patient-centered perspectives also advocate restraint: Consumers have the right and duty to set the agenda for the medical visit. For these models, defining the territory

for intervention is straightforward: In the first, doctors are best equipped to know the limits of their expertise and practice accordingly; in the second, patients are in the best position to know what ails them and are obligated to choose among available services. Hospice care, committed to serving unmet needs at the end of life,<sup>29–32</sup> demonstrates a more fluid resolution: Delineation of needs and the associated care plan evolves from a collaboration of providers, patient, and family members.

The dynamic process of suiting the mode of exercising authority to the needs of the patient, generally embraced by hospice providers, exemplifies the strengths of the relationship-centered model and the challenges in implementing it. The functionalist and patient-centered models are prescriptive, and guidelines for their realization can be conveyed in protocols for behavior to cover most situations. Adoption of the relationship-centered approach demands a layer of judgment, and preparation of physicians to apply it poses distinctive challenges to medical educators.

Emotional involvement of physicians with their patients is proscribed in the functionalist model, irrelevant to the patient-centered model, and central to the relationship-centered model. The experience of hospice providers is instructive in countering the assumption that such emotional exchange is unhealthy to the doctor-patient relationship. Physicians' ability to acknowledge and deal with their emotional responses to patients may be critical to preserving their clinical judgment and reducing stress in their work lives. Benefits to the patient, summarized earlier, were evident throughout the observations and interviews conducted for this study.

### *Preparing Physicians to Assume New Roles with Patients*

The contribution of training to prepare physicians to play these roles may be limited by the extent to which basic elements—e.g., expression of emotion and authenticity—depend on personality characteristics that predate medical school and may be immutable. Nevertheless, the perils of neglecting those aspects of patient care known as the art of medicine are increasingly recognized by medical educators.

Efforts to promote authenticity in relating to patients necessitate strategies to foster greater awareness among physicians of how they are perceived in their routine interactions and the emotional consequences for patients. Videotaping of students' encounters with patients coupled with guided review and feedback is a powerful mechanism for accomplishing this aim. Likewise, interactions with standardized patients (SPs) who are trained to portray specific roles and expose students to particular problems and issues, along with extensive feedback on their performance, can be effective in this regard. While in the past, SPs have been used mainly to teach physical diagnosis and clinical reasoning, they have been increasingly used to address communication issues as well.<sup>33</sup>

Increasing attention in the medical curriculum to addressing difficult issues in patient care is evidenced by the prominence of such topics as giving bad news, caring for angry patients, and addressing sexuality in the medical encounter. Consistent with much of clinical training, the focus of such teaching is often on learning to implement established protocols for handling particular issues, such as the SPIKES mnemonic specifying a process for giving bad news that requires attention to **S**etting, **P**erception, **I**nvitation, **K**nowledge, **E**motions, and **S**trategy.<sup>34,35</sup> The availability of such protocols may be valuable to young physicians in their initial experiences with these issues, and reliance upon them may satisfy the curriculum's demands for efficiency. However, protocols tend to support a view of patients as types (e.g., who progress through prespecified stages), potentially undermining authenticity and jeopardizing effectiveness. As such, protocols may be useful initially, but unless they are incorporated into a student's personal style, they may lack sufficient authenticity to achieve their intended effect. The role of training in this process, while seemingly elusive, has been demonstrated, not only through use of videotapes and SPs but also by explicit attention in clinical teaching to fostering personal awareness. Personal awareness groups, in the context of clinical rotations as well as continuing medical education, rely on individual feedback offered by peers and supervisors designed to examine the impact of providers' values, emotions, and preferences on how



they relate to patients. Similar in purpose is the reemergence of Balint groups run by and for physicians, focusing on aspects of the doctor-patient relationship and the role of emotions.<sup>36,37</sup>

Physicians in this study, in interviews and actions, frequently conveyed their feeling that it is a privilege to participate in the last chapter of their patients' lives, and their sense of wonder in doing medical work appeared to extend to a fascination with the complexity of the bonds they develop with their patients. Training may promote and sustain this outlook<sup>38</sup> through medicine and literature courses<sup>39</sup> focusing on the stories inherent in medical encounters<sup>40,41</sup> and providing a reminder of the common humanity that binds doctor and patient and confirmation of the individuality of both parties as they confront the seeming impersonality of the health care delivery system.

### **Conclusions**

Methodologically, this study shares several of the strengths as well as limitations of qualitative research. Its facility for generating hypotheses and conceptual models in underexplored terrain is paired with its incapacity to test those hypotheses. Similarly, the high degree of validity afforded by the intensity of data collection is matched by the inability to establish the frequency with which phenomena are distributed in the general population (which would require probability samples and adequate statistical power). Within these constraints, elements of the research design were aimed at maximizing the validity of the findings for the study sample and broadening their relevance to other contexts. Among the techniques used were systematic sampling, comparison of perspectives of doctors and patients, inductive analysis grounded in a prespecified conceptual framework, confirmation of insights from observations with those from interviews, and substantiation of the salience of major themes through review with patients as well as providers.

Study of hospice care provides evidence for challenging prominent assumptions about possibilities for doctor-patient relationships, questioning the merits of the prohibition on emotional involvement, dependence on

protocols for handling difficult communication issues, unqualified reliance on consumer empowerment to assure that care is responsive to patients' needs, and adoption of narrowly defined boundaries between medical and social service systems in caring for patients. In many instances, promoting patient-centered care necessitates rejecting functionalist as well as consumer-oriented perspectives on these dimensions in favor of the more fluid, complex, and less-well-specified precepts of the relationship-centered model. Particularly compelling are the lessons from hospice care for applying this model: serving an expansive set of needs; suiting the mode of exerting authority to the anomalies of individual patients and their situations; balancing expression of emotions, vulnerability, and protective defenses on the job; and maintaining authenticity in routinely treating patients in traumatic situations. Medical education can play a role in preparing doctors to assume new roles by openly addressing management of emotions in routine clinical work, incorporating personal awareness training, facilitating reflection on interactions with patients through use of standardized patients and videotapes, and expanding capacity to effectively address a broad range of needs through teamwork training.

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