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## Commentary

# The Dilemma of the “Doctor in the Family”

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**Abstract.** The twelve narratives written by physicians for this symposium address the same question: “What happens when I wear a white physician’s coat at the bedside of an ill or dying family member or friend?” This commentary addresses several key themes, which emerged as the author reacted to these narratives: (1) the physicians did not mention policy issues affecting the public inherent in a health system regulated by statutes and paid for by insurers; (2) the physicians did not follow the ethical rule against treating family members; (3) there was no discussion of whether hospital ethics committees or similar advisory bodies might have helped address conflicts as they arose; and (4) there was minimal discussion of Advance Medical Directives and Do Not Resuscitate Orders. These narratives show why individual experiences should have a strong voice in the debates over health care and health policy.

**Keywords.** Ethics committees, ethical rules, bioethics, Advance Directives, health policy

### Introduction

In Leo Tolstoy’s novella *The Death of Ivan Ilyich* (1886) Ivan Ilyich, the story’s protagonist, is dying a slow and painful death. His family avoids the subject of his death and instead pretends Ilyich is only sick and not dying.

Recalling Tolstoy’s story, Atul Gawande writes in *Being Moral* (2014):

*“As we medical students saw it, the failure of those around Ivan Ilyich to offer comfort or to acknowledge what was happening was a failure of character and culture . . . Just as we believed that modern medicine could probably have cured Ivan Ilyich of whatever*

*disease he had, so too we took for granted that honesty and kindness were basic responsibilities of a modern doctor. We were confident that in such a situation we would act compassionately. . . [but] we paid our medical tuition to learn about the inner process of the body, the intricate mechanism of its pathologies, and the vast trove of discoveries and technologies that have accumulated to stop them . . . So we put Ivan Ilyich out of our heads.”*

The twelve narratives discussed here reminded me of Tolstoy’s story, but in an odd way. In the story, Ilyich suffers an apparently trivial injury (he hurts his side in a fall from a chair while hanging curtains in his new apartment), which quickly

develops into something worse. Doctors offer all kinds of diagnoses, medicines, and guarded reassurance, but within weeks, Ilyich can see that he is a dying man, confronted with the agony, indignity, loneliness, and (in Tolstoy's description) foul stench of Ilyich's demise. For most of his family and colleagues, his death is an inconvenience and an embarrassment; they are relieved not to be dying themselves, but simultaneously aggrieved by the reminder of their own mortality. Only Ilyich's young servant, Gerasim, can look the processes of dying in the eye and care for his master with true humanity (Beard, 2013). At the end of the story, Ilyich is able to confront his death—he makes a clear split between an artificial life, such as his own, which masks the true meaning of life and makes one fear death, and an authentic life, such as that of Gerasim. Authentic life is marked by compassion and sympathy; the artificial life is marked only by self-interest. As he recognizes this, Ilyich no longer fears death (Freeman, 1997).

In Tolstoy's story, the doctors, Ilyich's wife and friends, and Gerasim are separate people, but in each of the twelve narratives the author plays all the roles—doctor, family member or friend, and caretaker. This ambivalence is perhaps why Gawande, and his fellow medical students, found it necessary to put the story of Ivan Ilyich out of their heads. As I read these narratives, I saw that almost all authors struggled with an inability to separate their role as "physician" from their role as "family member." Because of that, the narratives were particularly painful, both for the author—the physician and family member, and for me as the reader.

Four key themes emerged in these narratives for me. First, I noticed the authors didn't mention policy issues in these pieces. By "policy," I mean the word in several senses: general policies of the health system; and specific laws implementing health policy: Medicare, Medicaid, the Affordable Care Act. Second, the physicians didn't follow the provision in the AMA Code of Medical Ethics that physicians should not treat themselves or their families (American Medical Association, n.d.). Third, Hospital ethics committees or similar bodies within the hospital could have played a role in mediating

some of the difficulties within the families, but the authors didn't mention using this resource. Finally, I found minimal discussion about Advance Medical Directives, and DNR orders were rarely discussed.

Gawande looks at the physician's role and concludes how easy it is for the medical student to "forget" his or her compassionate role and focus on the technology of medicine. Ezekiel Emanuel (2017) addresses the broader policy and political picture, but focuses on how policy—particularly the economic and cost policies and the political frameworks—affect the average insurance system, the would-be patient and the actual patient. I thought about these issues as I read the narratives, so moved by their dilemmas, yet wondering about others who have no "Doctor in the Family."

There are clearly dichotomies in almost all of the narratives. The author is in a constant push and pull—a seesaw. On one end sits the physician, on the other the family member. The seesaw moves as their two roles vie for control. Often one can see the seesaw move, as the authors begin to change roles, as they cannot figure out where they are in the physician-family member dichotomy. In Frances Nadel's narrative, with three physicians in the family and a sister, Connie, as the patient, Nadel is clear about the "seesaw effect," and the contrast between her normal practice, and her conflicting roles in this story: "As a pediatric emergency medicine doctor and a facilitator for workshops in difficult conversations, I thought I was well prepared for the role. I didn't anticipate the challenges of speaking simultaneously as a family member and a doctor in an ongoing conversation."

## The Policy Perspective

All of the narratives, melded together, presented a fascinating view of the complexity of being a physician with an ill family member. However, none of the authors wrote about how their loved one's care might be different if, like the majority of Americans, they didn't have a doctor in the family. Moreover, there was no mention of Medicare—did the family member qualify? Many Americans are too young to qualify for Medicare when they become ill, and

often have insurance policies that do not cover the treatments they need. Many have no insurance at all, and must turn to Medicaid, which has limited coverage. Although much has changed under the Affordable Care Act (“The Patient Protection and Affordable Care Act,” 2010), there are still gaps, where insurance coverage is minimal. But no one mentioned difficulties with medical insurance; no one encountered complexity with forms, arguments with insurance companies, which often say “no” at the first request, or frustration with the length of time Medicare and insurance companies often take to approve treatment or assistance. Even in my own upper middle class academic family, where we have fairly broad choices among insurance plans and excellent coverage (but no “doctors in the family”), we sometimes find ourselves confused by the fine print in forms. We wait on hold for a lengthy time to talk to someone, and are then referred to someone else, and again placed on hold. These narratives left me curious whether the physicians shared this frustration and if so, did this subsequently affect their view of patients?

### **The Code of Ethics: Why Should Physicians Not Treat Themselves or Family Members?**

The AMA Code of Medical Ethics (American Medical Association, n.d.) contains a specific provision that physicians should not treat themselves or members of their families. It may be acceptable to do so in limited circumstances, for example, in an emergency when no other physician is available, or for short-term minor problems. However, in some of the stories, physicians treated family members as their primary care physician seemingly without concern.

In some cases, the author admitted his or her awareness of the rules regarding treating family, but did so anyway. Alexander Kon became what he and his mentor felt was too closely involved as a physician with the medical care of his niece after brain surgery. He concluded by noting “Deeply and sincerely caring about your patients is essential, but becoming overly involved benefits no one.” He followed that comment by saying, “Since that

day, I never treat family. It drives my wife crazy. When our kids were young and she worried that they might have an ear infection, she would ask me to take a look with my otoscope. I would always say: “If you’re worried, we should bring him to the pediatrician.” “Drove her nuts, but as a PICU doc I don’t look in ears very often, and diagnosing an ear infection can be pretty subjective. I never wanted to make the same mistake I had made with my niece.”

In his narrative, Michael Rezak refers to the Code of Ethics but interprets it broadly: “Whether right or wrong according to the American Medical Association’s code of ethics (n.d.), as a neurologist, I would need to combine my professional skills with my role as a devoted son to make his life as meaningful and positive as it could be . . .” Rezak goes on to talk about the denial that came with treating his father. “The decision to hospitalize when my father was intermittently ill was also a dilemma. I had often seen this situation occur in my patients and their families. Now it was my turn; I would experience the ‘ostrich phenomenon’ and go into some form of denial. In reflecting on this, dealing with the bureaucracy of the hospital was overwhelming and I did not want him subject to painful invasive diagnostics and treatments, so I looked for reasons not to have him admitted.”

Toward the end of his narrative, Rezak thoughtfully notes: “Was I capable of compartmentalizing the role of the son, healthcare decision maker and the doctor sufficiently to make appropriate decisions that are in the best interests of this man who had already endured unspeakable tortures?” “Did I cross the line of ethical behavior in taking care of this man who was so close to me? I honestly don’t think so. . . . The rules of ethical conduct are just that—rules. As with any rule, there are exceptions and I felt this was one of them.”

Other authors had no difficulty treating family members, and no one else mentioned the Code of Ethics, or had questions about whether it was “legal” to move from physician to family member. But it was clear that the “seesaw” effect caused emotional strains in many of the stories. This, of course, is the reason why the provision is in the Code of Ethics. But despite the proscription in the

Code of Ethics, I'm sure it feels imperative to be involved in the treatment of a family member when he or she is ill. And in most of these cases, a specialist was involved at some point. Reading these narratives, I wondered if these are rules that might be interpreted as practice guidelines, rather than punitive offenses. Clearly, in all but a few of these cases, the "physician" side of the family member did not feel that his or her involvement treating a family member caused poor treatment, although a few did look back and wonder "did I do the best that could be done?"

### **Ethics Committees**

Aside from the policy issues I described above, the majority of what are framed as ethical disputes are more accurately understood as problems of communication and group dynamics. These problems are best addressed by standard conflict resolution processes, including listening to the patient and the patient's family. Most hospitals now have Ethics Committees, or some sort of advisory body that can be called upon to resolve conflicts between physicians and patients, or sometimes attending physicians and specialists. Most ethics committees don't make decisions for physicians; they generally act as mediators and advisory bodies to help the parties resolve their conflicts (Jonsen, 1998).

As a member of a hospital ethics committee, I believe there are a few cases in these narratives where resort to an ethics committee might have helped the parties reach a decision as to how the family member might best be helped. In the Joseph Fins case, Fins, as a son and a physician, was conflicted about his father's DNR request, because the hospital physicians were in favor of surgery. What to do? Maybe this was not the time to let his father go? Maybe the surgery would be successful. An ethics committee could have been useful in helping Fins work through his dual roles—physician and son—and help them make decisions that he and the family were comfortable with. Amos Ritter's father was so attached to his car that he lost confidence in his son. Ritter stated that he thought about changing physicians, but at that stage of

his father's condition it was too late. He might have gained valuable assistance either by asking for an ethics committee with a member expert in dementia to assist in resolving the conflict, or by consulting another physician himself. In Jessica Turnbull's situation, where the attending physician expressed a complete lack of interest in her uncle a consult with the hospital ethics committee might have helped mediate the difficulties she faced. Perhaps the Committee might have assisted her with her demand for a new physician; or finally, facing her uncle's death, helped her avoid her own guilt for the . . . physician's errors in treating her Uncle Dan, and her feeling that she had not been a "good physician" for her uncle.

### **Do Not Resuscitate Orders (DNR)**

Several authors discussed the internal conflict they had following DNR orders or Advance Medical Directives. In the narrative written by Joseph Fins, discussed above, it was difficult for him to remove himself from the middle of the seesaw. While he understood as a son, that his 93-year old father "had made it clear to me, in many occasions, that he would not desire any life prolonging procedures if he suffered from an untreatable disease." But as a physician, Fins struggled, asking the treating surgeon to "temporarily" cancel the DNR so that surgery could take place, until his sister, not a physician said, "hasn't Dad suffered enough?" He finally realized that he was engaged in "magical thinking," admitting that "It had been a long night full of life lessons for this humbled bioethicist, and still bereaved son."

### **Advance Medical Directives: The Essential Conversation**

For years, many organizations advocated that individuals complete Advance Medical Directive Forms, appoint proxies to be their advocates, and make clear their wishes in writing to their loved ones and medical providers (American Medical Association Judicial Council, 1985). Unlike DNR's,

Advance Medical Directives are more detailed documents, usually written before serious illness.<sup>1</sup>

Ambika Rao describes the conversation with her family: “As my family and I embarked on the road to recovery, we realized we had become quite adept at having difficult conversations. My father’s illness and death had given us a platform to express these vulnerable feelings. We understood that death didn’t discriminate between young or old, healthy or sick, and that we weren’t the only ones to experience a loss like this. What I didn’t realize, however, was how quickly I would have to engage in these conversations with people outside my immediate family.”

Advance Medical Directives are rarely mentioned in these stories. Some, however, suggest how difficult the conversation can be. Kathleen Fenton says in her piece: “I am a cardiothoracic surgeon, the oldest of three ‘kids’ in the family. My youngest brother is a Catholic priest. Both of us deal with life and death every day, and for years we had been trying to get our parents to formalize advanced directives. Finally, once my mother was in hospice, we got them done, with Mom and Dad both, who at that time were in their early 80s.” As I read these narratives I wondered if she, her brother and their sibling had formalized their own advanced directives.

## Conclusion

There are many more narratives with issues I would have liked to discuss in greater detail—conflicts over DNR orders or reluctant, final DNR orders; the pain it caused the Turnbull family to have a physician whom the patient trusted, but who abdicated his role. What was it like to have close friends whose small child was dying, when your own children

were healthy and thriving? How do you tell your grandfather that you have to take away a car that has defined his personality and masculinity? These narratives were wonderful “teachers” for me, a non-physician.

I serve on an ethics committee where we deal with difficult issues, such as many of the issues described here. But I have always looked at these with a “lawyer’s eye”: fascinated by the cases, but always wondering whether the ethics committee, or the physician or physicians, might be legally responsible for their decisions (even though I know that an ethics committee decision is only advisory). I have also been the daughter of ill and dying parents, always as the “family member” end of the seesaw, wanting to beg for a good medical advocate who would understand what I was going through.

The narratives shed thought-provoking light on what it’s like to be a physician-family member caring for an ill family member or the child of a friend. Practical concerns fall away, and, the burdens of the seesaw effect overwhelm the practicalities of routine medical practice. “My mother,” “My father,” “My grandfather,” pull at your heart as simply taking care of a patient would not. Apart from the questions raised above, I am left with other questions as well. What effect did the burden of taking care of family members have on the authors’ routine practice of medicine? What was the continuing relationship with the other doctors who treated the family member, whom they worked with in their “regular” practice. Finally, what did all of the writers learn about treating other patients? (Only some stories talked about this.) Did these experiences make them closer to patients, or “push” them away? What did they learn about treating a close family member that changed the way they looked at their patients in the future? These physician-family members were not like Ivan Ilyich’s friends or wife; whether physician or family member, they were like Gerasim, the servant. “They were able to look death in the eye” and care with true humanity.

As the country moves toward drastic changes in health care, health policy and the basics of treating individuals, both the “physician” and the “family

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<sup>1</sup> Information on Advance Directives can be found in the American Bar Association, Commission on Law and Aging, *Health Care Decision Making*. [https://www.americanbar.org/groups/law\\_aging/resources/health\\_care\\_decision\\_making.htm](https://www.americanbar.org/groups/law_aging/resources/health_care_decision_making.htm) (retrieved 1/19/18)

member” in each of these narratives, and others like them, will have to learn to deal with these changes, as will the people who make the changes. Nevertheless, I think that these poignant narratives show why individual experiences should have a strong voice in the debates over health care and health policy.

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