

Values, Quality, and Evaluation in Ethics Consultation

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ABSTRACT

Background: The American Society for Bioethics and Humanities has recommended regular evaluation of the quality of Health Care Ethics Consultation. This manuscript discusses the impact of ethics consultation on clinicians' perceptions of a patient's plan of care and on the personal values of clinicians who participated in an ethics consultation.

Methods: Following IRB approval, select data points were abstracted from case file report forms for ethics consultations over a 12 month period. Clinicians involved in the care of a patient who was the focus of an ethics consultation were invited to participate in an anonymous online survey. Clinicians who initiated an ethics consultation, were interviewed during the course of an ethics consultation, or were present at a patient care conference attended by an ethics consultant were invited to participate. A purposive sampling approach was used to invite clinicians to participate in an in-person interview.

Results: The survey response rate was 44.4% (123 respondents from 277 invited). Over 60% of participants felt the consultation helped clarify the values of the patient and/or patient's family and helped them clarify their own values. Only 32% of participants indicated the patient's plan of care changed as a result of the ethics consultation, yet 75% indicated their confidence in the plan of care increased as a result of the ethics consultation. Preliminary findings from the qualitative interviews support the overall positive assessments reported by survey respondents.

Conclusions: Ethics consultation can help clinicians clarify their own values and helps them clarify the values of patients and patients' families. Ethics consultation offers meaningful support when clinicians face ethically challenging cases, provides an opportunity to address moral distress, and is viewed favorably by those who experience the resource.

INTRODUCTION

Health Care Ethics Consultation (HCEC) has been defined by the American Society for Bioethics and Humanities (ASBH) as a set of services provided to help patients, families, surrogates, health care providers, or other involved parties address uncertainty or conflict regarding value laden concerns that emerge in health care (American Society for Bioethics and Humanities' Core Competencies Update Task Force 2011). There is considerable debate about the correct metrics for measuring quality in ethics consultation (Batten 2013). Evaluating the outcomes of ethics consultation is complex (Bruce et al 2014; Chen et al 2014; Moeller et al 2012; Nilson and Finns 2006). Regardless of this debate, any organization or institution offering a service to assist in addressing ethical challenges in the delivery of health care has an obligation to make certain the service meets some quality standards. A formal evaluation of HCEC services can and should inform institutional efforts at policy development, quality improvement, and utilization of resources.

ASBH has recommended regular evaluation of the quality of HCEC (ASBH 2011). The recommendations include evaluation of HCEC structure, processes, and outcomes. Other authors have discussed patient-centered outcomes from ethics consultation, such as effects on patient length of stay, particularly for patients that do not survive a hospital stay (Schneiderman, Gilmer, Teetzel et al. 2003; Schneiderman, Gilmer, and Teetzel 2000) or the financial impact of ethics consultation (Gilmer, Schneiderman, Teetzel et al 2005; Chen et al 2014). However, less is known about the process of ethics consultation that leads to these patient-centered outcomes, in particular the impact on clinicians: for example, reducing moral distress, providing

support to clinicians who face difficult patient care situations, or the role of values clarification (DuVal et al 2004; Pfafflin, Kobert, and Reitter-Theil 2009).

Of particular importance to ethics consultation is the role of values clarification. The general goal of ethics consultation, improving the provision of health care through the identification, analysis and resolution of ethical concerns, is more likely to be achieved if consultation accomplishes the intermediate goals of helping to identify and analyze the nature of the value uncertainty or conflict that underlies the consultation (ASBH 2011). An explicit evaluation of the impact of an ethics consultation on health care providers' values would be central to an evaluation of the quality of ethics consultation, yet has not been done.

In the experience of our consultation service, it is not uncommon for a requesting clinician to say something along the lines of “we need X from patient/family Y!”, suggesting that they expect the ethics consultant to “fix the problem” and presumably change the current plan of care to what the healthcare team wants. Our organization practices an ethics facilitation approach to ethics consultation. This approach is focused on supporting key stakeholders to appreciate the perspectives of others, elucidating the ethical issues, and improving communication (ASBH 2011). A facilitation approach can be applied to different models of HCEC. It is focused on a respectful process in pursuit of resolution. It does not provide a morally authoritative resolution to the conflict (ASBH 2011). The role then of ethics consultation is not to provide answers, but rather to help involved parties identify ethically supportable options that respect the values of patients, families and members of the healthcare team.

If ethics consultation is to help address value-laden concerns, then it is essential that there be an exploration of the relationship between individual health care providers' values and ethics consultation. This manuscript describes an evaluation of a clinical ethics consultation service at a Midwest academic medical center. A central element of this project was to explore how ethics consultation supports the organization's values. We investigated health care providers' expectations of an ethics consultation as an indirect measure of how providers value the service. We discuss the impact of ethics consultation on clinicians' perceptions of a patient's plan of care and the impact on the personal values of participating clinicians.

METHODS

Setting

The ethics consultation service (ECS) at our organization serves a single large health care system that includes two urban adult hospitals and one pediatric hospital. These three teaching hospitals are affiliated with schools of medicine, nursing, social work and other health professions. The health care system's mission, vision, and core values include total care of the patient, excellence in education for providers, quality care and respect, charity, leadership in wellness and health promotion, excellence in research, and an internal community of mutual trust. Combined, the facilities include more than 1200 adult and pediatric in-patient beds.

Ethics consultations in this organization are generally accomplished by following these steps: 1) intake from the individual requesting assistance, 2) review of the medical record and interviews with involved parties (members of the health care team, patient

and family), 3) formulation of the ethics question and initial ethics analysis (including consultation with other ECS members, and review of relevant literature and organizational policies when appropriate), 4) a coordinated meeting with concerned parties (when needed), 5) documentation of recommendations in the patient's medical record and in a case file report kept in the ethics center. Advisory recommendations are made in collaboration with involved parties. For complex cases, the ethics consultation service team members on call may seek guidance and input from the entire ethics consultation service team at a bi-weekly meeting prior to providing recommendations to involved parties.

Ethics consultation is available to anyone involved in the care of patients (including patients and families), and the service may be accessed 24 hours per day, 7 days per week. Less than 2% of consultation requests come from patients and/or families. The ECS is a volunteer inter-professional team including physicians, nurses, social workers, lawyers, chaplains, pharmacists and hospital administration. Volunteers have varying levels of training and experience. ECS members are encouraged to work as a team. Typically a team of individuals, including at least one physician, is on-call at any given time for consultation and support. Cases are discussed at biweekly ECS committee meetings. On average, the service fields 100 consultation requests per year covering a broad range of issues, of which many, but not all, occur in the context of end-of-life situations.

Participants and Procedures

This evaluation included three phases of data collection. First, following IRB approval, select data points were abstracted from case file report forms for ethics consultations over a 12 month period. Second, health care professionals involved in the care of a patient who was the focus of an ethics consultation were identified through case file report forms and invited to participate in an anonymous online survey. Survey data were collected over a 12-month period, and included health care professionals who initiated an ethics consultation, were interviewed during the course of an ethics consultation, or were present at a patient care conference attended by an ethics consultant. A research assistant (RA) sent potential participants an e-mail invitation to participate in the electronic survey to evaluate the ethics consultation. Potential participants received up to two reminder e-mails spaced two weeks apart. Third, we used a purposive sampling approach to invite potential participants, who were diverse with respect to clinical role, to participate in an in-person interview. Individuals eligible for interviews also received an invitation to complete an online survey, though completion of this survey was not a pre-requisite to participation in an interview. Individuals who participated in an interview received a \$10.00 gift card from the local coffee cart.

Case File Report Forms

Information was collected from case file reports completed by the primary ethics consultant for the consultations conducted in the 12 month study period. Reports included time spent conducting the consultation, a checklist indicating relevant ethics issues for the case (e.g. informed consent, withholding/withdrawing treatment, capacity,

patient/provider conflict), interventions performed by the ethics consult service (e.g. provide advice, refer to other resources, provide moral support), and information about the outcome of the case (what happened to the patient). When there is formal documentation in a patient's medical record, typically in the form of a chart note, a copy of the note was attached to every case report used in this study.

Instruments

Electronic Survey

To minimize confidentiality concerns, the only demographic information collected from respondents was their professional role (e.g. physician, nurse, social worker). We avoided age, gender, and ethnicity because the sample was small enough that individuals would be identifiable. Respondents who self-identified as the initiator of the consult request were asked additional questions related to the reason they contacted the ECS and if the consultant responded in a timely manner.

We examined three areas related to ethics consultation: expectations of ethics consultations, patient-related outcomes (e.g. change in plan of care), and assessment of the ethics consultation. Expectations of ethics consultation were measured through use of a checklist of actions and interventions generated from the literature (ASBH 2011; Craig and May 2006) and suggestions from members of our ECS. The list of 10 yes/no items included both acceptable (e.g. facilitate communication) and unacceptable (e.g. direct the plan of treatment) expectations. Participants had the option of providing a free text response.

Patient-related outcomes were measured with two yes/no items related to the plan of care. Respondents were asked whether the ethics consultation changed the plan of care, and whether the ethics consultation increased their confidence in the plan of care.

Overall assessment of the ethics consultation and the consultation's impact on values were measured with 11 items adapted from a tool developed by White, Dunn and Homer (1997) and outcome measures for ethics consultation (ASBH 2011). Example items included, "The Ethics consultant(s) explained things well," "The Ethics consultation helped clarify uncertainty regarding what was the right thing to do for the patient," and "The Ethics consultation helped me clarify my own values regarding this patient care situation". For each item, participants could choose a five point Likert-type response from "strongly agree" to "strongly disagree." Responses to outcome items were highly correlated. Using standard factor analysis techniques, we found that the items factored into two scales. The overall assessment scale contained six items ($\alpha=.91$) and addressed the respondent's overall assessment of the ethics consultation. Items addressed facilitating communication, enhancing understanding, providing support, and clarifying uncertainty. The values impact scale contained five items ($\alpha=.86$) and contained questions that addressed the impact of the ethics consultation on personal and professional values of the respondents.

Semi-Structured Interview

Questions for the semi-structured interview were generated following a baseline assessment of the available data from our ECS files and items suggested in the

literature (White, Dunn and Homer 1997; Craig and May 2006). Semi-structured one-on-one interviews were conducted by a trained RA (EM) who had no relationship with the ethics consultation service beyond the RA role. Interviews lasted from 30–60 minutes. Interviews were audio-recorded and transcribed, checked by the interviewer, and had identifying information removed. All transcripts were analyzed by the interviewer (EM) and lead author (LDW).

The interview guide started with focused questions regarding the participant's role in the ethics consultation (“Were you the one who requested the ethics consultation?”) then moved to questions about the consultation (e.g. “What was the ethical issue? How was it resolved?”). Participants were provided a brochure describing the mission, vision, and values of the organization and asked which values were represented in the experience with the ethics consultation. Finally participants were asked about any experience with moral distress in relation to their role in caring for the patient.

Data Analysis

Using case-file data, we will first describe characteristics of consults. Using survey data, we will then describe characteristics of survey participants and requesters of consults by frequency. Physicians and physicians-in-training provided similar responses, so these groups were combined for analysis purposes. Professions that were not well-represented (e.g., child life specialist, case manager, and pharmacist) were combined into an “Other” category. We will then describe expectations for ethics consults, perceptions of change in patient-related outcomes, and participants' overall

assessment and values impact of consults. We used bivariate analyses (Chi-square and ANOVA) to examine differences in expectations, patient-related outcomes, overall assessment, and values impact by professional role.

We hypothesized that one's overall assessment of a consult may be related to both expectations for the consult and patient-related outcomes (e.g., changes in plan of care), and wanted to examine the independent effect of expectations and patient related outcomes. Using bivariate statistics and logistic regression we examined how expectations and patient-related outcomes were associated with overall assessment and values impact of the ethics consultation. Overall assessment and values impact scales had non-normal distributions, so were dichotomized into higher overall assessment and higher values impact (scores of 4-5 on a scale of 1-5) versus lower overall assessment and values impact (scores of 1-3 on a scale of 1-5). Only predictors which were significant at the bivariate level were entered into and reported in the final logistic model. All analyses were done in SPSS 22 (IBM, USA, 2014). Because the sample size is small, we report one clinically relevant difference of $p < .10$; remaining p -values are all $< .05$.

Steps in the analysis of narrative data collected included preparation (immersion in the data to obtain a sense of the whole to determine the unit of analysis), organizing (open coding, creating and arranging categories) and verifying (review of transcript coding between two members of the team) (Vaismoradi, Tununen and Bondas 2013). Content codes were initially identified using "ethics issues" from internal case file report forms and contributing factors for moral distress items generated from items in the revised moral distress scale (Hamric, Borchers and Epstein 2012). Significant content

was sorted into categories then reviewed for themes. Credibility was established by first having each individual reviewer code the transcript then meet as a team to reconcile coding differences. All manuscripts were double coded. Preliminary findings of this effort are provided below to elaborate on the findings of our quantitative analyses.

RESULTS

Case File Reports

There were 94 ethics consultations during the 12 month data collection period for this project. Data from the case file reports revealed an average of 3 hours per consult with a range from 30 minutes to 13 hours. When completing case file reports, ethics consultants could select more than one ethics issue relevant to a case. Based on the case file report forms, the top five ethics issues identified for the consultations were moral distress of clinicians (69%), non-beneficial treatment (futility) (69%), patient best interest (62%), communication challenges (46%), and patient code status (46%).

Survey and Interview Results

A total of 277 invitations to participate in the online survey were sent out with 123 responding (44.4% response rate) and 115 (93.5%) completing the surveys. Table 1 details the professional roles of survey respondents, reasons for the consult request, and patient outcomes. Case file reports yielded a total of 198 potential individuals to participate in in-depth interviews. Of the 106 individuals contacted to arrange an in-depth interview, 81 (76.4%) responded and eventually 48 interviews were conducted (45.3% from the original 106 eligible participants). The remaining interviews were not conducted due to

scheduling conflicts or failure to follow up on requests to schedule the interview. There were no outright refusals to participate in an interview. The interviews represented 13 consultations, meaning there was more than one participant from some of the consultations. Interview participants provided rich data to support the electronic survey data. There were 9 social workers, 22 nurses and 17 physicians who participated in the interviews.

Of the 123 survey respondents, 44 (35.8%) indicated they were the person who contacted the ECS (requester). When asked what had prompted them to request a consultation, respondents most frequently identified “ethical concerns about the patient’s plan of care”. In 96% of cases, the ECS responded in a timely manner. Participants indicated what they expected of the ECS (Table 2). Respondents were able to select more than one expectation. Overall, the top six expectations of the consultation were to 1) facilitate communication between the team and the patient/family (54%), 2) clarify/define a plan of care (50%), 3) provide a neutral perspective (50%), 4) provide information (40%), 5) facilitate communication among the team members (35%), and 6) provide a safe space (35%). When we used chi-square tests to examine differences by disciplines of expectations of ethics consults, we found no significant differences among disciplines for all expectations, with two exceptions (Table 2). Nurses were less likely than other disciplines to expect that the consult would facilitate communication between family and team members (35% for Nurse vs. 57%-71% for other disciplines, chi square = 8.3, df = 3, $p < .05$) and physicians were more likely to expect that an ethics consultation would resolve a conflict (38% vs. 11%-24% for other disciplines, chi square = 6.6, df = 3, $p < .10$).

Patient-related outcomes from the ethics consultation were assessed by examining the impact of the ethics consultation on the patient's plan of care and the respondent's confidence in the plan of care (Table 3). Only 32% of respondents indicated the patient's plan of care changed as a result of the ethics consultation, yet 75% indicated their confidence in the plan of care increased as a result of the ethics consultation. When the plan of care changed, respondents were more likely to report that their confidence in the plan of care increased (94% increased confidence with change in plan of care vs. 66% with no change in plan of care, chi-square = 10.4, df 1, $p < .001$).

Interview participants provided several examples of how the ethics consultation increased confidence in the plan of care:

It reassured me and staff that this was an appropriate plan of care. It also helped the team be better able to support one another as well as nightshift staff.

[The] plan of care was appropriate from an outsider's view, and it helped define and clarify what the next steps should be in our plan.

It clarified the family's desires and helped me to know how to respond and what to continue doing. In other words how to best support the family.

In general, interview participants suggested that when the plan of care changed, especially in end-of-life situations, it was to set limits on or withdraw aggressive treatment.

Interview participants also provided comments reflecting the power and influence of participation in an ethics consultation:

I think part of it was the way they (the family) were getting information. The ethics consult kind of changed the conversation.

It's not always just giving them the information... it's how you frame it. I think in retrospect, I wish we had called the ethics consult sooner.

If I hadn't been a part of that (the consultation), I probably would have still believed that we should have done what the family wished to do. Being part of the consultation helped me see the whole picture...

Helped me realize there is no right and wrong, but shades of gray and that's why we get an ethics consult. I realize they can't tell us what we should do, but ethics [consultation] helps us discuss all the variables that that really helped.

Survey respondent's overall assessment of the ECS was favorable (Table 4).

Over 90% felt that the consultant explained things well, over 80% felt the consultation validated the team's approach and provided support, and over 70% felt the consultation helped clarify uncertainty, gave them a better understanding of ethical issues, and helped resolve a patient care problem.

The overall assessment was associated independently with both changes in plan of care and increased confidence in plan of care. In logistic regression analysis (Table 3), when respondents reported a change in plan of care they were 10 times more likely to have a higher overall assessment and when they reported an increase in confidence in plan of care they were five times more likely to have a higher overall assessment (Table 3). Respondent's overall assessment was not associated with expectations for the consult.

Respondents reported a high values impact from the consultation (Table 4).

Over 80% felt the recommendations of the consult were consistent with the organization's values (total care of the patient's mind, body and spirit, quality of care and respect for life), respected the respondent's values, and were consistent with their personal values. Over 60% felt the consultation helped clarify the values of the patient

and/or patient's family and helped respondents clarify their own values. In logistic regression analysis (Table 3), respondents who reported an increase in their confidence in the plan of care were 7 times more likely to report a higher values impact and those expecting the consult to facilitate communication between team members were over three times more likely to report a higher values impact. The relationship between change in plan of care and values impact was not significant.

Not all comments from participants were positive. Free text comments from the on-line surveys included specific comments suggesting that the ethics consultant could have communicated more effectively with members of the health care team:

Just let the person know what the plan is... i.e., in this situation call back and say we are asking the social worker to do this consultation.

I would have liked more direct communication personally with the Ethics team and I feel the Ethics team could have spoken with the family more. Ethics was only following peripherally... I made the decisions on my own

DISCUSSION

This study of 94 ethics consultations found that the majority of consults helped resolve problems related to patient care and clarified uncertainty regarding what was the "right" thing to do for a patient. Respondents' expectations of the ECS were consistent with activities described in the ASBH competency document (ASBH 2011). Respondents also reported that participation in ethics consultation led to better understanding of ethics issues and provided clinicians with support. These outcomes suggest an ethics consultation service performing consistently with quality measures recommended by ASBH.

Managing expectations is an important part of ethics consultations. We found that the most common expectations focused on assistance with and clarification of communication. Less than one-quarter of respondents expected conflict resolution or major changes in care plan from the ethics consultation. This suggests that the requests for assistance were less about conflict resolution and more about addressing uncertainty. Of importance, with the exception of facilitate communication, these expectations were not associated with either patient-oriented outcomes (e.g. change in plan of care), or the respondent's overall assessment of values impact.

The relationship between changes in patient-related outcomes (plan of care, confidence in plan of care) and both overall assessment and values impact is an important one. It illustrates the central importance of the plan of care in ethics consultation. Ethics consultation performs important patient-related functions such as clarifying goals of care, clarifying team members/patient values related to those goals of care, and communicating this information. Providing this clarification essentially reassures providers they are doing what is right for the patient. For providers experiencing moral distress (a significant percent of our study population), ethics consultation as an intervention could decrease moral distress. A formal assessment of the impact of an ethics consultation on moral distress is another opportunity for future research.

Three quarters of the participants indicated that the ethics consultation increased their confidence in the plan of care. When the plan of care changed, participants were more likely to indicate that ethics consultation increased confidence. A change in plan might suggest that a conflict was resolved with the ethics consultation; however, since

survey responses were anonymous to protect confidentiality, it was not possible to match these perceptions against the documentation from the consultation. A high level of confidence in the plan of care suggests that, at the very least, ethics consultations resolved some degree of uncertainty. If 80% of participants indicated the patient's plan of care was consistent with their values, the other 20% likely experienced some degree of a true values conflict, which may or may not be resolved with an ethics consultation.

This study offers an important contribution to the literature with its focus on clinician values, which are often not considered separately from patient values. Our quantitative findings demonstrate that ethics consultation can help clinicians clarify their own values, while the qualitative findings demonstrate that doing so can help them clarify the values of patients and patients' families. This clarity offers an opportunity for transparency in the separation of clinician values from patient values. It also makes it more likely that an ethics consultation will result in a treatment plan that is consistent with the patient's goals and values.

These results were consistent with previously published work in a number of ways: overall, respondents had a favorable assessment of the ECS (Levin and Sprung 2000; Craig and May 2006); clinicians felt their values were respected (Cohn et al 2007); and the majority of ethical issues identified during consultations were related to end-of-life care (Chen et al 2014; DuVal et al 2004; LaPuma et al 1988; Moeller, Garcher and Radwany 2012). Ethical issues related to death and dying are not the only issues confronted by ECSs, but clinicians consistently seek and benefit from the support of ethics consultation when patients are at the end of life.

Limitations

Because it is largely an evaluation of the process of ethics consultation, this study does not include patient/family perspectives, nor does it address patient outcomes resulting from ethics consultations. These are significant limitations at a time when ethics consultations are often sought for end-of-life situations. It is critically important that future studies assess what happens to patients who are the focus of an ethics consultation compared with control patients on key indicators (e.g. mortality, length of stay and interventions like attempted CPR, days on a ventilator, survival to discharge).

Ethics consultations are sensitive, and tend to occur at times of disagreement and crisis. Use of a voluntary, anonymous survey was necessary to avoid the appearance of undue influence and to protect the confidentiality of participants, but it also likely created self-selection bias. Pfafflin, Kobert, and Reitter-Theil (2009) argue that evaluating values is contingent on knowing the patient's values; however, even without discovering patients' values, this study makes a good step forward by examining the role of health care providers' own values and demonstrating that providers identify ethics consultation as an opportunity to better understand patient perspectives. Future studies should evaluate whether or not patients and/or their surrogates perceive recommendations from an ethics consultation as consistent with the patient's values.

Conclusions

Ethics consultation is valued by members of the health care team. It offers meaningful support when health care professionals face ethically challenging cases, provides an opportunity to address moral distress, and is viewed favorably by those who

utilize the resource. Ethics consultation is an important service whose quality could clearly have an impact on health care providers' perceptions of the plan of care.

It is noteworthy that special funding for this project was necessary for data collection and analysis. Our service, like many, is a volunteer operation, and without ongoing funding and resources, this level of quality monitoring is not feasible. Future studies should examine impact of ethics consultation from the patient/family perspective and explore what resources are necessary to establish, monitor, and maintain a quality ethics consultation service.

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