

What Ethical Issues Really Arise in Practice at an Academic Medical Center? A Quantitative and Qualitative Analysis of Clinical Ethics Consultations from 2008 to 2013

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Abstract As the field of clinical ethics consultation sets standards and moves forward with the Quality Attestation process, questions should be raised about what ethical issues really do arise in practice. There is limited data on the type and number of ethics consultations conducted across different settings. At Loyola University Medical Center, we conducted a retrospective review of our ethics consultations from 2008 through 2013. One hundred fifty-six cases met the eligibility criteria. We analyzed demographic data on these patients and conducted a content analysis of the ethics consultation write-ups coding both the frequency of ethical issues and most significant, or key, ethical issue per case. Patients for whom ethics consultation was requested were typically male (55.8 %), white (57.1 %), between 50 and 69 years old (38.5 %), of non-Hispanic origin (85.9 %), and of Roman Catholic faith (43.6 %). Nearly half (47.4 %) were in the intensive care unit and 44.2 % died in the hospital. The most frequent broad ethical categories were decision-making (93.6 %), goals of care/treatment (80.8 %), and end-of-life (73.1 %). More specifically, capacity (57.1 %), patient's wishes/autonomy (54.5 %), and surrogate decision maker (51.3 %) were the most frequent particular ethical issues. The most common key ethical issues were withdrawing/withholding treatment (12.8 %), patient wishes/autonomy (12.2 %), and capacity (11.5 %). Our findings provide additional data to inform the training of clinical ethics consultants

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regarding the ethical issues that arise in practice. A wider research agenda should be formed to collect and compare data across institutions to improve education and training in our field.

Keywords Clinical ethics consultation · Clinical ethics consultants · Quality attestation · Retrospective review

Introduction

The field of clinical ethics consultation is in the midst of articulating clearer standards and expectations for practice. The American Society for Bioethics and Humanities (ASBH) published the second edition of the Core Competencies in 2011 and has recently developed and pilot tested a Quality Attestation (QA) process for clinical ethics consultants (Fins et al. 2013; Tarzian 2009). In light of these steps, ethics consultants should be attentive to the type and number of consultations they conduct as questions arise about how their consultation experience and setting compares to other consultants and services. However, research literature on ethics consultation remains limited.

A few studies have been conducted in various hospital settings in the United States and elsewhere (Tapper et al. 2010; Swetz et al. 2007; Moeller et al. 2012; Dowdy et al. 1998; DuVal et al. 2001; Waisel et al. 2000; Forde and Vandvik 2005; Bruce et al. 2011). Even though there have been studies focused on ethics consultation in pediatric settings (Streuli et al. 2014; Kesselheim et al. 2010; Johnson et al. 2015) and intensive care units (Voigt et al. 2014; Johnson et al. 2012; Aulisio et al. 2004), the field of clinical ethics consultation would, nevertheless, benefit from a larger body of literature to provide data on the breadth and depth of ethics consultation activity, as well as to demonstrate both the common and uncommon, frequent and infrequent issues that arise in practice. The research generated will not only further inform how we train and what we should expect from ethics consultation that we should be studying.

Ethics Consultation at LUMC

Loyola University Medical Center (LUMC) is an academic, tertiary-care facility with 559 beds and approximately 30,700 admissions per year, which is nationally recognized for its contribution to the study and treatment of cardiovascular disease, perinatal and neonatal disorders, cancer, and burn injuries. LUMC's ethics consultation service (ECS) has been operating since 1986. It provides ethics consultation services, hospital policy recommendations, and staff education. LUMC uses the individual consultant model in its ECS. Several Clinical Ethics Consultants (CECs), including PhD-trained bioethicists, physicians, nurses, and lawyers, are "on call" for one- to two-week periods. A patient, family member, or employee of LUMC can request an ethics consult via telephone or through the Electronic Medical

Record (EMR) which is then logged with the bioethics department administrative staff. The staff member responds and completes a standardized intake sheet with basic information about the request. The request is then passed to the on-call CEC, who reviews the EMR, calls the requestor and other relevant parties involved in the patient's management, and gathers related policy information.

After gathering the relevant information, the consultant decides whether to resolve the issue via telephone, attend a scheduled family meeting, or facilitate a formal ethics consultation. The first two categories are considered "informal" consults and no note is placed in the EMR. A formal ethics consultation involves interviewing relevant parties, facilitating a meeting with the surrogate decision makers, medical team, ancillary staff and the patient, if possible, and making recommendations based on ethics policy and accepted standards of practice. After an ethics consultation, a note is entered in the EMR with a summary of the discussion, ethical issues and the ethicist's recommendations. A redacted version of the formal ethics consultation note is presented at a monthly ethics committee meeting to discuss recommendations, provide feedback for improvement, and increase inter-professional knowledge. Historically, the ethics consultation writeups were maintained on file in paper form or stored electronically. At the end of 2007, an "Ethics Template Note" was created in the EMR to facilitate a structured reporting mechanism by which to identify the ethical issues for clinical staff and highlight the ethics consultant's recommendations.

Methods

We conducted a retrospective review of Loyola's ECS, including consultations which took place between 2008 (the first full year that the standardized ethics template existed in the EMR) and 2013. Cases were included if a bioethics consult order request was on file, an ethics note was in the EMR, or an ethics consult write-up was submitted to the ethics committee. After eliminating duplicates and errors (e.g., the wrong service used the ethics template note, n = 17), orders that were cancelled before the consultant was able to respond (e.g., due to the death or discharge of the patient, n = 31), and initial orders with no write-up on file (n = 23), the final number of cases included in our analyses was 156, indicating our ECS averaged between 2 and 3 formal consultations per month.

We conducted qualitative content analysis of the narrative portions of the ethics consult write-ups (Forman and Damschroder 2008). First, a draft checklist and codebook defining checklist terms were developed by one author (KW) after an initial review of 30 cases for recurrent themes. Common ethical themes and issues found in the literature were incorporated along with categories to indicate which parties were mentioned in the ethics note. The checklist and codebook were then further revised after five authors (EA, EH, KP, KW, MM) pilot tested the instruments on an additional 20 cases. All cases were then randomized. Four coders (EA, KP, KW, and MM) reviewed cases, with two coders reviewing each case separately. If an issue (code) was mentioned in the ethics consult narrative, it was recorded as present on the coding sheet once per case, regardless of how many times

the code was mentioned. The main header categories (e.g., decision-making) had to be selected whenever a sub-category (e.g., patient wishes) was identified as part of the narrative (see Table 3), but a main category could be selected without a subcategory. Coders were required to select at least one conceptual category (respect for autonomy, beneficence, non-maleficence, and justice) for each case. In addition, each coder identified one "key ethical issue" per case. Once all the cases were coded, coders met in pairs to reconcile any differences, and final code selections were agreed upon for each case. We then conducted frequency analyses of ethical themes present in the cases, key ethical issues, the role played by the CEC, and parties mentioned in the case write-ups (data not presented here).

Findings

Table 1 describes basic demographic characteristics of 156 patients for whom ethics consultations were requested and who otherwise met eligibility criteria. Typically, patients for whom an ethics consult was requested were male (55.8 %), white (57.1 %), between 50 and 69 years old (38.5 %), of non-Hispanic origin (85.9 %), and of Roman Catholic faith (43.6 %). These patients reflect the general hospital census in terms of age, race/ethnicity, and religion. Women represent a higher percentage of overall patients (53.1 %) as compared with patients for whom ethics

Table 1 Demographics of patients with aligned athles	Mean age (Range) $N = 156$	53.3 (0-98)
patients with clinical ethics consultations	Age in years—no. (%) $N = 156$	
	≤1	7 (4.5)
	2–18	8 (5.1)
	19–49	43 (27.6)
	50-69	60 (38.5)
	≥70	38 (24.4)
	Male sex—no. (%) N = 156	87 (55.8)
	Race—no. (%) N = 156	
	Asian/Pacific Islander	4 (2.6)
	White	89 (57.1)
	Black	43 (27.6)
	Other/Unknown	20 (12.8)
	Ethnicity—no. (%) N = 156	
	Hispanic origin	20 (12.8)
	Non-hispanic origin	134 (85.9)
	Unknown	2 (1.3)
	Religion—no. (%) $N = 156$	
	Roman Catholic	68 (43.6)
	Non-Catholic Christian	56 (35.9)
	None/No affiliation	15 (9.6)
	Other	17 (10.3)

consults (44.2 %) were requested. One reason may be the number of obstetric admissions at LUMC which averaged 978 per year from 2008 to 2013.

Table 2 describes primary diagnosis upon admission, medical unit, and discharge disposition of patients for whom ethics consultations were requested. The most common diagnoses were malignancy (18.6 %), sepsis (12.2 %), neurologic disease (10.3 %), and pulmonary disease (9.0 %). Almost half (47.4 %) of all patients for whom a consult was requested were in the intensive care unit (ICU) at the time of the request, and 44.2 % died in the hospital. The average length of stay was 33.4 days (0–250 range).

Table 3 provides information about ethical issues that arose in each case. Major categories are listed as headers in order of most to least frequent: decision-making (93.6 %), goals of care/treatment (80.8 %), end-of-life (73.1 %), values/meaning (34.0 %), clinical issues (33.3 %), and professional/institutional issues (30.1 %). Within each major category, subcategories are listed in order of most to least frequent (excluding issues that appeared in less than 5 % of cases). Issues related to decision-making were most prevalent, with the following issues appearing in over half of cases: capacity (57.1 %), patient's wishes/autonomy (54.5 %), and surrogate

Table 2 Medical unit, primary disease, and discharge location of patients with clinical ethics consultations	Medical unit	No. (%) N = 156
	ICU	74 (47.4)
	General ward	45 (28.8)
	Specialty floor*	37 (23.7)
	Primary diagnosis	Frequency (%) $N = 156$
	Malignancy	29 (18.6)
	Other	24 (15.4)
	Sepsis	19 (12.2)
	Neurologic disease	16 (10.3)
	Pulmonary disease	14 (9.0)
	Complications of medical intervention	11 (7.1)
	Cardiac disease	9 (5.8)
	Trauma	9 (5.8)
* Includes: bone marrow transplant, emergency, hematology/oncology, heart transplant, intermediate care,	Prematurity	8 (4.5)
	Gastrointestinal disease	6 (3.8)
	Vascular disease	5 (3.2)
	Renal disease	3 (1.9)
	Burns	3 (1.9)
	Discharge	Frequency (%) $N = 156$
	Expired/deceased	69 (44.2)
	HHS, Hospice, SNF, LTCH, AMA, or other medical facility	55 (35.3)
oncology, pediatrics, rehabilitation, women's health	Home	32 (20.5)

Table 3 Basic frequencies ofethical issues from content	Ethical issues	Frequency Yes N (%)
analysis of write-ups (N = 156)	Decision-making	146 (93.6)
	Capacity	89 (57.1)
	Patient's wishes/Autonomy	85 (54.5)
	Surrogate decision maker	80 (51.3)
	Advance directives/Power of Attorney	53 (34.0)
	Refusal	36 (23.1)
	Advance directives/Living will	18 (11.5)
	Parental decision-making	17 (10.9)
	Informed consent	16 (10.3)
	Goals of care/Treatment	126 (80.8)
	Benefits & burdens/Harms	62 (39.7)
	Discharge	42 (26.9)
	Best interests	34 (21.8)
	Quality of life	20 (12.8)
	End of life	114 (73.1)
	Withholding/Withdrawing	67 (42.9)
	Comfort/Palliative care	67 (42.9)
	DNR/Resuscitation issues	65 (41.7)
	Life sustaining treatment	39 (25.0)
The following issues were	Futility	25 (16.0)
present in <5 % of cases	Values/Meaning	53 (34.0)
Assent (Decision-making); Dignity (Values/Meaning); Professional conduct, Professional codes, Institutional	Expectations	22 (14.1)
	Religion/Spirituality	19 (12.2)
	Suffering	17 (10.9)
policy, Ethical and religious	Clinical issues	52 (33.3)
directives (Professional/ Institutional issues); and	Neuro issues	25 (16.0)
Donation, Reproductive/ Pregnancy, Neonatal/NICU; Suspicious motives, and Brain death (Clinical issues)	Mistrust	14 (9.0)
	Professional/Institutional issues	47 (30.1)
	Legal/Regulatory	41 (26.3)

decision maker (51.3 %). Specific issues related to end-of-life care were also highly prevalent, including withholding/withdrawing treatment (42.9 %), comfort/palliative care (42.9 %), and DNR/resuscitation (41.7 %). Within the end-of-life subcategories, ethics consultations involving male patients were more likely to mention withholding/withdrawing (51.7 %), futility (20.7 %), and life-sustaining treatment (32.2 %) in the write-ups compared with females (31.9, 10.1, 15.9 % respectively). These differences were not observed in the frequency of DNR/Resuscitation (42.5 % males vs. 40.5 % females) or Comfort/Palliative Care (46.0 % males vs. 39.1 % females).

In Table 4, coders identified the key issue in each case. There was a great deal of heterogeneity; in 156 cases, 26 different key issues were identified. The most

Table 4 Key ethical issues	Key ethical issues	Frequency (%)
	Withdrawing/Withholding	20 (12.8 %)
	Patient wishes/Autonomy	19 (12.2 %)
	Capacity	18 (11.5 %)
	Goals of care/Treatment	15 (9.6 %)
	DNR	11 (7.1 %)
	Surrogate decision-making/maker	11 (7.1 %)
	Discharge	9 (5.8 %)
	Refusal	9 (5.8 %)
	Best interests	7 (4.5 %)
	Benefits/Burdens	6 (3.8 %)
	End of Life	6 (3.8 %)
	Parental decision-making/maker	5 (3.2 %)
	Family conflict/Difficult family	3 (1.9 %)
	Brain death	2 (1.3 %)
	Guardianship	2 (1.3 %)
	Organ donation	2 (1.3 %)
	Communication	1 (.6 %)
	Difficult patient	1 (.6 %)
	Futility	1 (.6 %)
	Informed consent	1 (.6 %)
	Mistrust	1 (.6 %)
	Moral distress	1 (.6 %)
	Pregnancy issues	1 (.6 %)
	Psychiatric certification	1 (.6 %)
	Quality of Life	1 (.6 %)
	Resource allocation	1 (.6 %)

common key issues were not surprising given the overall frequency with which these issues appeared throughout all cases: withdrawing/withholding treatment (12.8 %), patient wishes/autonomy (12.2 %), capacity (11.5 %), goals of care/ treatment (9.6 %), DNR (7.1 %), and surrogate decision-making/maker (7.1 %). The majority of key issues (20/26) were coded as the key issue in fewer than 10 cases, and of these, 10 issues were the key issue in only one case. Raters also identified which of the four bioethics principles applied per case (any number of principles could be selected): respect for persons/autonomy (57.1 %), beneficence (53.8 %), non-maleficence (44.2 %), and justice (7.7 %).

Raters also identified the roles played by the CEC in each case and the person who requested the consult. Overwhelmingly, the CEC clarified (79.5 %) ethical issues, options, medical facts, or goals of care. Less frequently, the consultant educated participants about ethical or policy issues (27.6 %); provided support to the medical team or family (25.6 %); addressed conflicts between the patient and his/her family, among family members, or between the patient/family and health care team (23.7

%); or facilitated communication between parties (11.5 %). The reviewed ethics consultations were most frequently requested by a resident/intern/fellow (35.3 %), a nurse or nurse manager (23.0 %), an attending physician (15.4 %), or a social worker (15.4 %). The remaining consultations were requested by a patient or parent, a chaplain, risk management, a palliative care professional, a case manager, a medical student, a hospital administrator, or provider relations in 4 or fewer cases.

Discussion

Our results identify that capacity and patient wishes/autonomy were two of the top three key ethical issues that arose in the cases we reviewed. They were also the most frequently observed specific ethical issues (after the broad header categories), similar to what has been reported in other studies (Swetz et al. 2007; Moeller et al. 2012; McGee et al. 2001). Surrogate decision maker/making was the next most frequent ethical issue in our cases. These are closely related and often overlapping areas, and it is understandable that they were frequently mentioned together in the ethics consultation narratives. These issues indicate our ECS is consulted when the medical team wants guidance with decision-making about a case and the patient's wishes are unknown or unclear, which is unsurprising given that 47.4 % of our patients were in the ICU. The frequency of these issues may highlight the need for ethics education in the hospital to better equip clinicians to deal with them as ethics consultation may not always be necessary.

The next most frequent issues that arose in ethics consultations were withholding and withdrawing treatment (42.9 %), DNR/resuscitation issues (41.7 %), and comfort/palliative care (42.9 %). In other published studies of ethics consultation services, the frequency with which withholding or withdrawing treatment appeared varied substantially (18–68 %) (Swetz et al. 2007; Moeller et al. 2012; Tapper et al. 2010). It is not surprising that withholding/withdrawing came up frequently in our cases given that end-of-life was noted as an issue in 73.1 % of cases, somewhat more frequently than in other reported studies (33.3–60 %) (McGee et al. 2002), even at a similar level 1 trauma center (44 %) (Johnson et al. 2012).

Interestingly, comfort/palliative care was recorded in 42.9 % of our cases, much more frequently than was reported in studies in other similar settings (Swetz et al. 2007; Moeller et al. 2012). This may be because our ethics consultants raised the issue more routinely as an alternative or because many of our cases were based in the ICU with acutely ill patients. It could also have been that the timing of the consult requests leaned toward the end of life. Given that 44.2 % of patients died in the hospital it seems plausible that palliative/comfort care was an appropriate option to explore.

Futility appeared less often than expected (16.0 %), given the regularity of endof-life issues, and much less frequently in our cases compared to 54.0 % in Swetz et al. (2007) and 25.0 % in Moeller et al. (2012). This finding is surprising given anecdotal conversations with clinicians along with the focus on futility in the academic bioethics literature. One reason may be that the clinicians use futility language when talking to the ethics consultant, but not the patient and family, and/or the consultants choose not to use that language in the notes. Alternatively, clinicians may use "futility" to cover a range of situations or to indicate "I need help", and when pressed to be more specific by the ethics consultant, they refine their language or are encouraged to articulate the conglomerate of issues involved in the case (e.g., withholding/withdrawing, DNR/resuscitation, benefits vs. burdens, or goals of care/ treatment).

In keeping with the literature from similar institutions, most of our consults occurred in the ICU and malignancy and neurological disease were two of the most common diagnoses (Swetz et al. 2007; Moeller et al. 2012; McGee et al. 2001). Physicians (attendings 15.4 %, residents/interns/fellows 35.3 %) most frequently called ethics consults despite our service allowing any party to place a request. Other studies noted 52-72 % of consults were called by residents or attendings, indicating our finding was on the lower end of that range (Swetz et al. 2007; Moeller et al. 2012; McGee et al. 2001; Waisel et al. 2000; Bruce et al. 2011). It may be that physicians at LUMC do not see the need for ethics consultations and/or feel equipped to deal with ethical issues themselves. It might also highlight an educational need regarding what ethics consultation can provide. Alternatively, consults initiated by residents or attendings might be more easily resolved over the telephone as they are the parties ultimately responsible for the patient, and if the ethics consults are informal, they are unlikely to be recorded in the notes meaning a lower number of physician consult requests are captured than initially requested. Our nurses and social workers called 17.9 % and 15.4 % respectively of our consults as compared with 5–11 % in other studies (Swetz et al. 2007; McGee et al. 2001), which may indicate the multidisciplinary team is identifying the need for consultation and acting accordingly. If this is the case, it is positive news that nurses and other health professionals feel able to and do initiate ethics consultations.

Other studies of ethics consultation services reported that hospital policy allowed anyone to make the ethics consult request (Fox et al. 2007), and a few studies reported that about 9–10 % (Swetz et al. 2007; McGee et al. 2001, 2002) of requests were from patients and their family members. In contrast, we found that less than 1.3 % of our consults were called by patients and their family members. This finding could be due to lack of education on the existence and purposes of such services, fear of outcomes of the process, or that patients and/or their families do not feel the need to call an ethics consultation. In the past several months (after our study period concluded), hospital staff initiated a preemptive palliative care consult trial in the Medical ICU if the patient's case meets certain conditions. To empower patients and their families, we could consider initiating a similar procedure in the ICU for patients with certain diagnoses, such as malignancy or sepsis, where an automatic ethics consultation offer would be triggered if the patient and family are amenable. More research is needed to determine the most appropriate triggers in order to most efficiently utilize resources.

Regarding the role of the CEC, Swetz et al. found that 76 % of their cases involved conflict resolution, while Du Val et al. found that 34.6 % of physicians wanted help resolving a conflict. We found that 23.7 % of our cases involved conflict resolution (Swetz et al. 2007; DuVal et al. 2001). Although Du Val's survey was taken from physicians across the U.S. and would be expected to represent a

broader scope, we report similar numbers of cases and types of physicians. Our findings exceeded Du Val's 15 % of physicians having legal or administrative reasons for consults with 26.3 % of our cases explicitly mentioning legal/regulatory issues, most commonly guardianship issues (Johnson et al. 2012).

The average number of formal ethics consultations per month (2–3) is relatively modest given the size of our academic health center. One reason for this may be that there is no mechanism for systematically tracking and recording informal consultations, commonly in the form of telephone conversations. As mentioned above, we identified 23 requests for ethics consultations that did not have write-ups; these may have been informal consults. An additional 31 requests were subsequently cancelled because the patient died or was discharged before the consultant was able to respond (usually within 1–2 hours). When ethics consults are not requested until patients are imminently dying, there is little time for the ethics consultant to be effective. This is an educational issue; clinicians must be educated to involve ethics consultants earlier in the case. Another reason for the modest consultation numbers may be that until 2013, the ethics consultation service did not have dedicated resources to support it, thereby limiting outreach efforts. That is, there was no funding for the consultation service and conducting ethics consultation was a voluntary activity performed by various faculty members in their "spare time". Clinicians and bioethicists had to be sure that their coverage of the ethics consultation service did not interfere with their compensated responsibilities, which meant we were cautious about becoming overwhelmed. This situation is not uncommon for many hospitals across the country who have no dedicated positions or funding for clinical ethicist consultation. Now that dedicated resources have been allocated, we have initiated a variety of educational efforts in the hospital and are able to provide a wider array of ethics support. Comparing the data from consults before and after the dedication of resources and exploring methods to capture informal consultations consistently are important next steps.

Limitations

As our study was a retrospective review, we were bound by the information that had been captured at the time. There was a fair amount of variation in how different ethics consultants approached their notes, beyond the basic structure in the EMR template of minimal information on patient demographics, health professionals requesting the consultation, actions taken and recommendations. For our informal ethics consultations, there are generally no written notes, and this could have biased the data towards more complex cases. Unlike other published studies, we do not have data on how much time was spent per consult. In addition, because we allowed the coders to identify the key ethical theme per case, we had a wide variation of topics. Moreover, the four coders of the narrative portions of the data could have exhibited their own biases in coding the data. To minimize this likelihood, we randomized the cases, switched the pairings, and required coding pairs to reach agreement on the categories included for each case.

Future Directions

Given our findings, we have identified specific educational needs for our own institution. The frequency with which patient autonomy and wishes, capacity, and surrogate decision-making arise as ethical issues leads us to believe that clinicians and other staff could use additional education on these ethical standards. We have already initiated regular ethics education in the MICU and will explore other key units which may benefit from such input.

Given the move toward a quality attestation process for clinical ethics consultation, we see a need for institutions to collaborate and compare their data on ethics consultation. The literature remains fairly limited and the field would benefit from knowing what issues really do arise in practice, rather than continuing to base our educational efforts on what we think are the most frequent issues. Are there core issues that continue to trigger ethics consultation requests? What emerging or less frequent issues must new CECs realistically be prepared to address? If we aim to fine tune our training for CECs, knowing what issues and themes are prevalent is a key starting point. We propose that hospital systems and academic health centers begin a dialogue to agree to a core set of data that all institutions conducting CECs should collect in order to be able to compare our findings. This endeavor will involve further refining of the categories and subcategories of ethical issues tracked and their definitions. If any institution wants to add additional information within their service, they are free to do so. The larger health systems already have transitioned to EMRs which greatly facilitates our thinking strategically about how to compare findings to further the knowledge and educational specificity for CECs in the future.

Compliance with Ethical Standards

Conflict of Interest The authors have no financial conflicts of interest to disclose.

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