Neglected Ends: Clinical Ethics Consultation and the Prospects for Closure

Introduction

In the section titled, "What are the goals of HCEC?", the American Society for Bioethics and Humanities' Core Competencies for Healthcare Ethics Consultation lists two: 1) "identify and analyze the nature of value uncertainty or conflict;" and, 2) "facilitate resolution of conflicts." Within the practice of healthcare ethics consultation (HCEC), a "resolution" is the moment when the consultants "render a decision," "make a recommendation" or "fashion a plan." This overly narrow understanding of the "resolution" or "end" of an HCEC neglects the residual, lingering aftermath that can occur for patients, families and providers – even sometimes the consultants themselves.⁴ In this paper, I argue that we should reconsider the ends of HCEC in two different senses of the term: "end" as "ending" and "end" as "aims," reevaluating how an HCEC ought to conclude after employing a more robust conception of its goals. I argue that if we had a more expansive notion of what we ought to be striving for in HCEC, we would clearly recognize the insufficient closure that is part and parcel of the HCEC ending that constitutes business-as-usual. I will argue that the key to achieving the best end in both senses is an HCEC process that prioritizes assisted conversation between all of the stakeholders in the conflict, what is often referred to as bioethics mediation.⁵

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¹ American Society for Bioethics and Humanities' Core Competencies Update Task Force. 2011. *Core competencies for health care ethics consultation: The report of the American Society for Bioethics and Humanities* (2nd ed.). Glenview, IL: American Society for Bioethics and Humanities.

² Bernard Lo, "Behind Closed Doors: Promises and Pitfalls of Ethics Committees," *New England Journal of Medicine* 1987; 317: 46-50.

³ ASBH p.7

⁴ Paul Ford and Denise Dudzinski, *Complex Ethics Consultations: Cases That Haunt Us* (New York: Cambridge University Press, 2008).

⁵ Dubler, N., and C. Liebman. 2011. *Bioethics mediation: A guide to shaping shared solutions*. Nashville, TN: Vanderbilt University Press; Fiester, A. 2011. Ill-placed democracy: Ethics consultations and the moral status of voting. *Journal of Clinical Ethics* 22(4): 23-32; Fiester, A. 2013. Mediation and Recommendation. *American Journal of Bioethics* 13 (2): 23-24; A.Fiester. Mediation and Advocacy. *Am J Bioeth* 2012; 12(8): 10-11; A. Fiester, "The "Difficult" Patient Reconceived: An Expanded Moral Mandate for Clinical Ethics," *American Journal of*

Neglected Ends: Resolution vs. Closure in HCEC

Clinical ethics consultants understand the goal of their work to be the resolution of ethics conflicts. In fact, the Core Competencies for Healthcare Ethics Consultation quite explicitly states this to be the goal.⁶ So when a recommendation has been made or a plan has been created, consultants believe the work of the HCEC is finished. But in what sense is it finished and for whom?

To see how much is left unfinished in a typical HCEC, let's scrutinize the conventional view of the case-ending. Although the consult is traditionally considered concluded at the moment when a decision has been reached in the case, the situation in which the various stakeholders find themselves has certainly not come to an end, and, in a profound sense, this moment might actually be perceived as being more like a beginning than an end. In the Fiction of Bioethics, Tod Chambers insightfully remarks of clinical ethics cases, "Isn't the very problem knowing what is the beginning and what is the end?" In fact, he argues that if the beginning and ending are "the tick and tock of the bioethics case", then, "bioethics is a battle over the tock of the case." For his purpose, he is focusing on the various ethical analyses and moral considerations that will be debated as being central in the clinical ethics conflict, but in HCEC the same insight holds. How we define the beginning and end of the HCEC determines our obligations to the stakeholders and/or the institution, the standards for measuring our success or failure, and the process of HCEC that achieves our aims.

Bioethics, Volume 12, No. 5, May 2012; A. Fiester, "The Failure of the Consult Model: Why 'Mediation' Should Replace 'Consultation,'" American Journal of Bioethics, Volume 7, Number 2, 2007: 31-32; Edward Bergman, Surmounting Elusive Barriers: The Case for Bioethics Mediation," *Journal of Clinical Ethics* 24(1), 2013, 11-24; Wahlert, L. and A. M. Fiester. 2012. "Mediation and Surrogate Decision-Making for LGBT Families in the Absence of an Advance Directive." Journal of Bioethical Inquiry 9(3).

⁷ Tod Chambers, *Fiction of Bioethics* (New York: Routledge, 1999),p.81.

⁸ Chambers, p. 96.

If the case-ending is achieved when a recommendation or plan is offered, we recognize no obligation to attend to all of the affective, relational, moral or psychological loose ends that are inevitably attached to the conflict. We have an HCEC case with an ending, but not one with any closure. For closure, the stakeholders (the patient, family, providers, and consultants) need a deeper sense of completeness than an "action plan" could ever provide. They need closure: a "feeling that something has been completed or that a problem has been solved." Reaching a resolution is not the correct metric of whether a case has really ended – or at least it is not a metric of whether it has ended *well*.

We can use the following case to highlight the difference between the resolution to an HCEC and the case having closure:

Mr. Roberts is a 73-year-old man who presented to the hospital with respiratory distress. He required intubation and mechanical ventilation upon arrival. Subsequently, he underwent a battery of tests that diagnosed metastatic lung cancer. His hospitalization has been complicated by pneumothorax, venous thromboembolism, cardiac arrhythmias, anemia, pneumonia and severe malnutrition. He has undergone multiple procedures including a tracheostomy and feeding tube placement. One month into his course of treatment, he has persistent respiratory failure and remains ventilator dependent. Additionally, he has now developed acute renal failure which requires renal replacement therapy to sustain life. He is otherwise hemodynamically stable. Mr. Roberts has no advance directive or living will and has never communicated his explicit wishes to his family. His wife has medical power of attorney. During previous conversations, both his wife and daughter have verbalized a strong desire to continue aggressive therapy and indicated that their best understanding of the patient's wishes would be to continue with aggressive therapy indefinitely. The medical team feels that hemodialysis will not alter the patient's prognosis. He has metastatic cancer and is too unstable to safely receive even palliative chemotherapy. His life expectancy is weeks, and while withholding this life sustaining treatment could hasten his demise, it will not change the outcome of certain death as a direct result of complications from his lung cancer. Therefore, the medical team is refusing the dialysis.¹⁰

To talk through how the HCEC for this case would likely proceed is bit like pinning down a moving target because there is no universal method or process for how consultations are conducted nation-wide. The most comprehensive study of HCEC to date demonstrates a wide range of approaches and strategies employed by ethics consultants or committees, but there are

⁹ Merriam-Webster. http://www.merriam-webster.com/dictionary/closure. Accessed May 25, 2013.

¹⁰ Acknowledgement to Dr. Joshua Kayser for the case write-up.

some patterns of what is likely to occur in any given consult. ¹¹ The most prevalent configuration of a HCEC is the use of a "small team of individuals" to conduct the consult, with 68% of hospitals employing this method. ¹² In this model, the study found a median of four consultants involved per case. ¹³ The process that these four individuals were most likely to use would be a series of one-on-one conversations between a single member of consultant team and one stakeholder, but different categories of stakeholders were more or less likely to be invited to participate. While 69% of the small teams reported that they "always" conducted one-on-one conversations with the clinical staff, only 45% of small teams "always" talked to either the patient or the family members. ¹⁴ Having gathered information from the clinical staff and possibly the patient or family, the small team would either recommend a single best course of action or a range of acceptable actions, and the HCEC would come to an end. ¹⁵ Only in 13% of HCEC's would the consultants remain actively involved after the recommendation(s) were made. ¹⁶

Given this backdrop, the likely approach to a HCEC for this case would be that a small team of ethics consultants would divvy up the task of holding one-on-one meetings with the MICU physician in charge of the case, other members of the clinical team, such as the consulting nephrologist or oncologist, and maybe with a representative from nursing. If we assume that this is a consult service that does routinely converse with family members as part of the consult process, one of the consultants would speak with the patient's wife and adult daughter. The HCEC team then would talk among themselves to determine the best course of action, and they

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¹¹ Fox, E., S. Myers, and R. A. Pearlman. 2007. Ethics consultation in United States hospitals: A national survey. *American Journal of Bioethics* 7(2): 13-25.

¹² 23% of HCEC use a committee-approach and 9% use a single consultant. Fox. P. 16

¹³ Fox 19.

¹⁴ Fox 18

¹⁵ Fox 18.

¹⁶ Fox 19

would make a recommendation to the treating MICU physician, either to continue aggressive care or to refuse the family's request for dialysis.

The HCEC would now be considered complete, but regardless of the course of action recommended, the case would surely lack closure for some subset of stakeholders. If the consultants sided with the MICU physician and recommended forgoing dialysis, how will the patient's wife and daughter react? If the consultants recommended that aggressive treatment continue and dialysis begin, how will the clinicians feel? Either way, this resolution to the conflict will be perceived as a bad ending by someone.

Bad Endings: Moral Distress and the Moral Emotions

The aftermath of a bad ending for stakeholders who have not been able to achieve closure in an ethics conflict takes two forms: moral distress or the moral emotions. Both of these amount to an indictment of the HCEC process, so I will refer to them as the "moral residuals." Although both categories of stakeholder could experience either type of moral residual, it is likely that providers – nurses or physicians – will find themselves in moral distress after a difficult HCEC and that patients or families members are more likely to experience one of the moral emotions post-HCEC.

To explore the repercussions of an HCEC without closure, we can trace the stakeholders' reactions on both possible outcomes: a recommendation in favor of dialysis and a recommendation against it. Let's start with an HCEC that sides with the patient's wife and daughter and urges the treating team to start the dialysis on grounds that it will be life-prolonging and on concern that there is no independent indication, such as an advance directive, that Mr. Roberts would choose to forego this treatment. Now imagine the perspectives of the MICU

attending and the nurse in charge of Mr. Roberts' care. From the physician's vantage point, this is a cowardly decision on the part of the hospital's consult service that demonstrates more concern with lawsuits and bad press than with the moral assault on a dying man. This is a blatant violation of the ethic of "do no harm" as the team pummels Mr. Roberts with procedure after procedure that offers no prospect of even minimally conscious existence – not to mention the squandering of resources on a patient who cannot benefit at the expense of others who could. The nurse in charge of Mr. Roberts care-plan is equally disturbed by the decision. Mr. Robert's wife and daughter seem oblivious to the patient's wasting, skin breakdown, and grimacing whenever he is turned. Every day the nursing staff complain to her that this isn't "care," it's "torture," and they are complicit in the continuation of this patient's obvious suffering.

This residual experienced by this treating team is known as "moral distress," a strong conviction about what is right to do in a particular situation but being unable to take the action perceived as morally correct.¹⁷ A concept that traces back to Andrew Jameton, ¹⁸ moral distress has garnered significant attention in the nursing literature, ¹⁹ but it is a phenomenon not limited to nurses, but also seen in physicians and even ethics consultants.²⁰ When moral distress goes unresolved, the consequence of these lingering feelings is referred to in the literature as "moral residue." ²¹ Moral residue has been demonstrated to be "lasting and powerful," ²² moored by the self-censure of having "seriously compromised ourselves or allowed ourselves to be

¹⁷ Epstein and Delgado; Ulrich, Hamic, and Grady; G Webster and F Bayliss, "Moral Residue," in *Margin of Error: The Ethics of Mistakes in the Practice of Medicine*, eds. S. Rubin and L. Zoloth (Hagerstown, MD: University Publishing Group, 2000), 217-230.

¹⁸ Andrew Jameton, *Nursing Practice: The Ethical Issues* (Englewood Cliffs, NJ: Prentice-Hall, 1984)

¹⁹ ADD NURSING

²⁰ Ford and Dudzinski, 2.

²¹ Epstein and Delgado, 1; Epstein and Hamric; L. Hardingham, "Integrity and Moral Residue: Nurses as Participants in a Moral Community," *Nursing Philosophy* 2004; 5(2): 127-34.

²² Epstein and Hamric 333

compromised."²³ The concrete fallout can range from feelings of disempowerment²⁴ and stress²⁵ to job burnout²⁶ and thoughts of leaving the healthcare field.²⁷

The second type of moral residual that comes from a lack of case-closure are the moral emotions.²⁸ Imagine now that instead of advocating for the start of dialysis, the consult team recommends foregoing it on grounds that it will neither alter Mr. Robert's grim prognosis nor offer him any enhanced quality of life. Protecting the hospital's limited resources, the consult team recommends siding with the unanimous views of the medical team. When the MICU attending relays the news to Mr. Robert's wife and daughter that dialysis will not be started and Mr. Roberts will likely die within a handful of days, they are outraged. For an entire month, these doctors have done one thing after another to fight for his life and now they are just arbitrarily giving up? What was the tracheostomy and feeding tube for if they were just going to quit when they felt like it? Why weren't we warned that this hospital could just up and decide his life was no longer worth fighting for?

An emotional response to a situation that testifies to the individual's perception of moral offense, wrong-doing or harm is called a "moral emotion." More formally put, moral emotions are "those emotions that are linked to the interests or welfare either of society as a whole or at least of persons other than the judge or agent."²⁹ Among the most potent moral emotions are guilt, anger, resentment, and indignation. Two classes of moral emotions are figure prominantly

²³ Webster and Bayliss, 208

²⁴ A Nathaniel, "Moral Reckoning in Nursing," Western Journal of Nursing Research, 2006; 28(4):419-438;

²⁵ Connie Ulrich, et al, "Everyday Ethics: Ethical Issues and Stress in Nursing Practice," Journal of Advanced Nursing 2010 66(11), 2510-2519.

²⁶ Meltzer and Huckabay 2004

²⁷ Corley 1995; Hamric and Blackhall 2007; E Elpern, B Covert, and R Kleinpell, "Moral Distress of Staff Nurses in a Medical Intensive Care Unit," American Journal of Critical Care, 2005; 14(6): 523-530; Debra Wiegand and Marjorie Funk, "Consequences of Clinical Situations That Cause Critical Care Nurses to Experience Moral Distress," Nursing Ethics 2002, 9(4): 479-487.

²⁸ Jonathan Haidt, "The Moral Emotions," in *Handbook of Affective Sciences*, eds. R.J. Davidson, K.R. Scherer, and H.H. Goldsmith (Oxford: Oxford University Press, 2003), 852-870; Roger, Giner-Sorolla, Judging Passions: Moral Emotions in Persons and Groups (London: Psychology Press, 2012); Izard, Carroll, Human Emotions (New York: Plenum Press, 1977); Justin Oakley, Morality and the Emotions (New York; Routledge, 1982); Sabine Roeser, Moral Emotions and Intuitions (New York: Palgrave Macmillan, 2011); Wallace, R. Jay, Responsibility and the Moral Sentiments (Cambridge, MA: Harvard University Press, 1994); Russell Cropanzano, Social Justice and the Experience of Emotion (New York: Routledge, 2011); ²⁹ Haidt, 854.

in this case, what Jonathan Haidt terms the "self-conscious family" (e.g., guilt) and the "other-condemning family" (e.g., anger, resentment, indignation). ³⁰

1. self-conscious family: guilt

- --unresolved feelings that stakeholders did the wrong thing, didn't do enough, failed others involved
- --guilt: feeling when "one believes one has caused harm, loss, or distress to a relationship partner," to someone with whom one has a relationship: professional, kinship, friendship, spousal, collegial.
- --creates long-lasting moral burden
- --case option 1: recommendation by HCEC that dialysis is withheld: without closure, feelings of guilt by wife and daughter: that let "let him die," "didn't fight for him when he would have fought for us", "gave in too soon to the doctors", "should have sued for continued care" --or case option 2: recommendation by HCEC that dialysis is continued: MICU staff feels guilt that they prolonged the patient's suffering, that they "caved" to the family and HCEC, --can be consultant who feels guilt too for decisions, recommendations, inability to assist, etc. 32

2. other-condemning family: anger, resentment, indignation

- --second set of emotions triggered by perception of being wronged or witnessing wrong done to others
- --recognized as our reaction to injustice even by Greek philosophers: Aristotle argues that indignation is a response to a "conspicuous slight directed without justification towards what concerns oneself or towards what concerns one's friends"³³
- --stakeholders angered or resentful at a consult hold the belief that they or someone they care about has been wronged
- --from a study of patients and families dissatisfied with ethics consult, commenting on dissatisfaction: "The hospital was covering its mistakes"; "They [consultants] only listened to the doctors"; "Surrogate felt 'badgered' by doctors: "They [doctors] kept coming after me"; ³⁴ --that study's own analysis of dissatisfaction with consult: "families may perceive...unfair coercion toward a particular goal of treatment," echoing concerns about HCEC recommendations raised by Bernard Lo 25 years ago. ³⁶

Concrete Fallout/Consequence: Maligning hospital, policies, ethicists

-- this is the set of negative consequences when there isn't proper closure

II. The Quest for Better Endings and the Obligation to Promote Closure (i.e., the obligation to a better ending)

³¹ Haidt, 864.

³⁰ Haidt, 852.

³² M.J. Blinton and S.G. Finder, "Traversing Boundaries: Clinical Ethics, Moral Experience, and the Withdrawl of Life Supports," *Theoretical Medicine* 2002, 23: 233-58; R. M. Zaner, "Listening or Telling? Thoughts on Responsibility in Clinical Ethics Consultation," *Theoretical Medicine* , 1996, 17(3): 255-77.

³³ Aristotle, *Rhetoric*, W. Rhys Roberts, trans. (New York: Dover Press, 2004), Lines 1373-1375, p. 60

³⁴ Schneiderman et al "Dissatifaction with Ethics Consultations" 103

³⁵ Schneiderman et al "Dissatifaction with Ethics Consultations" 105

³⁶ Bernard Lo, at 47.

A. Obligations to Patients and Families: Family Centered Care

--new attention to families³⁷

B. Obligations to Providers (clinicians and consultants)

--how do we get better endings? Better process

III. Process-Models and the Prospect for Closure (i.e., respective odds of a better ending)

- --let's describe 2 models for HCEC process: Deal-Making Model, or the Assisted-Conversation Model
- --in our case: 1) a resolution could be crafted by talking to individual clinical team members individuals and/or to family members separately one-on-one or 2) stakeholders could talk together in a conversation facilitated by the HCEC

A. Deal-Making Model (low odds of closure): engenders bad endings

- -- Process used in our case above
- -- "Non-facilitated consultation"

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B. Assisted-Conversation Model (high odds of closure): promotes genuine closure

1. What are the features of "assisted conversation"? by any other name is "Mediation"

- --"honors the validity of both sides in a dispute" ³⁸
- --emphasis on "interests"³⁹
- --reframing: "Mediators function largely by exploring the interests of the parties and reframing positions ('I won't consent to that operation') into interests ('So you are worried about the potential side effects?'), and then generating options that are satisfactory to both parties" ⁴⁰
- --understanding respective perspectives⁴¹ and integrating: "Mediation can also create an environment in which multidisciplinary teams can learn to integrate the psychosocial, cultural, ethical, legal, and medical concerns in a case"
- --"opportunity to reopen a conversation, in a new frame, to explore all avenues, to reframe relevant statements, to renegotiate options, and to arrive at a conclusion that contains concerns from all parties with the hegemony of none"⁴²
- --"conduit for complex communication among patients, their families (including relatives, significant others, close friends, and appointed surrogates), and the care team."
- --understands itself as having a mandate to create a "shared resolution"

³⁷ Davidson, et al 2007; Balik et al 2011; Dubler and Liebman 2010

³⁸ Fiester, 2011, 370

³⁹ Antommaria, 279; Gibson 7

⁴⁰ Gibson, 7

⁴¹ Bowman, S21

⁴² Dubler, Clinical Ethics, 377

⁴³Dubler, 379

2. Core Competencies' Facilitation Model

ASBH's Core Competencies for Healthcare Ethics Consultation support for facilitation

- --describes facilitation as "ensure that involved parties (e.g., patients, families, surrogates, healthcare professionals) have their voices heard" "assist involved individuals in clarifying their own values" "apply mediation or other conflict resolution techniques, if relevant 44
- -- Take for example even the suggestion: "An ethics consultant may listen empathetically to the moral distress experienced by an administrator, nurse, or physician and help to identify their values or commitments" 45
- --Task Force reaffirms this model: "helping the parties voice their concerns and define interests; and identifying and expanding possible resolutions for conflicts, highlighting agreement, and ensuring that consensus is ethically justified" 46

3. Parallel to the Calls from Moral distress literature

- --important call, but fairly vague: "Reducing moral distress calls for identifying efficient and effective mechanisms to support health care providers" 47
- --one suggestion: "Develop policies to encourage open discussion, interdisciplinary collaboration, and the initiation of ethics consultation" ⁴⁸
- --one institution: Moral Distress Consult Service⁴⁹ plays the same role as a HCEC factilitated/assisted conversation
 - --discussing the case, the moral positions, validating the feelings and values, attempting to find shared resolution
- --but it is not merely NURSES who face moral distress: patients, families, physicians
- --don't need a specialized MDCS, need MEDIATION

4. Evidence from empirical consultation literature that Closure is needed

- --from study of consult dissatisfaction: "As for the cause of dissatisfaction that medical ethicists readily can act upon, some surrogates expressed disappointment in the lack of follow-up contact. ...Follow-up of the outcomes of the consultation, including making oneself available to the participants, should be regarded as part of the intervention" ⁵⁰
- --"Just as a physician should not abandon a patient, neither should a medical ethicist abandon those who suffered along with the patient" ⁵¹
- --not quite the right analysis, but in the right direction: people need closure

45 ASBH, p. 7

46 Tarzian 2013, 5

⁴⁴ ASBH, p. 8

⁴⁷ Ulrich, Hamric, Grady, 21

⁴⁸ Epstein and Delgado, 7

⁴⁹ Epstein and Hamric, 10

⁵⁰ Schneiderman et al "Dissatifaction with Ethics Consultations" 105

⁵¹ Schneiderman et al "Dissatifaction with Ethics Consultations" 105

--in the study of national ethics services, HCEC service only continued contact throughout the patient's entire stay only 13% of the time.43% did no follow up, with 41% touching base "periodically" touching base base "periodically".

IV. In Praise of Assisted Conversation in HCEC: Mediation and Closure (i.e., the path to better endings)

A. Conclusion: Mediation is best prospect for closure, and closure better serves patients, families, and clinical team

B. Objections

1. Costs to assisted conversation/mediation

- --What Core Competencies call "Formal meetings", also say "not always necesary
- --Fox/Chanko paper say not always necessary to have formal meeting
- --reasons: "logistically difficult", "time consuming to arrange" "inefficient" 53;
- --not without grounding: reason why some internists don't want to call a consult⁵⁴
- -- Task Force reiterates this: "such meetings are not always necessary" because
- "formal meetings may be inefficient or even harmful, particularly if poorly led or if incomplete or inaccurate information is present" 55
- --RESPONSE:Dubler's STADA (Sit, Tell, Admire, Discuss, Ask): first, "Sit with all in one room" 56

2. Failure of assisted conversation

-- Mediation can fail to bring closure

3. Closure, even in assisted conversation, might be elusive

--Dudzinski and Ford refer to the "lack of closure inherent in many consultations" ⁵⁷

⁵² Fox 19

⁵³ ASBH 14

⁵⁴ DuVal G, Clarridge B, Gensler MS; Marion D. A national survey of U.S. internists' experiences with ethical dilemmas and ethics consultation. J Gen Intern Med. 2004; 19(3):251-258

⁵⁵ Tarzian 2013, 8

⁵⁶ Dubler, Clinical Ethics 376

⁵⁷ Dudzinski and Ford, 3