Patient Advocacy in Clinical Ethics Consultation

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Abstract: The question of whether clinical ethics consultants may engage in patient advocacy in the course of consultation has not been addressed, but it highlights for the field that consultants’ allegiances, and the boundaries of appropriate professional practice, must be better understood. I consider arguments for and against patient advocacy in clinical ethics consultation, which demonstrate that patient advocacy is permissible, but not central to the practice of consultation. I then offer four recommendations for consultants who engage in patient advocacy, and consider the implications of this issue for the field.

Keywords: advocacy in clinical ethics consultation, patient advocacy

Practicing clinical ethics consultation is—or ought to be—unsettling for reflective individuals. It has an ambiguous professional status, and occurs in emotionally fraught situations involving contested moral values, suffering, and death. Consultants must neither be too prescriptive with their recommendations nor fail to offer any at all. They must acknowledge, respect, and support diverse moral values, yet not fall prey to egregious relativism, paternalism, or ethical imperialism. They must justify the value of consultation services without relying merely on regulatory mandates for their existence or on the language of marketplace value. They must not be watchdogs or moral policemen, yet must also reject being used as mere window dressing for other purposes. Balancing on the intersection point between these various axes of obligation seems difficult, if not impossible. The usual recourse for a professional would be to hold oneself bound by professional guidelines regarding appropriate conduct, but what guidelines exist in clinical ethics consultation are often too vague to help with these kinds of questions.

One area in which these tensions must be navigated is the role of the clinical ethics consultant (CEC) in supporting a patient’s interests and wishes, and the lengths to which

1 Ideas in this article were initially explored in a panel discussion with Maureen Kelley, Dien Ho, Susan Miller, and Boris Yudin at the 6th International Conference on Clinical Ethics Consultation in 2011 in Amsterdam, the Netherlands, and subsequently developed for formal presentation at the Wake Forest University Junior Scholars in Bioethics Workshop in September 2011. I thank the sponsor of the Workshop, the Center for Bioethics, Health and Society, which made possible a rich environment for the extended exchange of ideas. My gratitude also goes to the workshop participants whose insights helped to shape my work on this article, particularly my formal commentators Heather Gert, Hannah Hargrave, Michael Hyde, Ana Iltis, John Moskop, and Rebecca Walker.
a consultant may go in that cause. For example, imagine a case in which a patient’s desires are at odds with hospital policy or meet resistance from a health care team. Clearly the consultant behaves within her professional role if she ensures that other parties know of those desires.\(^2\) It seems unproblematic for her to convene a meeting so that the stakeholders can explain their views and listen to the views of others. But how much further must she or may she go in attending to those desires? How stridently, or how far “up the chain,” can or must she push the issue? At what point would she clearly be failing in or overstepping her professional role, and why? This is the question of patient advocacy in clinical ethics consultation.

Patient advocacy is a concrete situation that raises the question of the appropriate loyalties or allegiances of the clinical ethics consultant, the obligations that stem from them, and what to do when professional loyalties come into conflict internally or with extra-professional obligations. Although I cannot hope to resolve these questions here, examining the conditions under which clinical ethics consultants may or must engage in patient advocacy may illuminate the more general issue of how to navigate the loyalties and obligations of clinical ethics consultants.

The term “patient advocacy” is problematic, because it means different things to different people.\(^3\) However, it is difficult to come up with a better term for what in fact constitutes advocating for patients, even if that occurs as discrete actions of advocacy rather than full-time employment or dedication as an advocate. Therefore, for present purposes, I use “patient advocacy” as shorthand for the general activity of supporting or pursuing a patient’s interests in the course of clinical ethics consultation. I explicitly do not mean the kind of dedicated patient advocacy undertaken by patient advocates, in which the only activity they may be responsible for is advocating for a patient’s interests, in pursuit of which an adversarial role is common.\(^4\) Instead, I use the term as a way of identifying circumstances in which a consultant is called to represent, draw attention to, or address a

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\(^2\) I use feminine pronouns to refer to a consultant and masculine pronouns for others both to disambiguate individuals and also to avoid the cumbersome ‘he/she’ and ‘his/her’ throughout the paper, though my choice is not much more satisfying than the alternative.

\(^3\) One could view the issue of patient advocacy in clinical ethics consultation as merely semantic. If one has a particular conception of patient advocacy and of clinical ethics consultation, it is straightforward to examine whether or not they are compatible. However, conceiving of the problem as merely terminological is doubly problematic. First, there is no singular use of the term “advocacy.” For some, it means an adversarial relationship in defense of the patient’s interests, while for others it simply means speaking up for the interests of another. Between the two is a wide continuum of activities, each of which might appropriately be termed “advocacy,” so assigning the term to only one particular segment of the continuum is arbitrary. Second, treating it as a straightforward terminological distinction (“given that advocacy = X, and that clinical ethics consultation requires Y, advocacy is/is not permissible for a CEC”) misses the more fundamental point.

\(^4\) See for instance the Sloan-Kettering Cancer Center’s website for “Patient Representatives,” which states: “If you are a patient at Memorial Sloan-Kettering Cancer Center and have a concern, question, or complaint about your care, or would like someone to serve as your advocate, our patient representatives are here to help. Patient representatives are committed to ensuring that your rights are respected and that your concerns are addressed. We can speak on your behalf, represent your interests, and answer questions about hospital policies and procedures.” Available at: http://www.mskcc.org/cancer-care/counseling-support/patient-representatives.
patient’s interests, either as an implication of her role as CEC or in the course of her actions as CEC. I argue that the relevant question is not whether consultants may engage in advocacy at all, but rather, under what conditions they may or must do so.

To discuss patient advocacy in clinical ethics consultation, I first consider a pair of cases that together offer an example of the range of advocacy that consultants potentially face. They serve as a heuristic only, to illustrate the kind of case in which the issue of patient advocacy may arise, rather than to provide case studies in search of a decision. An assessment of professional guidelines for clinical ethics consultation shows that they fail to offer much guidance regarding patient advocacy, so I next consider other arguments. These arguments demonstrate that patient advocacy is permissible, but not central to the practice of consultation. I then offer four recommendations for consultants who engage in patient advocacy, and conclude with a brief consideration of the implications of this discussion for other areas in clinical ethics consultation.

TWO ILLUSTRATIONS

When, in the course of a clinical ethics consultation, a patient’s interests seem insufficiently attended to, what are a consultant’s options? Consider two cases in which consultants may pursue a patient’s interests to differing degrees. In the first, a 14-year-old Jehovah’s Witness, “Luke,” with severe aplastic anemia is facing a choice between blood transfusion contrary to his perceived religious obligations, and possible death without the transfusion. According to the author, who was also one of the consultants in the case, the patient clearly meets the conditions for seeking pediatric assent and respecting his wishes as a mature minor, displaying sophisticated awareness of his situation, a developed sense of his religious obligations, and a warm relationship with his parents. The ethics consultants recommend respecting the wishes of Luke and his family. The hospital decides instead to pursue legal remedy, eventually winning the case, and the court requires the parents to bring Luke in for a transfusion using restraints and sedation if necessary. In the second case, “Mike,” a homeless, moderately mentally incapacitated adult ward of the state with treatable cancer, presents a challenge to the health care team, who must decide whether or not he ought to receive what would otherwise be the standard of care, given his unstable social situation and the difficulty he will likely encounter maintaining the post-therapeutic regimen. An ethics consult is requested. The ethics consultants recommend that the patient receive the standard of care, and that the state work to provide help stabilizing Mike’s social situation.

Though there is much to say about both cases, I consider here only the way in which they raise the issue of patient advocacy in clinical ethics consultation. In case 1, Luke was forcibly transfused. The author (and member of the consult team) wonders whether the

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5 This case is summarized from Spike (2011).
6 This case is abstracted and altered based on a case discussed by Kelley et al., 2012.
7 However, given the nature of aplastic anemia, one wonders what the long-term result was: Did Luke need to be forcibly transfused repeatedly, and would this fact undermine the court’s requirement for forcible transfusion? There is also the hair-splitting (but potentially helpful) point that for some Jehovah’s Witnesses, agreeing to the receipt of blood products is a worse offense (or sin) than being forced against one’s will to take them. For example, in Hoener v. Bertinato (1961), parents of a newborn fourth child
team ought to have informed Luke’s family of a legal case in which another family successfully appealed a related decision, asking, “Might it be that the ethics consultation team was partly to blame for the outcome, due to being too willing to accept the hospital’s maneuvers without any intervention . . . ?” (130). One might put the question this way: “Should the ethics team have done more to advocate for the patient’s interests?” If at least some advocacy is permissible in clinical ethics consultation, to what extent, if any, is it ever required as part of any responsible clinical ethics consultation? In case 2, imagine that the consultants had to pursue Mike’s case avidly, all the way up through hospital administrators and the courts, with potential negative repercussions to themselves. If patient advocacy is ever permissible in clinical ethics consultation, can clinical ethics consultants go too far in patient advocacy, and if so, how can we recognize when they have reached that point? When would negative repercussions be justified (for example, chastising consultants for being overzealous), and when would a consultant be justified in arguing that whether or not she antagonized someone, she was doing her job appropriately?

PROFESSIONAL GUIDANCE?

In response to disagreement regarding the appropriate scope of one’s professional role, one might normally turn for guidance to a set of practice standards. However, as clinical ethics consultation is in the early stages of professionalization, it has no such official guidelines. The closest thing the field has is the recently revised report of an American Society for Bioethics and Humanities task force, Core Competencies for Healthcare Ethics Consultation (ASBH 2011). This document contains only four mentions of the word “advocacy” and its variants, none of which address the issue of patient advocacy or the normative question involved.  

requiring transfusion for an RH condition (after having their second child forcibly transfused and surviving, and their third child not transfused and subsequently dying), stated that though they could not consent to the transfusion, “If the transfusions were ordered by the court—a matter beyond their control and against their wishes—they would nevertheless accept the child into their home as their child” (Hoener v. Bertinato, 142).

8 Just as the professional boundaries of clinical ethics consultation are nebulous, so too are the professional consequences when others are unhappy with the consultant’s actions, as well as the consultant’s ability to defend herself from those consequences. Negative repercussions could range, depending on the consultant’s employment conditions, from lawsuit (e.g., if a particular confidence has been breached) or termination to more “unofficial” repercussions such as the unwillingness of colleagues to call on that consultant.

9 Appendix A mentions advocacy as part of a proper noun. The rest of the text contains only three mentions. On p. 30, the words “advocacy” and “advocates” are used, but focus on disability rights advocates: “members of the ethics consult service should be familiar with disability rights advocacy to ensure that all voices are represented when considering quality of life assessments in cases involving physical and/or mental impairment”; the second mention is simply that ethics consultants should have access to disability rights advocates. On p. 50, under the section “Righting Wrongs,” the authors observe: “It is not uncommon for health care ethics consultants to learn of misconduct on the part of others and, in consequence, to be uncertain of the scope of their duty to address it. Here the ethics consultant can become an advocate—not merely an advisor.” Instead of explaining what this constitutes, the authors conclude the section with two rhetorical questions: “Must one work exclusively within the clinical setting or can one go outside it—becoming a ‘whistleblower’ if necessary? How far should one go in rooting out incompetence?”
However, several claims are made regarding the aim of the clinical ethics consultant, which may offer some help with the issue of patient advocacy. First, the authors conceive of healthcare ethics consultation (HCEC, the preferred term in the document) as “a set of services provided by an individual or group in response to questions from patients, families, surrogates, healthcare professionals, or other involved parties who seek to resolve uncertainty or conflict regarding value-laden concerns that emerge in health care” (ASBH 2011, 2, emphasis added). Second, they state that “the general goal of HCEC is to improve the quality of health care through the identification, analysis, and resolution of ethical questions or concerns,” which involves two intermediary goals: helping both to “identify and analyze the nature of the value uncertainty or conflict that underlies the consultation” and to “facilitate resolution of conflicts in a respectful atmosphere with attention to the interests, rights, and responsibilities of all those involved” (ASBH 2011, 3). Third, and of direct relevance to the question of patient advocacy in clinical ethics consultation, in the section entitled “What are the boundaries of HCEC?,” they state that ethics consultants should: know when to refer a concern to another appropriate institutional resource; avoid role confusion; “foster trust between the HCE consultant and healthcare staff”; not function as the ethics police while also reporting “egregious violations to supervisors or oversight bodies”; and, where a referral is made, “follow up as appropriate” (ASBH 2011, 4–5).

Unfortunately, none of these general statements helps us to assess or direct the consultants’ actions in the cases of Luke and Mike, for the very questions in these cases regard what constitutes “appropriate” follow-up or referral, or acceptable means of resolution of ethical tensions. For example, in Luke’s case, should the consultants have demanded to testify in court, in order to address or resolve the issue raised by Luke’s refusal of transfusion? Should they have referred the family to a nonhospital lawyer, even telling them about a similar case precedent to their advantage? In Mike’s case, does “appropriate follow-up” mean that once the consultants made a recommendation for Mike, and ensured that the consulting physician received and understood it, they had fully discharged their responsibility? Or, given that they made recommendations at the hospital level, were they required to argue for their recommendations forcefully, in front of hospital administrators? At what point might advocacy in that situation pass over into the territory of the “ethics police,” a role often eschewed by consultants because it implies that consultants have a moral authority that cannot be justified? It is not enough to eschew the role of “ethics police,” while simultaneously encouraging consultants to resolve ethical tensions and follow up as appropriate, without offering a way to discern how tension in those areas should be navigated. The very large interpretive space between these guidelines begs for further investigation and clarification, even if utter precision is impossible.

The issue of patient advocacy in these two cases points to ways in which this tension can occur regularly in the course of consultation. In the closest thing the field has to a consensus view, the role of patient advocate is neither prohibited nor enjoined. Moreover, the guidelines that are offered give little to no guidance to consultants in similar situations who desire to steer an appropriate professional path between an impossible

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10 This possibility was raised by Spike, 2011, 130.
neutrality and an objectionable partisanship.

The fact that the *Core Competencies* document does not provide robust guidance in the appropriate limits of clinical ethics consultation may indicate either its own limits as a guiding document or the limits to what can be articulated regarding a new profession like clinical ethics consultation (or in any profession that must allow substantial latitude to accommodate the important yet diverse moral values of individuals). Whatever the reasons, the fact is that the field lacks a set of professional standards. Proposed professional standards are tendentious precisely because in response to this lack, individuals identify different balancing points as appropriate. One consequence of this lack of agreement is that arguments for or against particular actions of CECs can seem ad hoc or subjective, reflecting the convictions of the proponent rather than expressing a substantive, justifiable common purpose underlying the actions and roles of clinical ethics consultation.

Whether or not a more fine-grained and helpful set of professional guidelines can be articulated for the field as a whole, we may be able to make progress with respect to patient advocacy in clinical ethics consultation by considering other arguments regarding the activity. A first step is considering how patient advocacy in clinical ethics consultation expresses a fundamental legacy from the history of bioethics and a paradigm example of the tensions within clinical ethics consultation.

**PATIENT ADVOCACY IN CLINICAL ETHICS CONSULTATION**

The issue of patient advocacy in clinical ethics consultation is compelling for several reasons. First, the historical precedent for patient advocacy in bioethics does not point obviously to a single contemporary stance on the issue. On one hand, it is true that contemporary bioethics arose partly in response to physician paternalism and abuses of human subjects of research. From this perspective, acting on behalf of patients seems integral to the aim of bioethics, and ought to be part of any activity that calls itself “bioethics.” On the other hand, clinical ethics consultation also has roots in physicians’ requests for help in thinking through the moral issues at stake in clinical settings, with the result that another integral aim of the field seems to be to help health care professionals confront ethical issues in their practice. These two strands are not inescapably in conflict, but can nevertheless result in a substantial amount of tension and uncertainty as bioethicists, and clinical ethics consultants in particular, attempt to puzzle out their responsibilities and the boundaries that ought to be respected. Moreover, regardless of historical precedent, bioethics—and in particular, clinical ethics consultation—has grown far from its historical roots, reducing the normative force of any particular “original purpose,” even if a single one could be established.

Second, the question of patient advocacy also makes clear the more general need to articulate, for those who make use of clinical ethics consultation, how to understand the profession’s aims and boundaries. To that end, if we can explain and justify limits to patient advocacy in clinical ethics consultation, there may follow some implications for other limits in the profession.
Third, given that some models of clinical ethics consultation suggest neutral or mediating roles, the question arises of whether patient advocacy might ever be in tension with those roles. Is it possible to work toward a patient’s interests, while also legitimately claiming to serve all parties to a consultation? If so, are there any activities that take one so far down the road of patient advocacy that one has ceased to function appropriately as a clinical ethics consultant, and has “gone native”? This tension in clinical ethics consultation has not yet been confronted in any detail, though there are a few brief uses of the term worth mentioning. One point of view is that “it is not the goal of the ethics consultation service to advocate for the patient” (Joan van Riper, VA Teleconference 2009, 6). Similarly, in a consideration of the role of advocacy in clinical ethics consultation, Don Self and Joy Skeel state:

Personally [we] do not view this model as a viable option for the role of the medical ethicist, but some of our colleagues in medical ethics do see their role as exactly this—a patient advocate. If not performed carefully the role will result in the ethicist’s being an adversary rather than an ally of the physician . . . the role of a medical ethicist should be . . . only indirectly, if at all, as patient advocate. (Self and Skeel 1986, 37, 38).

On the other hand, Sherwin and Baylis observe that “succeeding [in the task of ensuring that patients’ needs and interests are attended to by powerful stakeholders] may require a move of the consultant from the role of architect to that of advocate” (Sherwin and Baylis 2003, 150).

Clearly these authors may mean different things by the term “patient advocacy,” so what appears to be a disagreement might be dissolved by a clearer definition of the term.

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11 The term “going native” is often used pejoratively. Colonialists worried about members of “their” society “going native,” viewing it in the extreme as abandoning the civilized world or the proper moral order. Cultural anthropologists worry about “going native” when they get so close to their subjects that they fail to maintain their proper objective and scientific stance. However, “going native” also means more broadly that one has taken on a new affiliation, and it is in this sense that I mean it for patient advocacy. The point is that patient advocacy is a situation in which a person can step far enough away from the responsibilities or roles that put her in that situation that she questions whether she can still be said to operate on those responsibilities. An example may help to consider the issue: Sarah Chayes was a reporter for National Public Radio in Afghanistan, but after the fall of the Taliban, in 2002, she left NPR to live in and help the rebuilding of the country. Without knowing the specifics of her decision, one can imagine that at a certain point, she made a decision that she desired to, or felt she was obligated to, work toward, rather than report on, the rebuilding of the country, because it was impossible both to do that and to report on it simultaneously. The issue of patient advocacy in clinical ethics consultation is similar to this: A reporter can engage in acts of, say, advancing the interests of the country without compromising herself as a reporter, just as a consultant can engage in acts of advocating for a patient’s interests without violating her responsibilities as a consultant. But at some point, the reporter and the consultant travel far enough down the road that they cross a line and can no longer be said to be fulfilling their professional responsibilities. I am interested in exploring where that line is, how it can be recognized, and what guidelines help consultants to do so.

12 It is interesting that, as presented in Self and Skeel’s work (1986), patient advocacy was seen as a way of conceiving of the work of clinical ethics consultation at the outset of the field. However, arguments against it resulted in its hardly being mentioned again, rather than being worked into the field in some compromise position.
However, it is interesting that none of them offers such a definition, suggesting that each thinks the term’s use straightforward. Moreover, Self and Skeel observe disagreement (between themselves and their colleagues) about the issue, and I suspect that the disagreement goes deeper than mere terminology. Consultants disagree, and likely are internally conflicted as well, about how far they may go in pursuit of a patient’s good, knowing that the role of “ethics police” is a bête noire of clinical ethics consultation. In the absence of professional guidelines or any evidence of consensus among practitioners, the extent of permissible patient advocacy in clinical ethics consultation must be considered in its own right.

Support for Patient Advocacy in Clinical Ethics Consultation

There are several good reasons to view patient advocacy as an appropriate role of the clinical ethics consultant. Already noted is the fact that patient advocacy has obvious affinities with one impetus for the rise of bioethics, the reaction against medical paternalism. It is difficult even to understand the question of whether consultants should advocate for patients without understanding this aspect of the field’s history. From this historical vantage, patient advocacy is merely the activity of supporting patients’ rights in the clinic, a fundamental part of the field of bioethics.

Second, insofar as clinical ethics consultants must sometimes lead and/or facilitate discussion with various parties, the basic needs of such conversations must include the ability to “represent the views of involved parties to others” (ASBH 2011, 24) or ensure “that involved parties have their voices heard” (ASBH 2011, 24). On the basic understanding that instances of “patient advocacy” are those that advance or support a patient’s interests, at least some instances of patient advocacy (e.g., ensuring people have their voices heard) are permissible and even expected in clinical ethics consultation.

A third argument for patient advocacy in clinical ethics consultation is that when a patient needs an advocate, a consultant may at times be the best or the only person in the position to play that role. Direct involvement in a case provides a consultant with knowledge of the clinical situation, the tension at issue, the patient’s wishes, and so on, making it possible for her to function as an effective advocate. For example, it is reasonable to assume that in both cases discussed, as with any complicated ethics case, the consultants spent a great deal of time speaking with the various involved parties, and thus uniquely possess a more complete picture of the situation than any other party. Or, via her involvement in the case, a consultant may also be in a position to notice if others are failing to acknowledge or address a patient’s needs. Though others could in theory advocate for patients, the consultant may in fact be the right person at the right time—the one person who can bring together the knowledge, skills, and resources required to advocate successfully.

Fourth, the clinical ethics consultant often does not have the overt affiliations with institutions or professions possessed by other health care providers, making it easier for her to function as patient advocate because she is not already “aligned” with one side or another. Simple time requirements may also make it difficult for any other health care provider to act as patient advocate. The drive for maximizing billable hours (to which
CECs are not—yet—subject) may make physicians, nurses, therapists, and so on much less able to invest time in complex cases such as those discussed earlier. In contrast, a consultant may have more time to explore a case and help to defend or articulate a patient’s interests. Additionally, often the tension in a case is between the patient or family and the health care provider, making it critical that someone outside of that relationship step in to serve as a patient advocate.

Finally, there is the “ethics” part of clinical ethics consultation to consider. Even if a consultant aims at a relatively neutral role, simply raising the ethical issues in a case may involve some advocating for patients. For example, in case 2, an ethical issue raised was whether Mike’s social situation sufficed to rule him out of receiving what would otherwise have been the standard of care. If “raising” an issue requires agitating for sufficient attention from the relevant parties, that same action can be described as patient advocacy. It is impossible to imagine that a clinical ethics consultant should be prevented from appropriately raising an ethical issue simply because it is an issue about a patient’s interests, merely to avoid acting as a patient advocate in any way.

These arguments make clear that at least some instances of patient advocacy are permissible in clinical ethics consultation. What they do not help us with is establishing the appropriate boundaries of the activity. A consideration of arguments opposing patient advocacy may offer aid in this respect.

**Arguments Against Patient Advocacy in Clinical Ethics Consultation**

Arguments against patient advocacy in clinical ethics consultation fall into two general areas. The first is, ironically, a consideration of the patient’s interests: It is possible that a consultant’s functioning as a patient advocate may have the paradoxical result of rendering the patient’s interests less well served. The second area is professional conflict—that is, that functioning as a patient advocate can conflict with other aspects of the consultant’s professional obligations enough to compromise her very role.

Were there no intent to support a patient’s interests, the question of patient advocacy would never arise in clinical ethics consultation. This makes arguments compelling which suggest that the wrong advocacy might compromise rather than advance a patient’s interests. The first argument for this position is that clinical ethics consultants are not trained advocates, and may not know best how to ascertain and advance a patient’s interests. The best advocate is often someone who can devote considerable time and energy to pursuing an individual’s interests, so although the consultant may have

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13 I note this fact without endorsing it. In an ideal world, perhaps no patient advocates would be needed because a patient’s actual and/or best interests (they are of course not always identical) were being served by their attending physician, consultants, and health care team. In this less-than-ideal world, where time is in short supply, it seems uncontroversial to note that often patients could be better served. Patient advocacy may present an opportunity to remedy that fact.

14 If this view is accepted, it raises the issue of whether consultants ought to be paid by the institutions in which they work. I take no stand on this question, except to note the impracticality of that suggestion for those medical facilities not affiliated with other institutions (e.g., a philosophy department or medical humanities division) by whom a consultant might be paid.
somewhat more time than other members of the health care team, she still has many other tasks for which she is responsible. If a patient is in need of an advocate, a dedicated advocate may be the patient’s best option. Although at present there is no national certification for advocates, some institutions provide advocacy services, sometimes under the umbrella of the ombudsman or, in extreme cases, a guardian ad litem. Even if these services are not available, arguably it is best for a patient to have a dedicated advocate, rather than one whose other loyalties or responsibilities may be in tension with functioning as an advocate, or whose available time is insufficient to the task.

The other type of argument against CECs as patient advocates focuses on diverse ways in which such functioning could compromise other aspects of the consultant’s job. The simplest and most obvious arguments concern issues of redundancy and efficiency: Where it is the case that a hospital or individual has a dedicated advocate, ombudsman, or similar service, there may be no reason for a consultant to play that role. This argument is of limited significance because not all hospitals have such services. However, those that do are likely to be larger ones with more active ethics consultation services, so it may be a more effective argument than it initially appears.

More importantly, serving as a patient advocate is in tension with other possible functions of the CEC and may compromise the CEC’s ability to perform them. For example, if mediation is a critical function of a clinical ethics consultant, that could be in tension with advocating for a particular party in a clinical situation. Could a consultant both advocate for a patient’s interests and remain detached (and be perceived as detached) enough from any particular stakeholder to maintain the trust of participants and the necessary wider view of the issue at stake? Or at a certain point, would vigorous advocacy become incompatible with mediation? It may be possible in some instances to advocate for patients without sacrificing other clinical ethics consultation roles, but there are potential

15 Consider, for example, the model of the consultant as “navigator” in clinical contexts offered by Zoloth and Rubin: “If the physician is the captain of the ship, then . . . it is the ethicist who is the navigator: knowing the map, being familiar with the terrain and its complexities, calling attention to how the desired or expected course might be changed by the immediacy, temporality and particularity of a given case” (1997, 429). A navigator’s task of directing a course could be compromised were she to take up the duties of others on “the ship.” By taking her eyes off of the central aims of the consultation in order to pursue other aims, a consultant may place the central aims at risk. This does not mean she should let an important task go undone (she could help to find someone to fill that task), but it may mean that she ought not to try to complete the task herself.

16 Although patient advocacy is in the initial stages of professionalization and (like clinical ethics consultation) lacks official sanction or credentialing, there are training programs offering certificates (e.g., the University of Miami offers “The Alfus Patient Advocacy Online Certificate Program,” http://www.educationmiami.com/en/packagedetail.aspx?p=100). There are also numerous patient advocacy groups, some selling services. See for example www.healthadvocate.com or www.patientadvocate.org.

17 However, the case of “Mike” makes clear that even this approach can potentially fail.

18 For example, those familiar with the literature in clinical ethics consultation will recognize that the U.S. Veterans Administration has a significant and active dedication to scholarship and practice in the field. It also happens to have a dedicated patient advocacy service. According to the VA website, “A Patient Advocate is an employee who is specifically designated at each VHA facility to manage the feedback received from veterans, family members and friends. The Patient Advocate works directly with management and employees to facilitate resolutions. You may contact the Patient Advocate at your facility” (http://www.patientadvocate.va.gov/HearFromYou.asp, accessed June 18, 2012).
costs in both the short and long term. In the short term, advocating while presenting oneself as simultaneously neutral can compromise the consultant’s effectiveness during that particular case. In the longer term, a consultant who attempts to play multiple roles may confuse colleagues who never know in a particular case which “side” the consultant will take. If a consultant is trusted by colleagues in part based on the fact that they know what role she plays in a clinical ethics case (whatever form that takes—for example, as a relatively neutral party), the uncertainty and confusion bred by a changing role could destabilize the consultant’s effectiveness. One heated case, engendering ill will, may brand the consultant (e.g., as “anti-physician”) in a way that makes it harder for her to interact candidly and successfully with health care teams. Of course there will be tensions and disagreements in working relationships, but there is a difference between them arising in the normal course of professional interaction versus arising as a result of an adversarial relationship, particularly where that relationship’s occurrence is unpredictable. Recall my earlier mention of “going native,” which refers to the usually unacceptable practice of acculturating to a set of beliefs, practices, and so on that are not one’s own, or not the ones one is “supposed” to have. The danger of “going native” in patient advocacy (expunged of the derogatory connotations) is taking up the patient’s “side” to the exclusion of other legitimate perspectives that it is a consultant’s job to include in the discussion and resolution of a case. If a consultant “goes native” in this way, she may be seen as a patient’s lawyer might be seen, converting clinical ethics consultation to an adversarial arena and compromising vital lines of communication.

If we interpret the question of whether CECs should advocate for patients to mean “should CECs represent themselves primarily or exclusively as patient advocates?,” the answer is clearly that they should not, for the reasons just discussed. The most decisive argument against this position is that it would utterly compromise the consultant’s ability to do most of what is currently understood to be her job. For example, many consultations have nothing to do with a patient needing advocacy, so why would one invite someone who is primarily or exclusively an advocate to help with such issues? Consultants should thus not be seen primarily or even in a significant way as “patient advocates,” understood as parties to whom patients should regularly look for representation in the clinical context. However, from the preceding section, it is also clear that some instances of patient advocacy are permissible for clinical ethics consultants.

Therefore, some instances of patient advocacy are permissible, but clinical ethics consultants should not be seen as patient advocates per se, and that should not be a major component of consultation activity. Unfortunately, these uncontroversial results do not help us to address the cases described earlier, or to say whether the consultants in these

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19 Lance Stell notes that “advocacy presupposes adversity,” at least when “advocacy” is understood to be a zealous pursuit of a patient’s interests (2009, 134). What follows from this is that clinical ethics consultants (and physicians, nurses, etc.) cannot be advocates in this more extreme sense if they are to function in their professional roles as colleagues.

20 Of course I do not mean to imply that the consultant’s conclusions ought to be predictable, or that a consultant should never challenge others’ views or even agitate for change. However, it seems clear that it will be difficult for others to work with a clinical ethics consultation colleague whose loyalties, purpose, and aims are opaque or fluctuating.
cases went too far, should have gone further, or behaved within appropriate boundaries. What is required is further conceptual granularity to identify some other substantive limits to the appropriate extent of patient advocacy. In the next section, I offer four guidelines for engaging in patient advocacy in clinical ethics consultation.

GUIDELINES FOR UNDERTAKING PATIENT ADVOCACY IN CLINICAL ETHICS CONSULTATION

No existing professional guidelines succeed in clarifying under what circumstances patient advocacy is permissible in clinical ethics consultation. However, it may be unnecessary for professional guidelines to address this issue specifically: If patient advocacy is permissible, and not a main goal of the activity, then it is an instrument with which clinical ethics consultants may pursue whatever central aim of the profession is eventually regnant. Though meager, this tactic gains some ground in identifying appropriate limits of patient advocacy: If, within clinical ethics consultation, patient advocacy is merely a tool, its use as a tool is lost when the tool becomes instead the focus of the activity. Even more important, if the use of a tool compromises the aim of the activity, either the tool or the activity must be set aside. This point suffices to help us begin to articulate guidelines for patient advocacy in clinical ethics consultation.

The kind of case that raises the question of whether a clinical ethics consultant should advocate for a patient is bound to be rare, because most patients have friends or family who undertake that role. But Mike had no such friend or family member, and Luke was a minor with a family relatively uninformed about their options in the face of the court’s decision. In such cases, it would be wrong for a consultant to ignore these facts and insist that advocacy is not her job. But several limits to advocacy follow from the arguments already discussed.

First, a consultant or consultation team should evaluate whether a dedicated advocate ought to be engaged for the patient, either because it is better for the patient or because the tension between the role of consultant and the role of advocate is untenable. There are often trained and experienced patient advocates who are arguably better situated to represent a patient’s best interest, so in such cases the burden of proof lies on the consultant to demonstrate why a dedicated advocate will not be or cannot be engaged.

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21 I specifically do not mean to claim or imply that patient advocacy is only ever a tool. It is of obvious value as an aim in its own right. Within clinical ethics consultation, however, it is instrumental: a tool to be used toward the main aim of clinical ethics consultation.

22 However, even in such cases a consultant may advocate at times, insofar as she clarifies the patient’s views to the health care team, for example. I take this to be an example of unproblematic advocacy, stemming directly from a consultant’s obligation to help air the views of stakeholders to a consultation. What that implies, though, is that a consultant may likewise be a nurse advocate, physician advocate, family advocate, and so on, rendering it rather unnecessary to use the term “advocate.”

23 Joel Zimbelman argues along the same lines: “[Health care ethics committees], like any institutional committee, can become complacent or ineffective in their case review. . . . [Professional advocates] can substantially mitigate these problems, and for that reason ought to become an integral part of the HEC process” (1994, 170). It is not clear whether becoming part of the HEC process means becoming a consultant (at the time he wrote the article, consultations were probably less frequently conducted by a single person and more often conducted by a committee), but he does note the same kinds of issues I argue
This is optimal, as it provides the patient with a dedicated, trained advocate, offers a recognizable figure as representing the patient’s interests without role confusion, and avoids committing the consultant to potentially conflicting roles.

Second, if a consultant must take up in earnest the role of patient advocate, this may mean abdicating her role as clinical ethics consultant if she will therefore not be able to fulfill some of her obligations. If the person involved is the main consultant on the case, someone else may need to step in and take over as consultant.

Third, and following from the second condition, in the relatively rare circumstance in which a consultant does begin to act in earnest as a patient advocate, this fact should be *explicitly recognized and announced*, rather than being merely “fallen into.” It is dangerous, from the standpoint of a consultant’s effectiveness or trustworthiness, for her to slip into the role of patient advocate while other members of the consultation team or health care team think she is speaking as, for example, a mediator or other neutral party. After all, if the role change is not announced, colleagues have no reason to think that anything about the consultant’s role has changed. Not least important is the issue of confidentiality: a CEC as colleague could be expected to keep conversations confidential, but it is hard to reconcile the idea of a consultant advocating for a patient while keeping information from that patient. Making clear to all concerned why a consultant is taking up the role of patient advocate, what that means, and what the endpoint is seems imperative if one is to avoid the problems of playing competing roles.

Fourth, if it is the case that another advocate is not available, the consultant should be careful that advocacy does not become an excuse to be an activist for her own reasons. For example, a passive wife with a domineering husband may seem to need advocacy so that her voice can be heard over that of her husband’s, but a consultant motivated by feminist concerns may have a hard time distinguishing this actual patient’s wishes from a more generalized concern with the role of women. In this way, advocacy can pass over seamlessly into activism, or “ethical policing,” in the absence of a clear border delineating the roles.

Under these conditions (which may require revision and specification as the obligatory roles for CECs become better articulated), it seems permissible for a clinical ethics consultant to engage in patient advocacy in a very limited way.24

How do these four guidelines help one to think through cases such as those of Luke and Mike? First, in both cases the patient might have benefited from a dedicated advocate. Both Luke and Mike were in situations that were at least partly adversarial, and needed

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24 Lisa Newton notes a few other difficult issues raised by the deployment of CECs as patient advocates (though the scenario she imagines is somewhat different), including questions such as what triggers the appointment of an advocate; the extent of her authority and accountability; and the possibility of conflicts of interest (Newton 1994, 173–174). These are clearly salient issues, but my focus is on the more immediate question of whether the activity ought to be engaged in at all in clinical ethics consultation.
support in order for their interests to be respected. The adversarial situation created the potential for a CEC to have role conflict. If it was not possible for consultants to enlist a dedicated advocate, they might have addressed the potential for conflict by clearly stepping into an advocacy role and out of a consulting role, to avoid the potential problems discussed. Finally, it does not seem that the consultants’ activism played a role in either case, but it is possible to imagine cases in which it did. This would not necessarily be objectionable, but it might result in conflicted motives for a CEC, and thus merit attention.

These guidelines are less specific than might be desired. It would be good to know, for instance, which specific types of role conflict one should guard most against, or how much tension between roles is enough to trigger a consultant’s departure from her role as consultant if no other advocate is available. Given the current state of clinical ethics consultation’s professional definition, however, it is not clear that we can be any more specific than this. Prospects for more specificity in the long run are not encouraging either; each clinical situation manifests differently, and generates a distinct set of tensions to manage. It is impossible to offer general guidelines for when, in specific cases, the tension between advocacy and other roles of clinical ethics consultation must be addressed and one or the other chosen. However, these considerations at least indicate when a terrain change in the moral landscape of such cases may signal a change of moral obligation.

Another problem with the guidelines I have offered is that they do not specify when consultants are obligated to do more in the way of advocacy as an implication of their professional role. In Luke’s case, for instance, Spike asks whether the consultants should have done more to direct the family to seek legal relief, by telling them of a case precedent that might have helped them. It would be comforting to have professional direction in such cases, but it is unlikely (for reasons articulated earlier) that a generally worded guideline can give such specific direction. In addition, however, until the aims and obligations of the profession of clinical ethics consultation are articulated in more detail and receive general approbation, it is impossible to indicate when a professional line has been crossed in the pursuit of advocacy.

FURTHER IMPLICATIONS

There are two issues related to clinical ethics consultation and patient advocacy that deserve more discussion than I can afford here, but that I must at least mention. First, to the extent that a consultant believes she is obligated to advocate for a patient, it is not clear that such a belief stems from her role as consultant rather than from simply being a moral agent. For many, the perceived need of another registers a moral imperative to aid,

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25 Whether it was necessary or prudent to do so might depend on factors such as personality, the nature of ongoing relationships, thebrittleness of hospital hierarchy, and so on. In a work environment with stable and trusting work relationships, a consultant could press much further for a patient than she could in an institution of strained relationships or itinerant staff. The implication of this is that to the extent that patient advocacy is an implied function of consultants, there is a concomitant responsibility to foster work conditions in which it is possible to exercise that function.
the motivation for which is not always clear to the agent him- or herself. Particularly because the consultant encounters a patient’s need in the course of her duties as consultant, it is difficult to disentangle what she is obligated to do as a professional versus what she feels called to do as a human being, a moral agent. In this respect, a consultant encountering a patient whose need begs for advocacy resembles a foreign aid worker encountering need in areas that he or she cannot fulfill without abandoning his or her assigned task. Patient advocacy may be just another example of a moral dilemma in which one must judge which among competing obligations (particularly those experienced by professionals between their role obligations and their personal obligations) has the greatest claim.

Second, patient advocacy in clinical ethics consultation raises a deeper question of partisanship or taking sides that extends all the way to a battleground for normative commitments, because it concerns what “side,” if any, a consultant is on, and what to do when one has incompatible obligations. For example, how much neutrality is required or even possible in clinical ethics consultation? How far can a consultant take her personal commitments, and to what extent is she required to abandon them in the face of others’ need? In Luke’s case, the consultants possessed a piece of information that might have been helpful to the family, and could have passed that information on anonymously, so as not to threaten the consultant’s professional effectiveness. But such an anonymous action, while resolving the potential problem of role conflict, hardly seems satisfactory. If the action would have been permissible, it would have been so had it been done transparently as well (though it may be wise for other reasons not to be public with such actions). Role conflict is thus not the only potential problem when a clinical ethics consultant engages in instances of advocacy; advocacy raises a fundamental question of the allegiance of the clinical ethics consultant in a deceptively simple way, and a consideration of that question may serve as a bellwether for what we think about the field as a whole.

CONCLUSION

In arguing for limits to patient advocacy in clinical ethics consultation, I have been equally concerned with a consultant’s ability to defend unpopular yet professionally justifiable behavior and an employer’s ability to identify when a consultant has acted objectionably. It is unfathomable that a professional would not be able to articulate for him or herself or an employer at least a general scope of appropriate professional behavior. Without such guidelines, a consultant is at the mercy of employers if his or her action is displeasing, and an employer would have no justifiable grounds for deeming a consultant’s actions unprofessional. Patient advocacy is merely one area in which this problem arises in clinical ethics consultation; it is problematic in part because the role and aim of the consultant is only roughly articulated (without even a consensus on that rough articulation), leaving the commitments of such a professional role ambiguous. If consultation enjoyed a clearer professional definition, the presumed loyalties of the

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26 One may wish to suggest that the consultant is on the side of what’s morally right, but this can create more problems than it solves, given the contentious nature of moral values in a pluralist society. This is a much larger issue than I can address here, but it is worth pointing out just how quickly this profound problem arises when one begins to ask how to understand the allegiances of the clinical ethics consultant.
consultant would be likewise clearer and we might know whether or not, and under what circumstances, to expect patient advocacy from consultants. Even then, it is likely to be the case that clinical ethics consultation inescapably lives in the unsettling space between sometimes conflicting obligations. In the end, however, if the pursuit of one obligation threatens to undermine the entire enterprise, a consultant may have to choose between following the obligation or sustaining the activity. Most have only one opportunity to fall on the sword for a cause.

REFERENCES


