



HHS Public Access

Author manuscript

HEC Forum. Author manuscript; available in PMC 2019 December 01.

Published in final edited form as:

HEC Forum. 2018 December ; 30(4): 379–387. doi:10.1007/s10730-018-9357-4.

Characteristics and Outcomes of Ethics Consultations on a Comprehensive Cancer Center's Gastrointestinal Medical Oncology Service

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Abstract

Objectives—To review and describe the characteristics and outcomes of ethics consultations on a gastrointestinal oncology service and to identify areas for systems improvement and staff education.

Methods—This is a retrospective case series derived from a prospectively-maintained database (which includes categorization of the primary issues, contextual ethical issues, and other case characteristics) of the ethics consultation service at Memorial Sloan Kettering Cancer Center (MSKCC). The study analyzed all ethics consultations requested for patients on the gastrointestinal (GI) medical oncology service from September 2007 to January 2016.

Results—A total of 64 patients were identified. The most common primary ethical issues was the DNR order (39%), followed by medical futility (28%). The most common contextual issue were dispute/conflict between staff and family (48%), dispute/conflict intra-family (16%) and cultural/ethnic/religious issues (16%). The majority of ethical issues leading to consultation were resolved (84%), i.e., the patient, surrogate, and/or healthcare team followed the recommendation of the ethics consultant. Twenty two percent had a DNR order prior to the ethics consult and 69% had a DNR order after the consult.

Conclusions—In this population of patients on a gastrointestinal oncology service, ethics consultations are most often called regarding patients with advanced cancers and the most common ethical conflicts arose between families and the health care team over goals of care at the end of life, specifically related to the DNR order and perceived futility of continued/escalation of treatment. Ethics consultations assisted with conflict resolution. Conflicts might be reduced with improved communication about prognosis and earlier end of life care planning.

Introduction

Ethical dilemmas frequently arise in patients with advanced cancer as they approach the end of their lives. Health care ethics consultation (HCEC) teams serve to “identify, analyze and attempt to resolve” ethical conflicts that arise in clinical care (Siegler 1992). Ethics

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Conflicts of Interest:

Virginia Corbett, MD owns stock in Aetna Inc, Metlife Inc, Bristol-Myers Squibb, Pfizer Inc, and Seattle Genetics Inc
Andrew S. Epstein, MD and Mary S. McCabe, RN, MA have no conflicts of interest to disclose.

consultations are most often called in emotionally charged situations, and after attempts to resolve the conflict by the health care team have failed (DuVal et al. 2001; Hurst et al. 2005). Gastrointestinal (GI) malignancies include a wide spectrum of primary tumors including colorectal, hepatopancreaticobiliary, esophagogastric, anal cancer and other types of malignancies of the GI tract. GI cancers are common, and in the year 2016, over 300,000 new cases of GI cancers will be diagnosed in the US (American Cancer Society 2016). Patients with advanced GI malignancies face a variety of decisions including whether to undergo non-curative chemotherapy or procedures at the end of life, but data on the characteristics and outcomes of ethics consultations in this common and vulnerable population do not exist. Therefore, we examined issues that trigger ethics consultations in these patients in order to address this knowledge gap, provide value in clinical practice, and to guide education, policy, and research intended to prevent conflicts from occurring.

Methods

This retrospective case series describes characteristics of all clinical ethics consultations requested for patients on the Memorial Sloan Kettering Cancer Center (MSKCC) GI medical oncology service, inpatient and outpatient, from September 2007 to January 2016. MSKCC is an academic, tertiary care center with a National Cancer Institute designation as a comprehensive cancer center. Ethics consultations are available to any patients treated at MSKCC and may be requested by any provider, patient, or family member. Ethics consultations are conducted by a sub-set of the Ethics committee, including physicians, ethicists, and nurse practitioners, all with training in medical ethics. A secure MSKCC database of all the institution's clinical ethics consultations is maintained and prospectively updated as consultations occur. The MSKCC Institutional Review Board evaluated this study and deemed it exempt from full review. Qualitative and quantitative data were collected from the electronic medical record (EMR). Demographic and clinical information was collected from the database, from case summaries of each ethics consultation, and from EMR chart abstraction, which included all inpatient physician notes as well as documentation from case managers, social workers, specialty consultants, and primary oncologist outpatient notes. In addition, variables including context of ethics consultation, code status before and after consultation, and involvement of other consultation services, were also collected. The reason for and context of consultation were reported according to a standardized classification schema for ethics consultation (Nilson et al. 2008). Primary and secondary ethical issues were identified for each case, as were primary and secondary contextual issues, also according to a standardized classification schema (Nilson et al. 2008).

Results

Patient characteristics

Sixty-four patients cared for by the GI Medical Oncology Service received formal ethics consultations between September 2007 and January 2016 (Table 1). The mean age was 64 years old (range 23-95). Patients were 55% male and 45% female. Most patients listed English as their preferred language (86%), with the second most common language being Russian (6%). Many religions were represented, the plurality of patients identifying as

Jewish (36%). The second most common religion was non-Catholic Christian (23%). Most patients were on a general in-patient medical oncology unit at the time of ethics consultation (66%) with 25% in the ICU and 9% in an outpatient setting. Most patients had metastatic disease (95%) at the time of consultation. The most common GI cancer diagnoses were colorectal (n=16), pancreatic (n=12) and cholangiocarcinoma (n=8). Most consults were requested by attending physicians (67%) followed by nurses (17%) and patient services representatives (11%).

Time from consult to death (0 days to 996 days) was less than 7 days for 42% of patients, 7-30 days for 31% of patients and 30 days to 1 year for 19% of patients. The time of cancer diagnosis until date of ethics consult was less than one year in 50% of patients (n = 32), within 1-4 years in 34% of patients (n=22), and more than 4 years in 16% of patients (n=10). Of patients who received an ethics consult, 60% also received a palliative care consult and 79% received a pastoral care consult. Of all patients in this study sample, 22% had a DNR order prior to the ethics consult and 69% had a DNR order after the consult. Prior to ethics consult, 69% of patients had identified a health care proxy and 14% had a living will in place. In total, 13% of patients who received an ethics consult underwent an attempt at cardiopulmonary resuscitation (CPR).

Ethical and contextual issues (Table 2)

The most common primary ethical issue was the DNR order (39%), followed by medical futility (28%); the most common secondary ethical issue was also the DNR order (27%), followed by surrogate decision making (23%). The most common primary contextual issue was dispute/conflict between staff and family (48%), followed by both dispute/conflict intra-family (16%) and Cultural/Ethnic/Religious issues (16%). The most common secondary contextual issues were dispute/conflict between staff and family (30%), followed by physician attitude toward treatment (16%). The majority of ethical issues leading to consultation were resolved (84%), i.e., medical records indicated that the patient, surrogate, or healthcare team followed the recommendation of the ethics consultant; however, a small number remained unresolved (11%). In 5% of cases there was inadequate information to assess the effect of the consult on subsequent clinical care/decision-making.

Discussion

This review demonstrates that many ethics consults in patients on a GI oncology service are called for ethical issues surrounding the DNR order in the last month of patients' lives. Almost all of these patients had metastatic GI malignancies and most had no DNR order in place prior to the ethics consult. Consults were often called due to conflicts between the health care teams and families or surrogates. Our results are consistent with prior studies in terms of the age of patients who receive ethics consultations (patients in their 60s) and the fact that the majority of patients have a poor or terminal prognosis (Swetz et al. 2007; Wasson et al. 2015). Our results are also consistent with prior studies at our institution, which demonstrated that the majority of ethics consults involved issues surrounding code status and withdrawal and withholding life sustaining treatment, and common contextual features, including interpersonal conflicts and communication barriers (Shuman, McCabe, et

al. 2013; Shuman, Montas, et al. 2013). Our work is also consistent with an outside institution's case series, in which the most frequent reasons for ethics consultation involved decision making, goals of care and treatment, and end of life care (Swetz et al. 2007).

The specific ethical issues identified in our cohort suggest that end-of-life discussions about the DNR order and the futility of life sustaining treatment are a focal point of moral and emotional distress for health care teams and patients' families and surrogate decision makers. These conflicts, may have serious consequences for both surrogate decision makers and for physicians. Surrogates making decisions for critically-ill patients, including deciding to complete the DNR order, may have long term sequelae, such as emotional distress due to guilt, which can last years after the event (Handy et al. 2008; Wendler and Rid 2011). Residents and physicians may experience moral distress and burnout when providing what they perceive to be futile or harmful care. (Dodek et al. 2016; Dzung et al. 2016).

GI cancer patients' admissions to the inpatient units often occur as they approach the final flexion point in their end of life illness trajectory (Murray et al. 2005). The events in this review represent ethical conflicts beyond the capacity of medical teams to resolve, leading to ethics consultation. The surrogates in this study are similar to a group of surrogates in a study conducted after an academic medical center implemented a policy of withholding CPR when physicians and the ethics committee determined that the harm outweighed the benefits, despite surrogate requests for CPR to be performed. The policy was designed to remove a medically futile intervention "out of the realm of shared decision-making". In this study, there was a small group of surrogates who requested CPR despite the determination of the ethics committee that it would be harmful to the patient (Courtwright et al. 2015; Robinson et al. 2017). These surrogates were less likely to accept a patient was in pain or actively dying, visualized their role as family member rather than using substituted judgment to act in the patient's interest, and feared that the DNR orders would lead the medical team to "give up" on the patient.

There are a number of reasons why these types of conflicts are likely to occur at our institution. Conflict between physicians and surrogates is often due to discordance between the physician and surrogate about prognosis, with surrogates holding more optimistic views (White et al. 2016). There is fear that a DNR order will lead to less aggressive treatment (Fuchs et al. 2017). Surrogates also face more decisional conflict when there is confusion between curative and non curative goals (Higginson et al. 2016). Finally, patients who seek care at our institution as a tertiary cancer center likely self-select with high expectations of prolongation of life and are less willing to consider a DNR order.

Advance care planning is the first step to preventing conflict at the end of life. Guidelines recommend initiating discussions about prognosis and life expectancy in patients with terminal cancer after the diagnosis of advanced stage disease is made (Smith et al. 2012). Advanced directives have been shown to increase the likelihood that a patient will receive care associated with their preferences at the end of life, and DNR orders are associated with improved quality of life at the end of life (Silveira et al. 2010; Garrido et al. 2015). Caregivers rated quality of care as poorer when patients died in hospital (Higgins et al. 2015). Despite the established benefits of early end of life discussions in patients with

terminal cancer (Mack et al. 2012), these discussions (including discussions of DNR orders, hospice, and palliative care) occur on average 33 days prior to a patient's death and most often occur in an inpatient setting (Levin et al. 2008).

In this study, 14% of patients had a living will in place prior to ethics consultation. Sixty nine percent of patients had identified a health care proxy prior to ethics consultation, which presumably entailed discussing their preferences with their proxy, but conflict still occurred, thereafter leading to ethics consultation. These findings suggest that these patients with advanced GI malignancies need to develop an understanding of their prognosis earlier and have ongoing discussions with their families about their wishes at the end of life. In our patient population, as in other similar patient populations (You et al. 2015), it is likely that even if the patient has a clear understanding of their prognosis, families and surrogate decision makers either did not understand the patient's prognosis or could not accept it.

Future studies should explore how improved communication between patients, surrogates, and the healthcare team with accurate discussion of prognosis could reduce conflicts over DNR orders and futility at the end of life. Discussing prognosis during outpatient oncology visits allows patients with advanced disease to have a more accurate understanding of their terminal prognosis (Epstein et al. 2016). Barriers that clinicians identify include family members' and patient's inability to accept a patient's poor prognosis and poor understanding of the limitations of life sustaining treatment (You et al. 2015). Only through clear and empathic communication about prognosis, and through advanced care planning that involves both the patient and their family, can oncologists and their teams minimize conflicts occurring at the end of life over the DNR order and medically futile interventions. In addition, efforts should be made to identify surrogates who have views that conflict with the recommendations of the primary team over code status. Involvement of ethics consultation and palliative care early may help avoid distress to patients, families and the medical team in the last days life of patients with GI cancer. In some cases, conflicts may persist despite improved communication. For example, patients and surrogates with strong religious preferences may request life-sustaining medical interventions. Despite improved communication and ethics consultation some surrogates may continue to request CPR: in this study 13% of patients underwent CPR after receiving ethics consultation.

This study has several important limitations. First, this is a retrospective, case series study within a specific GI oncology service at a tertiary cancer hospital. However, we believe that our finding of the high percentage of ethical conflicts over the DNR order triggering an ethics consultation at the end of life is generalizable to other large institutions caring for patients with advanced GI cancers. Although a specific coding system was used to identify ethical issues and contextual issues, coding of these complex ethical issues is often subjective and this study is limited by having only one coder for all cases. Finally, although an electronic form for documenting ethics consultations at our institution was created in 2011, ethics consultations prior to this time have some variation in documentation limiting the quantity and consistency of information available from earlier consultations.

Conclusion

In this population of patients on a gastrointestinal medical oncology service, ethics consultations are most often called in patients with advanced cancers, patients who are White and identify as Jewish, and patients within 7 days of death. The most frequent ethical issues were the DNR order and medical futility and the most frequent contextual issue was dispute/conflict between staff and family members followed by both dispute/conflict intra family and Cultural/Ethnic/Religious issues. In the majority of cases the ethical issues were resolved with the surrogate, patient and health care team following the recommendation of the ethics consultant. Our review suggests that ethics consultants should be involved early when complicated conflicts between surrogates and physicians arise. Conflicts faced by patients with advanced gastrointestinal cancers at the end of their lives might be reduced with improved communication about prognosis and early end of life planning involving both patients and their family members and surrogates.

Acknowledgments

This research was funded in part through the NIH/NCI Cancer Center Support Grant P30 CA008748

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Table 1

Patients' Demographic Data, Religious Affiliations, and Cancer Type.

Age (years):		Stage at time of consult:	
Mean	64	Metastatic	61 (95)
Range	23-95	Stage III	1 (2)
SD	13.6	NED (No Evidence of Disease)	2 (3)
Sex:	Number (%)	Time from cancer diagnosis to date of consult:	
Male	35 (55)	Less than 1 year	32 (50)
Female	29 (45)	Between 1 and 5 years	22 (34)
		Greater than 5 years	10 (16)
Preferred Language:			
English	55 (86)	Time from date of consult to death	
Russian	4 (6)	Less than 7 days	27 (42)
Spanish	3 (5)	7-30 days	20 (31)
Cantonese	2 (3)	30 days to 1 year	12 (19)
		Greater than 1 year	2 (3)
Religion:			
Jewish	23 (36)	Date of death unknown	
Non-Catholic Christian	15 (23)	Location at time of Consult:	
Catholic	13 (20)	General Ward	42 (66)
None/unknown	9 (14)	ICU	16 (25)
Hindu	2 (3)	Outpatient	6 (9)
Buddhist	1 (2)		
Muslim	1 (2)		
Race/Ethnicity:			
White	44 (69)		
Asian	7 (11)		
Black	6 (9)		
Unknown/not listed	4 (6)		
Hispanic	3 (5)		

Table 2

Reason for Ethics Consult and Contextual Issues

Primary ethical issue:	Number (%)	Secondary ethical issue:	Number (%)
DNR	25 (39)	DNR	17 (27)
Futility	18 (28)	Surrogate Decision Making	15 (23)
Capacity/informed consent	5 (8)	Futility	14 (22)
Surrogate Decision Making	4 (6)	Capacity/informed consent	7 (11)
Truth telling	3 (5)	Discharge/Placement	5 (8)
Withdrawal of ventilator	3 (5)	Refusal of Recommended Treatment	3 (5)
Pain management	2 (3)	Withdrawal of ventilator	1 (2)
Discharge/Placement	1 (2)	Pain management	1 (2)
Refusal of Recommended Treatment	1 (2)	None (no secondary issue)	1 (2)
Research ethics	1 (2)		
Resource allocation	1 (2)		
Primary contextual issue:		Secondary contextual issue:	
Dispute Staff-Family	31 (48)	Dispute Staff-Family	19 (30)
Dispute Intra Family	10 (16)	Physician attitude toward treatment	10 (16)
Cultural/Ethnic/Religious	10 (16)	Patient or family in denial	8 (13)
Dispute Staff-patient	5 (8)	Dispute Intra Family	7 (11)
Communication	4 (6)	Cultural/Ethnic/Religious	6 (9)
Dispute Intra staff	3 (5)	Communication	5 (8)
Patient or family in denial	1 (2)	None (no secondary issue)	4 (6)
		Dispute Intra staff	3 (5)
		Dispute Staff-patient	2 (3)
Resolution of consult:		Consult requestor:	
Resolved	54 (84)	Attending physician	43 (67)
Unresolved	7 (11)	Nurse	11 (17)
Inadequate information to assess outcome	3 (5)	Patient services representative	9 (11)
		Unknown	2 (3)
		Social worker	1 (2)
Advanced directives prior to ethics consult	Number (%)		
DNR	14 (22%)		
Living will	9 (14%)		
Health care proxy	44 (69%)		