

Stories Tell Us What We Need To Know: Perspective for Ethical Dilemmas— *The Story Study*

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Narrative in Ethics

We hear stories and tell stories every day we practice medicine without appreciating that the resolutions we seek in ethical dilemmas often unfold from the stories of our patients, their families, and our colleagues. A story holds so much life, and knowledge in context leads to better understanding. Yet, misguided, we search for detail in chemical blood levels, shadows in a radiographic image, rising and falling numbers on a graphic. More distracting are assumptions and perceptions from our single-minded perspective.

Stories clear the mind.

Relevance of Narrative Medicine

Physicians and health care professionals who read and write narratives of clinical encounters can improve their diagnostic and communication competence. By listening closely to patients' stories, physicians and health care professionals broaden their perspective and organize and integrate complex situations, leading to solutions to dilemmas. Stories clear the mind.

The Value of the Subjective

In medicine, we often speak of wanting objective data or evidence, thereby relegating the subjective realm to ineffectuality or to marginal value at best. Using S.O.A.P. notes, however, belies this devaluation. "S"—the subjective—is the history, the story. It is in this area, our medical elders constantly remind us, that we will find the diagnosis 90% of the time. Further, the subjective and objective are interdependent and, when embedded in a context, lead to the assessment and plan of care.

Story as Case Study

Using a clinical case study as educational methodology is embedded in medicine as a highly effective, relevant, and engaging intervention. It brings to life the interdependent factors at play in the application of medical knowledge in context. The story study is a dramatized case study that gives you an experience and, because of that, experiential knowledge and a lived perspective.

Several elements enhance the effect: you witness people's behavior; you hear their perceptions and beliefs expressed in dialogue; and, when beliefs and behavior are linked, your understanding improves.

The following two narratives are excerpts from short fiction based on true stories. They are annotated with clinically relevant commentary related to common ethical lapses, issues, and dilemmas.

Assess the value for you of the story study approach to broaden your perspective and your understanding of clinical encounters.

Additional information, including complementary and/or dissenting views on this issue, can be accessed on the Kaiser Permanente Intranet by visiting *The Permanente Journal* Web site (www.kp.org/permanentejournal); click on this article in the Table of Contents and then click on the link to Ethics Rounds.



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Case: “Just Missed”¹

Dementia and Depression

The Case	
<p>Ninety-three-year-old nursing home resident with recent dementia and depression stabs himself in the abdomen. He takes no medication. He has left hip arthritis but no other chronic medical conditions. He doesn't smoke or drink. He has outlived his wife and has one son. He was a farmer.</p>	
The Story	Annotation
<p>“Mr Will Clark? I'm Dr Eddie Stewart. Are you okay? What happened?” I touched his hand resting at his side, red on the white gurney sheet.</p> <p>“I tried to slash the main artery!” Will said. “I don't wanna go on no more. 'Nough said.”</p> <p>“Why would you want to do that?” I said.</p> <p>“Don't want nothin' to do with no nursing home,” Will said.</p>	<p><i>This response suggests a powerful and compelling narrative of attempted suicide. Gaining family member perspective is essential, particularly if the patient withholds information. Nursing homes are problematic for some. Why for him?</i></p>
<p>“All started,” Jeb Clark, his son, said, “when Will couldn't get around anymore as much as he wanted to. Or needed to. Hip hurt. And he started forgetting things. Like turning off the stove burner after he'd cooked his soup.”</p> <p>“Dangerous when you're living alone,” Agnes Clark added.</p> <p>“He was doing other strange things, like leaving bags of groceries on the check-out counter, and crossing main street in the middle of the block, like strolling in the park.”</p>	<p><i>Do these details suggest the onset of dementia? What is the patient's capacity to make medical decisions and consent to treatment?</i></p> <p><i>His safety at home creates at least a social dilemma for his family. His activities in public create concern for his personal safety and the public safety. Protecting the safety of others in society creates a civic ethics issue, if not a potential legal issue.</i></p>
<p>“Dad's attitude got worse when Agnes and I reminded him. Thought we were accusing him. Got grumpy. Paranoid even.”</p>	<p><i>Does this suggest the onset or exacerbation of depression? His perceived family criticism, along with his own sense of being out of control and losing faculties, could be a source of depression. His behavior could have created familial distress, eroding the goodwill of his support structure. Exploring this narrative could bring insight and greater perspective.</i></p>
<p>“So did you commit him?” I said. “Is that what made him so angry?”</p> <p>“In the end, he agreed,” Jeb said.</p> <p>“It took other friends altogether one night talking to him,” said Agnes. “We had the best intention. We had no place for him.”</p>	<p><i>The family's intervention averted a legal dilemma of committing a person and assigning guardianship, though Will may harbor anger from loss of home, independence, and control.</i></p>
<p>“We're all Will's got left,” Agnes said. “Even his doctor died. He'll only talk to me. Worse, Will tried to stab Jeb last week, with a knife he'd bought at Dornberg's Hardware. He was on home visit.”</p> <p>“Is he on any medication?” “Has he seen a psychiatrist?”</p> <p>“What can you do about gettin' old?” Jeb said. “We didn't tell anyone about the knife incident. We felt so bad putting him in that home.”</p>	<p><i>Not reporting domestic violence to nursing home medical personnel created an ethical issue for his family and now potentially for the doctor, depending on his treatment approach.</i></p>
<p>“Mr Clark, you lonely over there?” I said.</p> <p>“No, that's not it at all ... at least not all of it. Everyone's always takin' care of me ... tellin' me what to do ... won't listen to me ... won't let me do nothin'. I may be too damn old, but I'm not a baby ... gets me down.”</p>	<p><i>Probing the deeper current of his narrative yields information about a new source of the patient's personal distress, probably exacerbating his depression and possibly his dementia.</i></p>
<p>“What if I give you some medicine ... to not feel so down?”</p> <p>“Pills? No! I don't need no drugs.”</p> <p>“Mr Clark. It's an unnatural act, what you did.”</p> <p>“Seemed perfectly natural to me.”</p> <p>“What, to kill yourself?”</p> <p>“Not if you're killin' what's bad.”</p> <p>“Will, I need to have another doctor talk to you about that.”</p> <p>“No pills, no shrinks! Just get me outta that home. I'd rather stay with a son I hate.”</p>	<p><i>The patient's preferences complicate the routine medical decision to treat and create a dilemma over how to protect the patient's safety and the safety of others. It also requires the informed consent of his family, because Will may be incompetent secondary to his dementia and his depression.</i></p>

<p>“I called a psychiatrist,” I informed Jeb and Agnes. “Will refuses, but we need an assessment.” “Doc, where’s his mind goin?” Jeb said.</p> <p>“If he’s losing the present, the future’s next, then the past.”</p> <p>“I know now what triggered it.” Jeb looked to Agnes.</p> <p>“You go ahead, Jeb,” she said.</p> <p>“A month ago he turned everything over to me ... his house, his barn, his land. Told me, ‘It’s finally yours, Jeb, hope you like it.’ Well, I don’t want it. Never took a dime from him.”</p> <p>Jeb ran the index finger of his gnarled hand back and forth along the inside of his collar and tugged the front. “He must have thought we’d take him outta there.”</p>	<p><i>Continuing to unfold, the narrative helps to particularize the anger Will harbors toward his son, but this also increases the pressure on his family to reconsider social support in the home. Gathering such support may be especially compelling if it also serves to ameliorate his depression—a nonmedical intervention more in compliance with Will’s preferences.</i></p>
<p>“I prayed for Will today, but I couldn’t concentrate on the sermon,” Agnes said. “We just finished our new house,” Jeb said, lifting his eyebrows.</p> <p>“Jeb and I were picking him up for dinner. It’s Will’s birthday today! Ninety-three!”</p> <p>“It’s been our dream to build this house,” Agnes said.</p> <p>“He should understand,” Jeb said. “But dad said, ‘Why don’t you live in my house? I gave it to you.’”</p> <p>“He’s so determined. We tried to trick him, lied to him,” Agnes said.</p> <p>“Then he started saying, ‘Sell it and get the money. That’s what you want. The damn money!’” Jeb said.</p>	<p><i>Will exploring the patient’s and family’s spirituality facilitate resolution of the current dilemma?</i></p> <p><i>An anniversary in a person’s narrative journey is certainly a compelling event to motivate behavior.</i></p> <p><i>As the story becomes more psychologically complex, it may also open a window of opportunity for resolution. Perhaps a doctor-facilitated conversation between the patient and family could dispel misunderstandings and lead to a collaborative resolution.</i></p>
<p>“Will, maybe you’ll be able to visit your family,” I said, “but you need some treatment first.”</p> <p>“I might let <i>you</i> treat me,” Will said, “but no woo woo.”</p>	<p><i>The patient expresses trust in the doctor, a foundational bridge to a therapeutic outcome.</i></p>

Case: “You’ll Never Get Off the Table”² End-of-Life Decisions

<p>The Case</p>	
<p>Eighty-four-year-old man with a history of an abdominal aortic aneurysm and congestive heart failure. He presents to his rural ER at 3 a.m. with acute abdominal pain. BP is 90/70. His medications include two antihypertensives, and a lipid-lowering agent. No history of an MI or CVA. He is married. A recently trained emergency medicine physician is on duty as a locums.</p>	
<p>The Story</p>	
<p>“Hello, Mr Barry Colton? I’m Dr Eddie Stewart. Are you all right? Do you hurt?” Stewart scanned his patient’s face and belly for clues. Barry had this eerie look of painful calm on his round face. His ashen hair curled under his ears, matted with sweat against his neck.</p> <p>“Hurt’s here.” He points midabdomen. “Deep. God, it’s intense! I gotta have something for pain, doc. I’m dying from the pain.”</p> <p>“Mr Colton,” said Stewart, “we’re drawing up your pain medicine right now. This looks serious. It looks like your aneurysm is leaking.”</p> <p>“Tony,” said Stewart, now over in the corner close enough to the ambulance driver to talk to him softly, “Can Medic 3 take him to Houston? We can’t get a chopper in and outta here in time. They’d have to land up at the airport. Triple transfer.”</p>	
<p>“Doc, talk to my wife, Sara, first,” Barry interjected, overhearing them, “I’m not going anywhere ‘til you talk to her. She’ll tell you what we decided.”</p>	<p>Annotation</p> <p><i>How should a patient’s medically uninformed decision change the intense, largely dictated trajectory of treatment for a surgical emergency?</i></p>
<p>“Dr Stewart ... it’s his aneurysm?” Sara clutched her small black embroidered purse. She knew but didn’t want to, Stewart thought. She looked around him into the trauma room and saw the staff fussing around Barry. She saw Tony. “Oh dear ... Is he going somewhere?”</p>	<p><i>Is there an ethical issue in the doctor planning transport without a shared decision with the patient and his wife and an informed consent? Is this expert voice of authority too single-minded?</i></p>

<p>“To Houston. It’ll take a team of vascular surgeons to operate on his aneurysm. As a back up, Dr Sovitch, the surgeon, is on his way in. Honestly, even a great general surgeon couldn’t save him in Tyler. It’s a very complicated operation.”</p>	<p><i>Was making this statement good judgment? Is it an ethical lapse to precast the local surgeon’s competence or decision and to preplan a tertiary care course of action?</i></p>
<p>“Dr Stewart, he’ll never make it through surgery. He’s 84, and he’s got a bad heart.”</p>	<p><i>Previously eliciting her knowledge of his condition could have obviated her need to make this comment. This unfolding end-of-life narrative requires deeper exploration.</i></p>
<p>“The best thing for his heart could be to fix his aneurysm.”</p>	<p><i>What kind of a truth is this statement? Is this a confronted voice of authority creating confusion? An ethical lapse?</i></p>
<p>“Dr Gibon, he’s Barry’s family doctor, told us it was coming. He said we could either wait and panic or we could prepare and flow with it. After many talks we agreed to no heroics ... no tubes.” Sara searched for Stewart’s reaction.</p>	<p><i>This sounds like a definitive discussion and shared decision for an advanced directive, though oral. The patient and wife and doctor have an interdependent story, now hampered by a new doctor in a middle-of-the-night emergency setting. Is this enough information to shift the decision from definitive care at a center to local palliation?</i></p>
<p>“We’re definitely not there yet, Mrs Colton, though I’m an emergency doctor.”</p>	<p><i>Is this just a temporizing statement by the authority with questionable intent to comply?</i></p>
<p>“Dr Stewart, I don’t want you to be that kind of doctor,” said Sara, “I want you to be Barry’s doctor.”</p>	<p><i>This remarkable request demands individualized medical care, strong personal patient advocacy by the doctor in the face of conventional, surgical protocol, and potential medical-legal consequences. Can further exploration of the patient’s story help resolve this ethical dilemma?</i></p>
<p>Mrs Colton looked around Stewart again at Barry, then turned back, “Dr Stewart, Dr Gibon said straight to Barry’s face many times in his office, ‘You’ll never get off the table, Barry, you’re too old, and your heart’s too sick. If you did survive, you’d suffer a stroke.’ And once you took him into the OR, Dr Stewart, I’d never see him again. We planned to be together at the end.” She reached for his hand. “Your work now is to relieve his suffering.”</p>	<p><i>The patient, his wife, and local primary physician have a compelling story not only for nonaggressive treatment but for an active palliative, compassionate course of care.</i></p>
<p>“I’ll call off surgery then,” Stewart said. “And tell Dr Sovitch and the OR crew. I’ll call Dr Gibon. He’ll be awake. We can take good care of Barry right here.”</p>	<p><i>This ethical choice establishes the patient’s right to choose his end-of-life course of care versus the doctor’s right to practice medicine by training and convention in an emergency or in a strange setting, unfamiliar with local staff and physicians.</i></p>
<p>Stewart suddenly saw Tony across from him. Tony held his lift’s side rail behind him with his left hand; his right hand floated above Barry’s rail. Stewart called Tony off with a slight wave of his hand and shook his head back and forth several times messaging a “no go.” “Let’s get him down to his room,” Stewart said to Tony, Carla, and Jimmy, all still anticipating action. “Come on, let’s go. We’re admitting him to treat his pain.”</p>	<p><i>The doctor’s narrative journey moved from relative patient advocacy—when, from the frame of the authoritative voice, the curative approach was the standard of care—to true patient advocacy—when the patient and his wife’s right to choose a course superseded the doctor’s professional choice.</i></p>

References

1. Janisse, T. excerpt from “Just Missed,” unpublished manuscript, 2003.
2. Janisse, T. “You’ll Never Get Off the Table,” Perm J, 2003 Winter , 7(1):72-5.