

A Culture of Avoidance: Voices From Inside Ethically Difficult Clinical Situations

Carol Pavlish, PhD, RN, FAAN, Katherine Brown-Saltzman, MA, RN, Alyssa Fine, MS, RN, and Patricia Jakel, MN, RN, AOCN®



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Background: Healthcare providers experience many ethical challenges while caring for and making treatment decisions with patients and their families.

Objectives: The purpose of this ethnographic study was to examine the challenges and circumstances that surround ethically difficult situations in oncology practice.

Methods: The authors conducted six focus groups with 30 oncology nurses in the United States and interviewed 12 key informants, such as clinical ethicists, oncologists, and nurse administrators.

Findings: The authors found that many healthcare providers remain silent about ethical concerns until a precipitating crisis occurs and ethical questions can no longer be avoided. Patients, families,

nurses, and physicians tended to delay or defer conversations about prognosis and end-of-life treatment options. Individual, interactional, and system-level factors perpetuated the culture of avoidance. These included the intellectual and emotional toll of addressing ethics, differences in moral perspectives, fear of harming relationships, lack of continuity in care, emphasis on efficiency, and lack of shared decision making. This information is critical for any proactive and system-level effort aimed at mitigating ethical conflicts and their frequent companions—moral distress and burnout.

Carol Pavlish, PhD, RN, FAAN, is an associate professor in the School of Nursing at the University of California, Los Angeles (UCLA); Katherine Brown-Saltzman, MA, RN, is a co-director at the UCLA Health System Ethics Center; Alyssa Fine, MS, RN, is a student research assistant in the School of Nursing at UCLA; and Patricia Jakel, MN, RN, AOCN®, is a clinical nurse specialist at UCLA Medical Center, Santa Monica. The authors take full responsibility for the content of the article. This study was supported, in part, by a grant from the ONS Foundation Small Grants Research Program. The content of this article has been reviewed by independent peer reviewers to ensure that it is balanced, objective, and free from commercial bias. No financial relationships relevant to the content of this article have been disclosed by the independent peer reviewers or editorial staff. Pavlish can be reached at cpavlish@sonnet.ucla.edu, with copy to editor at CJONEditor@ons.org. (Submitted April 2014. Revision submitted June 2014. Accepted for publication June 10, 2014.)

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Rapidly expanding treatment possibilities, complex health-management systems, and fiscal constraints add to the importance of ethical decision making. Healthcare providers report increasing pressure from administrators, colleagues, patients, and families to provide life-extending treatments (Hamric & Blackhall, 2007). A study by Teno et al. (2013) compared 2000, 2005, and 2009 Medicare reimbursement patterns and noted that more people are now dying at home; however, intensive care unit (ICU) stays during the final month of life are steadily rising. Healthcare providers are confronted with profoundly important considerations, such as treatment harms and benefits, resource allocation, and how decisions are made in conditions of prognostic uncertainty. These ethical challenges coincide with increasing moral distress reports among healthcare providers (Ulrich, Hamric, & Grady, 2010) and a relatively high percentage (46%) of 7,288 physicians reporting at least one burnout symptom (Shanafelt et al., 2012).

The purpose of the current study was to examine the challenges and circumstances that providers encounter when working together to manage ethically complex oncology situations. Research indicates that oncology nurses encounter ethically difficult situations more frequently and experience more moral distress than other specialists (Rice, Rady, Hamrick, Verheijde, & Pendergast, 2008; Shepard, 2010). The authors of the current article decided to explore the healthcare processes and practices that potentially contribute to these situations.

Background

Stakeholders, such as patients, families, and providers, must interact to make important treatment decisions in the context of expanding options and sometimes contrasting moral perspectives. Many challenges result. For example, nurses experience moral distress when witnessing unnecessary patient suffering (Gutierrez, 2005; Huffman & Rittenmeyer, 2012; Varco, Pauly,

Storch, Newton, & Makaroff, 2012). A critical incident study with Canadian palliative care providers revealed challenging ethical circumstances, such as determining treatment appropriateness, watching patients suffer, and talking with patients about dying (Brazil, Kassalainen, Ploeg, & Marshall, 2010). In addition, nurses report that ethical challenges (i.e., advance care planning, staffing patterns, and protecting autonomy and informed consent) occur in their daily clinical practice (Ulrich, Taylor, et al., 2010). In a survey of 422 nurses, researchers found that oncology nurses reported not only encountering non-beneficial treatments more frequently, but also the highest intensity of moral distress (Rice et al., 2008).

Those findings indicate that ethical challenges often emanate from different moral perspectives, which can lead to ethics-related stress, ethical conflicts, and moral distress. Because these experiences can be time intensive and costly in terms of human suffering and financial burden (Austin, 2012; Hamric, 2012; Ulrich et al., 2007), learning more about the common circumstances in which these ethical issues occur seems warranted.

Methods

This article stems from a larger ethnographic study that explored challenges and circumstance in ethically difficult oncology situations. The authors' findings on focus group discussions regarding ethical challenges, such as witnessing patient suffering and balancing hope and honesty, were reported previously (Pavlish, Brown-Saltzman, Jakel, & Rounkle, 2012). Data from key stakeholders on the meaning of moral communities also

have been described (Pavlish, Brown-Saltzman, Jakel, & Fine, 2014). System-level and circumstantial factors that influence the development and management of ethically difficult situations are reported in the current article.

The aim of ethnography is to explore how people interact and attach meaning to everyday events within a specific context (Bernard, 2011). Specific details regarding data collection and analysis have been reported elsewhere (Pavlish et al., 2012) and are summarized here. After gaining approval from the University of California Office of the Human Research Protection Program, the authors conducted six focus groups with 30 oncology nurses who were recruited from an Oncology Nursing Society chapter in southern California. The authors subsequently interviewed 12 key informants, including five clinical ethicists, a bioethics nurse researcher, two oncologists, and four oncology nurse administrators who were directly recruited for their specialized knowledge (see Table 1). Among all participants, there were 30 European Americans, 6 Asian Americans, 4 Mexican Americans, and 2 African Americans.

During focus groups and key informant interviews, the authors asked questions about ethically complex situations and the situational factors that influence them (see Figure 1). All sessions were audio recorded, transcribed, and imported into Atlas.ti® software. The authors separated key informant from focus group data, but followed the same analytic process. One researcher initially read and inductively categorized all data into three major sections: ethically difficult cases, healthcare system characteristics, and challenges in ethically difficult clinical situations (see Figure 2). Data on ethics situations and system characteristics were analyzed. Using an inductive, descriptive approach, the research team detail coded all data in the two categories and often used participants' words as detail codes. These codes were subsequently sorted into similar, higher-level clusters that were finally conceptualized into themes (Saldana, 2009). The team met weekly to compare codes and to decide on level of abstraction in clusters and themes. All clusters and themes were linked to specific quotes. Codes and analytic decisions were recorded in a team-based codebook (MacQueen, McLellan-Lemal, Bartholow, & Milstein, 2008).

Findings

Culture of Avoidance

Nurses and key informants described a culture that is predominantly silent about ethical concerns until a series of painful events or a precipitating crisis occurs, and ethical questions can no longer be avoided. For example, administering aggressive treatments at the end of life was illustrated in 65% of the 62 ethically difficult situations that participants described. In those situations, healthcare providers often delayed difficult conversations about poor prognosis or end-of-life treatment options. Echoing other nurses who called for earlier end-of-life conversations, a nurse recalled an imminently dying young man who "was in pain and agony trying to breathe." Code status had not been discussed with parents despite the patient having been in ICU for a month. Describing delays, a nurse suggested, "Someone should say, 'We don't want to force you, but in the event that you go to ICU . . . ' but we don't do that here. Physicians really wait until the very end."

TABLE 1. Characteristics of Study Participants

Characteristic	Key Informants (n = 12)	Nurses (n = 30)
	$\bar{X}$	$\bar{X}$
Age (years)	53.1	42.5
Years of clinical work experience		
Health care	25.5	—
Nursing	—	16.1
Oncology	—	12.7
Characteristic	n	n
Gender		
Female	10	29
Male	2	1
Level of education		
Nursing diploma	2	—
Medical degree	2	—
Associate degree	—	7
Bachelor's degree	—	13
Master's degree	3	7
DNP	—	1
PhD	5	—
No response	—	2
Type of ethics education		
Formal ethics education	8	15
Informal ethics education	4	9
No ethics education	—	6

Participants emphasized that physicians need to be honest about prognosis and treatment limitations because, as one nurse noted, “Patients can make better decisions when they know what’s going on—even if it hurts them.” Several participants, however, acknowledged the challenge of honest conversations when prognosis is uncertain and families are hopeful. Describing a physician who delicately asked about a patient’s wishes on code status, a nurse summarized, “He [physician] didn’t lie, but I heard a lot of things he left out.” Further illustrations of avoidance are provided in Figure 3.

Factors That Perpetuate Avoidance

Four factors appeared to preserve the culture of avoidance. Some of these factors were at the intra- and interpersonal levels. However, most of the factors operated at the system level.

A different kind of complexity: The intellectual and emotional toll of addressing ethics often perpetuates avoidance. For example, an ethicist noted that healthcare providers work in settings that generally require the “language of solution—fixing and solving.” In contrast, encountering ethical concerns are “quite foreign” and require unusual ways of thinking that “challenge, disrupt, and shift” their view of clinical problems. The intellectual demand to think differently requires time and energy, which many providers indicated were in short supply. When time is short, an ethicist claimed, “Providers tend to think, ‘If I can get someone else to do it [raise ethical concerns], it’s just easier.’”

Some providers struggled with the emotional demand of working with seriously ill patients. Describing a situation when a terminally ill patient and his family declared a decision to withdraw treatments, one nurse explained, “The physician told the patient’s wife, ‘I am just not ready to terminate treatment.’ I sometimes think that physicians feel it’s a personal failure when patients do not do well.” A clinical ethicist claimed that some nurses avoid ethical concerns because they believe a call for help “reflects on me . . . that I’m unable to handle it . . . that my colleagues might see me as somehow less.” Another ethicist commented that nurses might be aware of ethical issues but think, “The nurse who was on the shift before me or the shift after me doesn’t see this as a problem so maybe I shouldn’t expose it.” Several nurses acknowledged inadequate preparation for clinically applied ethics. An ethicist commented, “I think they [providers] sometimes lack a language to talk about it [ethics] and a way to [legitimize] their viewpoints,” which discourages conversation.

Patients and families also experienced troubling emotions. An ethicist stated,

I don’t know if it’s particular to our institution, but some families distrust the medical system. They don’t actually believe that you’re doing the right thing . . . that you have some other agenda. There are a lot of those situations and some are cultural differences.

A physician substantiated the challenge of working across cultures in emotionally charged situations and recalled a situation when an elderly patient indicated she did not want “another painful biopsy,” but her daughter strongly persuaded her to sign the consent. The physician commented that determining patient preferences amidst family anxieties is difficult, which sometimes leads to avoidance.

Different conceptions of good care: Moral differences were evident and difficult to traverse. For example, a nurse stated,

“I don’t understand physicians . . . I understand their model of practice is cure not care, but I cannot understand some physicians’ subjective blindness to nurses’ distress, which is often very visible.” Another nurse commented, “It’s so fascinating to me that doctors and nurses work so closely together and yet our viewpoints on certain things like [aggressive treatment at end of life] are just eons apart.” In contrast, a physician stated, “We bond with patients. We know their families, dogs, kids. Nurses see patients at the end; that’s why they’re so willing to ‘pull the plug.’” These contrasting perspectives illustrate moral differences that can lead to significant disagreements. As one ethicist explained,

Identity is at stake in morality. I think that’s built into some differences. Understanding what it means to be a good physician, that you will do whatever is absolutely necessary—that must be dealt with . . . just like to be a good nurse is to help this person have a good death. So you have these fundamental differences.

Another ethicist commented that nurses and physicians have “different responsibilities, regulations, education, and disciplinary knowledge, so naturally there will be tensions over what gets defined as the best thing to do in a situation.” A nurse manager illustrated these different perspectives when describing arguments between physicians and nurses about the best time to discuss treatment options with patients.

Nurses say that conversation needs to take place at the beginning of serious treatments. Physicians shouldn’t wait until patients depend on a machine and say, “Okay, now you have to decide, do you want us to take it away?” It doesn’t make sense. But that’s how it happens.

Introductory Questions

- Please talk about how you, in your current position, have become involved in ethically difficult situations.
- What do you see as your role in those situations?

Key Questions

- Please tell us about a time when you were involved in an ethically difficult situation.
- How might the situation been avoided, altered?
- What were some of the earliest signs that an ethically difficult situation was developing?
- What early actions seem particularly effective in addressing ethical dilemmas?
- What strengths are in the current systems and structures that surround ethically difficult situations?
- What are the actual and potential barriers to those systems and structures?
- How are barriers being addressed and how would you like to see the barriers addressed?
- What would you like to see in the future for programs that seek to prevent ethical dilemmas?

Concluding Questions

- What concluding thoughts do you have about preventing ethically difficult situations?
- Of all the things we talked about today, what aspects seem most important or urgent to you?

FIGURE 1. Interview Questions

Fear of harming relationships: Some providers claimed that raising ethical questions could harm important relationships with patients, families, or colleagues. A clinical ethicist commented on nurses' frequently expressed worry that introducing ethical questions will "interfere with the relationship they have with the family and patient. Balancing those relational dynamics is key to actually being successful as a nurse. Requesting someone else [ethicist] into the situation may be interpreted wrongly and shift the balance." As a result, nurses often avoid "kicking up dirt," "rocking the boat," "stirring the waters," or "stepping on toes" for fear of offending someone and harming current and future working relationships. Physician participants were also concerned about maintaining relationships and remarked that

they sometimes hesitate to have serious ethical conversations for fear of alienating patients and families or even their colleagues.

System processes that entrench avoidance: In a culture of avoidance, powerful system processes that "inadvertently and easily silence people" often operate (see Figure 4). First, study participants emphasized that care inconsistencies, including varying caregivers and physician rotations, perpetuate avoidance. An oncologist remarked that physicians might change every two to four weeks, whereas an ethicist noted difficulties when fellows rotate monthly, and important questions such as guardianship are "passed onto the next team." A physician indicated "opinions and beliefs" about goals of care may change as frequently as physicians. Turnover can disrupt trust and communication, which are critical for creating strong team relationships.

Second, participants described a health system that prioritizes the efficiency of the acute care medical model—often to the detriment of ethical issues. Limited time at the bedside was often cited for hindering communication and preventing holistic care. Respondents referred to some providers "talking about the patient in terms of body parts," which prioritizes technical care and results in sizable service gaps, such as promoting informed decision making, team-oriented goal setting, and patient preferences.

Finally, unilateral decision making, often a result of power differentials in relationships, influenced moral action. An ethicist claimed that healthcare systems have powerful norms that signify "differences in status relationships and whose work is considered more important." Providers also described hierarchy between physician teams that silenced concerns and encouraged unilateral decision making. Some respondents even suggested that the health system's emphasis on patient autonomy and satisfaction contributes to providers acquiescing to patient or family demands, sometimes without regard to standards of care. Providers and ethicists called for more education and policies to guide healthcare providers' considerations regarding treatment benefits and burdens along with criteria for identifying non-beneficial treatment.

Discussion

Participants described numerous ethically difficult situations, most of which evidenced late conversations about ethically important topics such as code status, informed consent, and end-of-life treatment options. Ethical conflicts and their lingering effects featured prominently. Because conflicts are potentially time- and effort-intensive tasks, some stakeholders, including patients and families, sought to avoid circumstances such as unpleasant emotional responses, impaired relationships, retribution, or prognostic errors. Uncertainty about how and when to initiate difficult conversations also was evident.

Delaying ethical considerations is not unique to clinicians. Researchers found that providers continue high-intensity treatments relative to poor prognosis in the final weeks of older adult patients' lives (Morden et al., 2012). Bakitas et al. (2013) reported that providers delay referring patients with heart disease for palliative care services until the last month of life. Those findings may manifest patient preferences. However, research also indicates that when patients have knowledge that medical interventions are not likely to improve their condition, they usually refuse aggressive measures (Morgan, Howe, Whitcomb, & Smith, 2011).

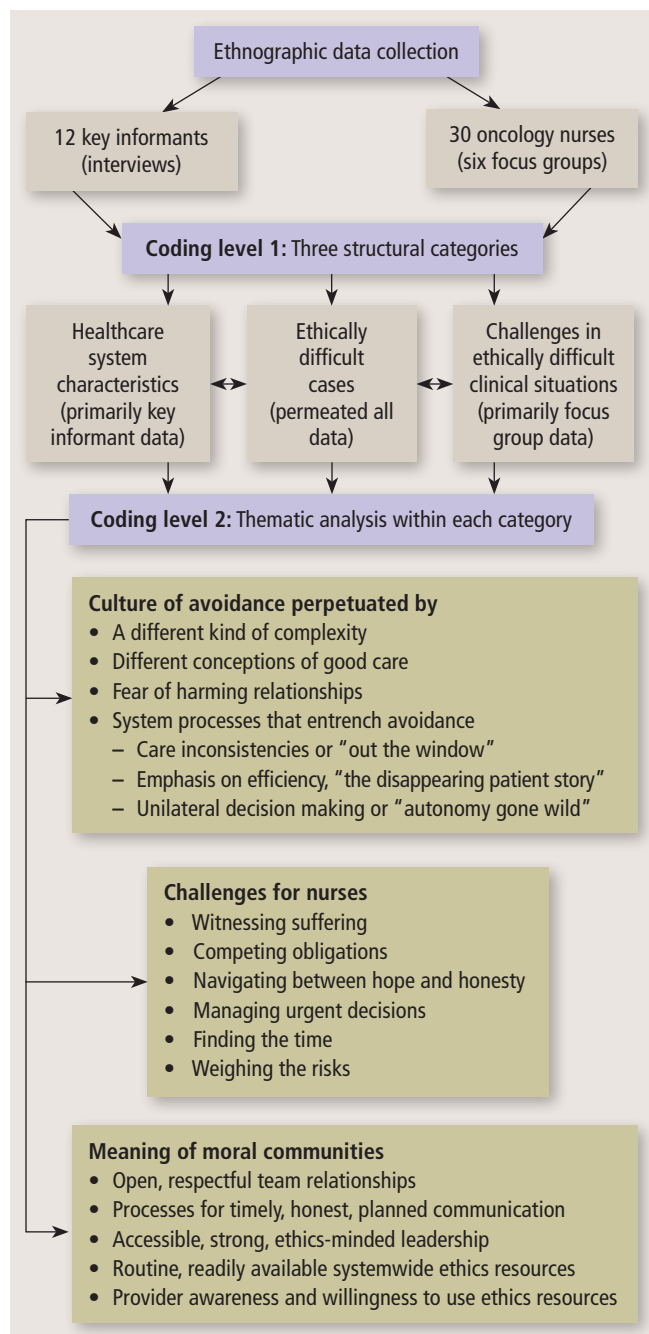


FIGURE 2. Ethnographic Data Analysis

Note. Based on information from Pavlish et al., 2012, 2014.

Implications for Practice

- ▶ Seek out opportunities for open dialogue about ethical considerations of treatment.
- ▶ Initiate goals-of-care conversations with patients and their families.
- ▶ Work to establish an environment conducive to comfortable, early, and inclusive conversations about all treatment options for patients, particularly as they experience the hardships of a failed treatment.

Some providers delay difficult conversations with patients and families. Fifty-five percent of 1,809 physicians said they described a patient's prognosis as more hopeful than the evidence supported (Iezzoni, Rao, DesRoches, Vogeli, & Campbell, 2012). Pimlott (2012) claimed that few older adults discuss end-of-life options with their physicians, and Barclay and Maher (2010) asserted that when prognosis is uncertain, physicians often are reluctant to discuss end-of-life options with patients and, instead, wait until they are asked or until prognosis becomes clearer. Investigating information that oncologists share with patients, Koedoot et al. (2004) found that physicians' time was primarily spent on active treatment options and not on watchful waiting. Similarly, White, Engelberg, Wenrich, Lo, and Curtis (2007) found that, during ICU family conferences, physician-family discussions pertained to functional status with limited time spent discussing prognosis. Researchers encouraged more direct discussion about end of life to avoid high prevalence of family misunderstandings. These studies seem to reinforce the current findings on a culture of avoidance. Delayed conversations are particularly noteworthy given the evidence that hospitalization and ICU stays in the last week of life decrease patients' quality of life (Zhang, Nilsson, & Prigerson, 2012).

Most study participants indicated that administering non-beneficial treatments was the most troubling situation that led to

conflict. Sibbald, Downar, and Hawryluck (2007) found that non-beneficial treatment is usually provided when families demand it, healthcare teams lack consensus, and in absence of timely or skilled communication. Researchers suggested mandating early and skilled discussion about resuscitation status, educating the public about appropriate care, and providing support for providers who encounter difficult situations.

Similarly, participants in the current study attributed futility situations to delayed family education about prognosis and treatment options for seriously ill patients. Indicating that physicians had this responsibility, some nurses stated they simply "shook their heads" and often remained silent. In a grounded theory study, Attree (2007) found that nurses avoided raising concerns about quality care because they fear retribution in powerful, blaming cultures. In other studies, healthcare providers sought to avoid conflict by accommodating differences rather than expressing concerns. Physicians responded to ethically difficult situations by avoiding conflict (Hurst, Hull, DuVal, & Danis, 2005). Strategies, such as detaching oneself, withdrawing from the case, or acquiescing, were evident.

Structural patterns such as power status differentials, inadequate opportunities for provider-patient communication, and insufficient interdisciplinary collaboration perpetuated avoidance. For example, a four-nation study found that nurses believed their perspectives regarding patients' treatment goals were not valued and, consequently, they often were silent about ethical concerns which sometimes interfered with collaboration (Malloy et al., 2009). Curtis and Shannon (2006) described nurses' and physicians' work environments as "parallel, but minimally interactive" (p. 16), with few opportunities for collaboration. The authors called for system improvements so providers can communicate on care goals and treatment plans and, consequently, increase sensitive, cohesive messages with patients and families. The importance of collaboration was substantiated by Larrabee et al. (2004), who associated good nurse-physician communication with higher patient satisfaction scores.

Clinical Nurse Specialist

"I think people start talking around patients instead of with patients about their condition. So physicians say, 'I'm going in to see Fred now. He's looking really bad,' but in the room they say, 'Oh hi, how are you doing, Fred?' So they talk among themselves, but they go in and maybe the blood counts are good or the patient is cheerful about a wedding, so they talk around and about but not necessarily address, 'Well, you know this is the third time that the tumor marker has gone up.'"

Oncology Nurse Manager

"Sometimes nurses look away from the problem in the hopes that it will just get better."

Clinical Ethicist

The clinical ethicist described a "rescue" or "keep patients hopeful" mindset among many healthcare providers, and the result often is a series of sequential treatments without any discussion about "if treatment does not work" or "what it really means to choose aggressive measures."

Nurse

"Even after a series of failed treatments, no one stands up to say, 'Is this sensible?'"

Clinical Ethicist

"If we see a person in an [intensive care unit] for seven days, we should be looking at advance directives, who is the decision maker, have they done a goals-of-care conversation. If we don't have those three things in seven days, we're on the road to tragedy."

Nurse

"Conflict arises when the family [doesn't] hear [the grim prognosis] . . . so their loved one is elderly, has renal failure, dementia, and [the family] wants all the treatments. Somebody should have had a discussion with that patient and family a long time ago. I think those are the hardest cases. I feel like it's battery what we do to these people."

Clinical Ethicist

"Often times these situations haven't just happened that day, but there's no planning. A lot of it is driven by health care, thinking we can cure everybody and keep them alive forever—that you can get anything you want if you have enough money and the right attorney. I think the public needs to be more aware about what's appropriate care and what's not, and is putting the person who doesn't really have quality of life on a ventilator in the [intensive care unit] the right thing to do?"

FIGURE 3. Supporting Quotes for Culture of Avoidance

Care Inconsistencies or "Out the Window"

- **Clinical ethicist:** "We had an ethics conference, but the provider changed and then what everybody agreed to last week is 'out the window' and we're starting all over again."
- **Oncologist:** "It's difficult being your first day on service, without a relationship with a patient to have a discussion on long-term goals of care."
- **Clinical ethicist:** "Institutions that create conditions that build relationships over time is fundamentally important."

Emphasis on Efficiency or "The Disappearing Patient Story"

- **Clinical ethicist:** "There is so much emphasis on efficiency with its metrics, checklists, and electronic medical charting. The patient story, which is especially important during ethical considerations, is disappearing."
- **Nurse:** "Hospitals operate like a GM plant floor, with patients rotating rapidly between settings geared to fixing medical problems with short-term solutions."
- **Nurse, outpatient setting:** "It's like a car wash or drive-thru due to scheduling. Patient turnover is just go, go, go, and by the time you have the time to look . . . you just run into all kinds of issues."

Unilateral Decision Making or "Autonomy Gone Wild"

- **Clinical ethicist:** "I call it 'autonomy gone wild.' How do we maintain mutual respect for families and patients who we believe might be making bad decisions? If you offer treatment and hope they won't accept it, that's crazy. Why would a physician offer something that's not going to work?"
- **Nurse administrator:** "We want to do the right thing, but then there's patient satisfaction scores, so we keep the status quo to keep everyone happy."
- **Nurse:** "In our institution, there's even a hierarchy between the attendings and fellows. The fellow is sometimes more aware of what needs to be done, but the attending says, 'Oh. He's eligible for a clinical trial,' or they really push the envelope and then they walk back across the street to the private side, and the fellow is left there holding the bag and sometimes he doesn't have a lot of guidance, but he follows whoever above him told him what to do even though it may be against [his own viewpoint]."
- **Clinical ethicist:** "Regarding pressure for aggressive treatments, it's very rare that the doctor will say, 'I'm done because this is inappropriate.'"

FIGURE 4. Supporting Quotes for System Processes That Entrench Avoidance

Limitations

Potential for bias exists because participants who responded to the authors' invitation could be more interested in healthcare ethics than other clinicians. In addition, although the authors drew from several settings, the results cannot be generalized.

Conclusion

Organizational cultures that discourage early, inclusive participation in ethics-related treatment considerations tend to concentrate moral authority, which renders "moral muteness" (Verhezen, 2010, p. 188) for some and can lead to moral desensitization and disengagement. The research findings suggest that healthcare organizations can benefit from developing processes and practices that make ethical considerations an early and routine part of everyday clinical practice. Opportu-

nities for the healthcare team, including patient and family, to discuss goals of care, consider medically appropriate and ethical implications of various treatment options, and make decisions together also are necessary. Those practices construct organizational cultures where interdependence and shared decision making are valued, moral differences are addressed, dialogue is encouraged, and where all voices blend in, providing the best care possible for seriously ill patients and their families.

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Learning From Disaster: Continued from page 156

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