This May, or May Not, Be an Ethics Consultation

Tarris Rosell and Britt Johnson

Introduction

We begin with the acknowledgement that with "The Zadeh Scenario," Finder has provided a rich and thick description of what clearly was a challenging opportunity for end-of-life ethics consultation. As such, his narrative now stands as opportunity for us to engage with him in the even more challenging opportunity of post-mortem moral reflection. We have organized our thoughts on this case mostly in the interrogative mode, as questions or queries, and from perspectives informed by our own interests in clinical ethics and healthcare law.

Was This an Ethics Consultation?

Philosophers, especially phenomenologists, do not shy away from the most fundamental questions of any particular occurrence. So we begin by asking: Was this an "ethics consultation," or something else entirely? Perhaps it began as an ethics

T. Rosell (✉)
Center for Practical Bioethics, Department of Bioethics,
Kansas City University of Medicine and Biosciences,
Kansas City, MO, USA

Central Baptist Theological Seminary, Department of History and Philosophy of Medicine,
University of Kansas School of Medicine, Kansas City, KS, USA
e-mail: trosell@practicalbioethics.org

B. Johnson
Department of Bioethics, Kansas City University of Medicine and Biosciences,
Kansas City, MO, USA
e-mail: BJohnson@kcumb.edu

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consultation and became something else, or began as something else and became an ethics consultation. Or maybe it was always something else and only seemed to the "consultant" to be ethics consultation. What was this phenomenon really?

Does an ethics consultation become that on account of someone wearing a name badge that says "Ethics"? Is the essential nature of ethics consultation in the title and role of the ethics consultant? Is human response inextricably linked with or independent of the respondent's title and role? Are there criteria by which we could differentiate an ethics consultation from, say, counseling or emotional care-giving? "The Zadeh Scenario" provides opportunity to ponder such questions, and others.

Perhaps an ethics consultation, as compared to something that is *not* an ethics consultation, is determined mostly by the nature of the request and not so much by that of the response. If so, it is the requestor who ostensibly defines what happens next, whether that be ethics consultation or something else.

Following that thread with particularity to the Zadeh narrative, it is Mr. Zadeh himself, the patient's son, who requests response from a gentleman in the hospital elevator who wears a badge with "Ethics" on it. Three years earlier, Finder's ethics colleague, Dr. Steve Moore, had followed up – and followed up and followed up – on the very first request for ethics consultation in regard to Mrs. Hamadani's situation. Initial consultation request had come from the patient's neurologist, we are told. Subsequent requests came from consulting nephrologists, ICU attending physicians, and social workers. Then the current attending physician, Dr. Broukhim, consults Dr. Moore as well, this request coming just 2 weeks prior to the request from Mr. Zadeh, which marks the beginning of Finder's involvement in the case. Before we turn to Mr. Zadeh, then, the question at hand is, for what were these clinicians looking from someone who wore an "Ethics" badge?

Is Ethics Consultation a Matter of "Stopping"?

The initial requestor had expressed concern to Dr. Moore that this family was inappropriately asking for aggressive intervention of a newly diagnosed cancer. Mrs. Hamadani already suffered from Parkinson's and other diseases, and her cancer had metathesized. Subsequent requestors, we learn, "were concerned that Mrs. Hamadani was suffering, that continued intervention was futile, that her children were making bad decisions" (Finder 2018: 23). Dr. Broukhim, too, asks for Ethics help at the point when he "felt there was nothing more he could do, that Mrs. Hamadani was at the end" (Finder 2018: 23).

It seems that each of these initiators of ethics consultation was looking for help in stopping things they thought ought not to be done to their patient. Or they wanted help to stop family members who were trying to make clinicians do things they believed they ought not to be doing. Is that what ethics consultants do? Stop things from happening?

The language used with patients and families often is that of "stopping" – dialysis, ventilator support, tube-feedings, transfusions, antibiotic therapy, chemotherapy. Otherwise, in ethics we speak of withholding and withdrawing. When clinicians

speak of "withdrawing care," we who teach ethics to them are quick to correct their language. It is not *care* that ethically may be withdrawn or stopped, but aggressive treatments that are withdrawn. Stopping ineffective and possibly harmful interventions is one way of caring for patients for whom aggressive palliative care is deemed most appropriate. This is what Mrs. Hamadani's healthcare providers were thinking should be done for her, starting 3 years ago, and yet they seemed unable to accomplish this transition of care due to family opposition to that plan of action. So Ethics is called upon, time and again. Help us stop. Get it to stop. Get them to stop. Isn't this what ethics consultants do, or are supposed to do?

Just as patients have the ethical and legal right to refuse treatment, physicians and healthcare providers are ethically, and sometimes legally, allowed to refuse to treat patients (Timmons 2008). Refusal to treat is limited by law in, for example, the United States' Emergency Medical Treatment and Active Labor Act (Department of Health and Human Services 2001). However, when the patient or patient's surrogate demands treatment that is not medically indicated, a provider need not comply (Timmons 2008). Some laws for individual states within the United States (e.g., Texas) require physicians to transfer the patient's treatment to another provider, while others (e.g., California) allow physicians simply to disregard requests for treatments deemed ineffective (Timmons 2008).

In this case, Dr. Broukhim ethically and legally might refuse to provide some or all treatments requested by Mr. Zadeh and his sisters on behalf of their mother. Her physician would have received a groundswell of collegial support for that course of action, or inaction. There had been a multi-disciplinary chorus of ethics consultation requestors over the years, all looking for things non-beneficial to stop. In lieu of mere refusal, Dr. Broukhim could have sought to transfer Mrs. Hamadani's care to a physician elsewhere with different inclinations as to what might benefit or harm this patient. Alternatively, Dr. Broukhim could have sought legal authority to provide comfort care only. A judge might have been persuaded to assign a guardian ad litem or to designate durable power of attorney to someone other than the patient's son.

However, it is unclear from the narrative that Dr. Broukhim was ready to take such drastic measures. He had a long professional relationship with this patient and family. Like many physicians in that situation, Broukhim was disinclined to cease being Mrs. Hamadani's primary care provider, especially now at the end of life. There is something virtuous about that. How then do things turn out less than good for everyone involved?

For three long years, what providers want stopped keeps going. New aggressive treatments get added rather than all of them being withheld or withdrawn. This occurs despite ethics consultation by Dr. Moore, who also is of a mind to stop aggressive treatment and to enable transition to palliative care. If the initial consultation goal was that of helping everyone stop, it seems to have been unsuccessful. Is that why the patient's son puts in his own subsequent request to Ethics?

Interestingly, Mr. Zadeh's request for ethics consultation, if that's what it was, is also a request to make something stop. But what he asks of Finder is to stop Dr. Moore from engaging in ethics consultation, one that had been happening, on and off, for the past 3 years.

> Your Dr. Moore, he has pestered us, always showing up when my mother has come into the hospital, asking us if we are ready to stop…. And so I beg of you, Doctor, please don't let Dr. Moore see my mother again. My sisters and I do not want him talking with us anymore (Finder 2018: 25–6).

Is Ethics Consultation a Matter of Giving Care?

Mr. Zadeh's request of Finder is not for more ethics consultation, but less – or none at all. How then does this become more of the same? Or did it? Instead of clinical ethics consultation, could Finder's response more accurately be described as a case of non-clinical, non-ethics, emotional care giving?

Perhaps care-giving is what competent and effective ethics consultants actually do. However, caring is not listed as one of the core competencies by the American Society of Bioethics and Humanities in a publication delineating what health care ethics consultants ought to know and do (ASBH 2011: 19–31). Maybe that is an oversight to be corrected. At least in this consultation scenario, Finder demonstrates a competency of care; he writes:

> Several times during these days I stopped by and stuck my head in to say 'Hello' to whoever was there [in the patient's hospital room] …. My aim in doing so was simply to keep tabs, much as Steve had done during prior hospitalizations. But unlike then, and unlike during the earlier part of this hospitalization, I did not inquire about whether they had thought more about CPR and DNAR or if there had been discussions of stopping the dialysis. Rather, I kept my focus on how they were holding up, especially the sisters who also had families for which they had responsibilities. I also asked about their father … (Finder 2018: 36).

Finder is giving care – and also showing compassion, patience, and tolerance, all of which are listed in the ASBH document as essential "traits" for health care ethics consultants (ASBH 2011: 32). He is kind and a good listener, in the normative manner of chaplains and counselors. He seems to care for and about this family.

So this is morality, but is it ethics? Finder is being morally upright, as ethics consultants should be, but is he doing ethics consultation? Was Dr. Moore doing so? What ethics purpose is served by "stopping by" to "keep tabs," without inquiring about stopping treatments deemed futile by clinicians? If the *Core Competencies* of ASBH is considered definitive, care-giving is not really the proper role of one who wears the badge titled, "Ethics." One can exhibit traits of compassion, tolerance, and patience without giving care.

Care-giving also is not what Mr. Zadeh had requested. His request was for ethics consultation to stop, for his family to be left alone, and for the ongoing attention of Dr. Broukhim alone. If the requestor's intent defines the response that is given, then what Finder did, in response, was neither ethics consultation nor emotional care-giving. Yet it seems to us that he did both. Are we mistaken, along with Finder, who clearly presents "The Zadeh Scenario" as a narrative of ethics consultation by one who is at least care-full?

We conclude that a request to stop ethics consultation, when asked of a consultant, does not mean that the response is exactly what the requestor asked for.

Is Ethics Consultation a Matter of Getting Fired?

Dr. Moore's consultation activities did stop when Finder responded. Should that have been the end of this matter, as far as ethics consultation goes? Perhaps. But how would Finder know unless he took things further – stopping by, keeping tabs, asking how things were going for the family? By further response, the consultant learns more about, and then becomes a participant in, a situation of conflict that had gotten Moore and several physicians fired by the family.

The context out of which many ethics consults arise is one of human conflict. Stakeholders are conflicted about means and ends. Not always, but often, these conflicts arise in contexts of end-of-life care, and pertain to starting or stopping aggressive treatment. It was so in the Zadeh narrative. The conflict Mr. Zadeh describes to Finder in their first meeting involved a mistrust and distaste for how Dr. Moore and providers had been treating the patient and her family. Do these clinicians, and this ethics consultant too, not know "what it means to love [a] mother?" (Finder 2018: 25). In particular, Mr. Zadeh wanted Finder to help the family attain some space from what they viewed as overly aggressive and insensitive questioning and badgering by Dr. Moore. Mr. Zadeh was asking for the ability to direct his mother's care as best he could without feeling urged towards options they had previously rejected.

Ethics consultation had been repeatedly requested regarding this patient during previous admissions, and Dr. Moore was the assigned contact for those interactions. Did the family ever ask for any of these consults or request Dr. Moore's presence? Apparently not. Ethically uncomfortable clinicians dial the Ethics pager. It is understandable then that the family views Dr. Moore's mere presence as a harbinger of conflict. Each time they see his face, they expect to be asked to rethink their choices and to cease aggressive treatment. Of course they seek reprieve.

The family's view of Dr. Moore as unwelcome is in line with their general mistrust of hospital staff. None of the children seem to think that their mother would receive the care she needed unless one of them is present at the bedside. The conflictual tension builds with each admission. Some health care providers have refused to participate further in this patient's care.

Finder replaces Moore as the consultant on the case, and attempts to forge a relationship with the family in order to understand their history and current situation. So long as he takes this tack, Finder finds acceptance, or tolerance anyway. Why then does Mr. Zadeh ultimately become as exasperated with Finder as they were with his colleague?

Mr. Zadeh makes clear that his family will make decisions when decisions are needed, i.e., in the crisis moment. Given that at least some of the children are nearly always present with their mother, this may be more reasonable than either ethics consultant and most physicians acknowledged. The narrative gives several indicators of cultural normative difference in regard to making end of life decisions. Majority culture within healthcare has come to value advance care planning, advance directives, and doctors' orders in advance to stop "futile" though default resuscitation attempts. Mr. Zadeh and his sisters reject these tools and processes. Their obstinacy perplexes and perturbs providers, inclusive of those who wear an Ethics badge.

Is the Persian Dr. Broukhim perhaps the only one who truly understands and respects this Persian family's norms for making end of life decisions? Is that why *both* ethics consultants ultimately get fired? This surely is one possible interpretation of Samir Zadeh's final, impassioned and rather angry speech: "Please, Dr. Finder, I do not wish to cause problems, and I apologize for raising my voice. But I do not want to talk about this anymore, and I do not want to talk with anyone else but Dr. Broukhim" (Finder 2018: 41).

If Ethics Consultation Fails, What About the Law?

Patients, and their surrogates, have the ethical and legal right to refuse care from providers. There are few, if any, limitations on this (CSB News 2013). "The patient has the right to make decisions regarding the health care that is recommended by his or her physician. Accordingly, patients may accept or refuse any recommended medical treatment." (AMA 2016) One of the underpinnings of the focus on patient autonomy in the United States is the personal freedoms guaranteed by the nation and states (Beauchamp and Walters 2003: 19). The process of informed consent is built around the pillar of autonomy. Not only are health care providers ethically required to provide complete and accurate information about proposed treatment options, they are to answer the patient's questions, give recommendations, and then provide active support of the patient's decision (Jonsen et al. 2010: 51). To be treated without consent can be a violation of state law; indeed, the most egregious cases of a patient receiving treatment to which she or he has not consented can result in a criminal charge of battery (Trehan and Sankhari 2002).

This situation is more nuanced. The patient's surrogate is not refusing treatment of a particular kind. Rather, Mr. Zadeh asks that certain providers not be involved in his mother's treatment. Just as a patient has no obligation to accept a specific treatment, patients may refuse to be treated by specific providers. When Dr. Moore had stopped by to ask about DNR decisions, the family simply said that it was "not a good time" to talk. When does this polite refusal to chat indicate that the patient or the patient's surrogate has no intention of discussing the matter at all?

The counter-narrative began to take on the persona of someone trying very hard to politely refuse an offer of a date. Not wanting to hurt the other's feelings or to indicate ill will, one might say something like, "Sorry, I'm busy," or simply, "No thanks." But there are times when this indirect refusal is not enough, and the suitor's asking continues. Mannerly rejection might lead to firm insistence with a raised voice – and a perplexed pursuer. So it seems to go for Finder, who is stunned when Mr. Zadeh raises his voice and essentially fires the ethics consultant.

Unfortunately, this is not merely a case of social interaction gone awry. Mr. Zadeh, on behalf of his mother, has the ethical and legal right to refuse "care" from any healthcare provider. Broadly construed, this includes all employees and staff of the medical center, up to and including the ethics consultants. This situation did not reach the level of legal concern; but it leads to yet another ethics question: Ought

ethics consultation, like treatment, be undertaken and continued only after documented informed consent by the patient and/or family?

Ethics Consultation as "Paying Attention"

Finder, and several others of us who do clinical ethics consultation, were mentored by philosopher Richard Zaner. Long before an ASBH committee delineated "core competencies" for this practice, Zaner had given us a thick description of the phenomenon referred to as "the clinical encounter." Place a philosopher in that foreign context, and one might further describe "ethics and the clinical encounter," which in 1988 became the title of Zaner's seminal book (Zaner 1988). Using phenomenological method, per the author, the primary activity of hospital foreigners like us is that of paying attention. Indeed, for Zaner and now Finder, too, what is referred to mostly as ethics consultation would be more accurately portrayed as ethics attention. When physicians or social workers or patients or their family call upon us for help, what they are asking us to do, mostly, is to be attentive, to pay attention.

Attentiveness is not our normal way of being in the world, noted Alfred Schutz, one of Zaner's mentors. Mostly we go through life taking things for granted. Citing Schutz, Zaner wrote:

> It has been made wonderfully lucid by Schutz (1973) that the veritable mark of everyday life is what he terms its "taken-for-grantedness." By way of culturally and socially inculcated typifications, we learn in the usual course of affairs simply and habitually to take hosts of things for granted, as going to be more or less as they have proven to be in the past, at least for all practical purposes. Only if something does not conform to our typified expectations are we at all alerted to it specifically, called on to take notice of it, and then to do something about it (Zaner 1988: 66).

So if clinical ethics consultation is fundamentally a practice of paying attention, what specifically does Finder do that constitutes this activity?

His account in "The Zadeh Scenario" indicates that Finder had paid significant attention to this case long before he was asked to get involved directly. Details of this patient's situation had lodged in his memory despite dozens of other cases that must have also begged his time and attention over the course of 3 years. Clearly, there was something about this one that was out of the ordinary, that did not conform to typified expectations of the taken-for-granted world. Hence Dr. Finder pays attention.

When Mr. Zadeh unexpectedly calls his name, Finder understandably pays close attention. "How did this stranger know my name?" Finder wonders. And even when realizing that a name badge has given him away, fulfilling its purpose, the consultant's curiosity has been piqued, memories of this man and his family are elicited, and attention is paid to what happens next.

Certainly there is much evidence of an inordinately attentive ethics consultant in the days and weeks that followed that initial clinical encounter. Finder "stops by"

the patient's room time and again, "keeping tabs" on what was happening, asking questions, demonstrating care and compassion by the attention given to strangers.

If Finder's approach to ethics consultation is mostly that of paying attention, there also is evidence in "The Zadeh Scenario" of notable inattention. Surprisingly, lack of attention retrospectively is noted in regard to what for Zaner was the central point of attentive interest in virtually every clinical encounter of which he wrote: the patient. In this narrative, where is the patient?

In Zaner's words: "Careful attention to the complex and subtle ranges of emotive, volitional, and valuational feelings serves to focus a crucial moral question: What is it about any specific patient that evokes, directs, and aims just these specific feelings and serves to orient the discussions, decisions, and actions of others (physicians, family, nurses)?" (Zaner 1988: 56). He might well have added "ethics consultant" to that parenthetical list of "others."

When looking carefully at the contexts out of which clinical ethics consultation arises, for Zaner and others of us, the patient is found at the contextual center. However, Mrs. Hamadani is mostly absent in this consultation activity. There is much interaction with clinicians and family members and the patient's (electronic and paper) chart. There is little if any mention of interacting with the patient herself, not even during the time immediately following dialysis when "her mental status did improve somewhat, and there were points when she was purposeful" (Finder 2018: 35). Assumedly, she still was not communicative; but what attempts by the consultant were made to communicate with her, to observe and reflect on the patient herself – and not just those who speak for her? How did the patient look? What was she doing? Did she appear comfortable or in pain? Was she awake, seeing, hearing, or responding in any way?

Conclusion

After reading "The Zadeh Scenario," Finder the ethics consultant's lengthy and fascinating narrative, we feel that we know the three Zadeh children, can picture them. But there is no picture or sense of their mother, even though she is the patient. Why not? Why do we not even think to raise the question until this late in a retrospective reflection on "The Zadeh Scenario"? It seems that none of us have been sufficiently attentive to the patient. Perhaps she had been too much "taken for granted"? If so, this is an unexpected and atypical lapse on the part of Finder, whose thick description narrative otherwise takes very little for granted.

Albert Jonsen has written that ethics consultation involves "thoughtful, compassionate, honest attention … given to a deeply troubling, perplexing human problem" (Ford and Dudzinski 2008: xix). By that definition, what Finder documents as his primary activity – indeed, this entire retrospective venture to which others of us have been invited – is the epitome of ethics consultation. It is, in fact, the act of paying attention.

As such, there is no tidy ending point for something that was begun as a request for help in stopping something or someone. Note the irony of this. As long as attention is paid, there is no stopping whatsoever, and the ethics consultation goes on and on. By Jonsen's definition, even the writing of this chapter is a sort of ethics consultation in the context of an unfinished narrative.

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