H E C FORUM
1994; 6(1):18-30.

AN ASSESSMENT OF A FORMAL ETHICS COMMITTEE CONSULTATION PROCESS

JANET R. DAY, M.Ed., M.B.A.
MARTIN L. SMITH, S.T.D.
GERALD ERENBERG, M.D.
ROBERT L. COLLINS, M.D.

Background

In January 1989, the Cleveland Clinic Foundation (CCF) Institutional Ethics Committee (HEC) established a written protocol to guide prospective case consultations. Specific steps included data gathering and issue identification by a staff bioethicist; meeting as a committee first and then with individual health care providers; discussion with the patient and the family or surrogates, and the health care providers; and deliberations by the HEC members.

Variances within this protocol occurred. For example, patients or their surrogates were not always invited to be present at the meeting, and committee deliberations sometimes occurred in the presence of the health care providers.

Additional criteria for meetings included which members were present, chairpersons for specific meetings, time of day and length of the meeting, and location and size of the meeting place.

Why the Assessment was Conducted

Between August 1985 and April 1992, 17 prospective case consultations were referred to the HEC. During that same period, more than 350 cases were discussed by staff bioethicists acting as individual consultants. The 17 cases that went before the committee required greater multidisciplinary review as a result of their complexity.

The HEC wished to determine what qualitative improvements and enhancements could be made to the process of a formal HEC consultation regarding the care of individual patients. Many groups participated in the

consultations, each in a different way. Feedback was sought from each group to determine the effectiveness of the consultation. A task force composed of three members of the IEC (one of whom was also a staff bioethicist) and a staff person from the CCF Market Research Department was formed to develop a process for obtaining the desired information.

How the Assessment was Conducted

This assessment was begun in Spring, 1992. Patient medical records and the files of the Department of Bioethics were reviewed to determine who participated in each HEC consultation, and background information was collected on each case. Forms to record this information were developed and used by the bioethics staff.

Feedback was solicited from any individual who was involved in any capacity (e.g., family member, physician, nurse) in the IEC consultation. It was determined that sixteen of the seventeen consultations conducted to date were appropriate for evaluation. It was also decided that multiple family members from the same family would be eligible to participate in the assessment.

The survey instrument was designed as a self-administered questionnaire. Two versions of the questionnaire were developed, one for family members of the patient (Appendix A) and one for CCF staff involved with the case (Appendix B).

Because of the private and personal nature of an HEC consultation, family members who directly participated in the consultation were sent a letter explaining the purpose of the survey and a copy of the questionnaire. They were informed that they could complete and return the questionnaire, or complete and mail an enclosed card indicating that they preferred to speak to someone in person, or that they preferred not to participate at all. A follow-up telephone call was made to individuals who did not respond to arrange for an interview or for the completion of a questionnaire.

CCF employees involved in a consultation were sent a questionnaire through interoffice mail (or by regular mail if they were no longer employed by CCF). The questionnaire was accompanied by a letter explaining the purpose of the study and an appropriate pre-addressed return envelope.

Family members were not present in three of the 16 cases evaluated. For the remaining 13 cases, 20 family members' mailing addresses were available, and each family member was mailed a packet. Six questionnaires

were returned (response rate = 30%). No one indicated that they wished to speak about the experience in a phone conversation. One individual indicated that the questioning was inappropriate but did not explain further.

Staff members with valid addresses totaled 74. Forty returned usable questionnaires (response rate = 54%). There was at least one complete survey for each case. Five additional staff questionnaires were returned, but were unusable because the individuals indicated that they no longer recalled the case.

What was Learned from the Assessment

Because the number of respondents in this study is relatively small, the findings are generally reported as frequencies rather than percentages. Since not every respondent answered every question, the valid number of responses varies for each question.

Understanding of who requested consultation

When asked who had requested the consultation, seventeen of the 33 staff respondents stated that the consultation was held at the request of the attending physician, six stated it was held at the request of the patient or family, six stated someone other than CCF personnel had requested it, and four did not know. A case-by-case analysis revealed that attendees did not always agree about who had requested consultation. Of the sixteen cases, four cases had only one respondent. Of the twelve cases with more than one respondent, there was disagreement 66% of the time (eight out of twelve) on who had requested the consultation.

Understanding the purpose of the consultation

Almost all respondents (staff and family) stated they had an accurate understanding of the purpose of the IEC consultation before the consultation began. The one respondent who did not understand the purpose was a nurse. Responses indicated that the consultations were generally held to help define the appropriate course of action for the family and attending physician when the next course of action was not clear or when the physician and family did not agree on "appropriate care." Other respondents stated that the purpose was to make certain that everyone understood the ramifications of a decision before the decision was made.

Issues regarding appropriateness and numbers of attendees

All but one respondent indicated that they were introduced to all attendees at the HEC consultation. One family member and four staff members stated that all appropriate individuals were not included in the consultation sessions. The family member felt that the patient should have been included.

All six family members who responded felt that they understood why each person was present at the IEC consultation. Of the five staff members who did not know the role of each attendee, three were attending physicians, one was a resident physician, and one a psychiatric consultant.

Two of six family members (two separate cases) thought that there were too many attendees. Some staff members mentioned that the group was too big, that resident physicians need not be present, and that the primary nurse and the referring outside physician should have been included.

Role in consultation

Only one staff person indicated a desire to have had a greater role in the meeting. Only one family member and one staff person (n = 40) desired more time to present their views. All family members felt that they could have spoken to a committee member privately if they had wished.

HEC consultation opinion

Although most participants agreed with the HEC's opinion, two family members and two staff members disagreed. The open-ended responses from families regarding how the opinion was shared with them reveal that the opinion was not conveyed to two participants, two others did not remember, and two said it was "ok" and "done nicely."

Environment of HEC consultation

Although half of the respondents rated the room size as just right, there were some differences of opinion regarding the appropriateness of the room size. Attendees generally felt that the location of the conference was convenient. Half of the family member respondents (two of four) and six of 28 staff members indicated that the seating was uncomfortable. Each of

the respondents who were uncomfortable was at a different consultation. Only family members were asked whether the time of the IEC consultation was convenient. Five indicated it was convenient and one said it was not.

Helpfulness of and satisfaction with the process

Most staff members felt that the HEC consultation was a valuable experience that would help them to some degree in their clinical practice. The two who felt it would not be helpful were physicians. One stated that each case is too unique to have future applicability.

Four of the six family members (two cases out of four) were very satisfied and two were very dissatisfied with the process. The two "very dissatisfied" family members were also the same individuals who disagreed with the Committee's opinion.

Most (23 of 32) staff members indicated that they were "very satisfied" with the process of the consultation. Seven were somewhat satisfied and four were somewhat dissatisfied. Of the nine who were less than "very satisfied," only one disagreed with the final opinion of the HEC.

Suggestions for improving HEC consultation

The questionnaire was designed to obtain qualitative feedback and suggestions for improvement. Staff members' suggestions centered primarily on who was or was not present. Several thought that referring physicians and care givers who were directly involved with the patient should be included. Others suggested that the attending physician should take more of a leading role in the discussion. Staff members felt that the families may have been intimidated by the large groups. Several stated that they were never told of the Committee's final recommendations.

Some family members mentioned that a final recommendation was never formally shared with them and that "the people who knew the patients best were not present." Their responses frequently implied however that it (the HEC consultation) was handled well for a stressful situation.

What was Learned About Improving the HEC Consultation

Family members need to feel that the caregivers who know the patient best are included in the consultation. Thus, the outside referring physician, primary nurse, social worker, hospital chaplain or pastor, or

friends should be invited to the meeting.

The Committee's recommendations, as a result of the consultation, need to be shared with family members and other participants. The Committee should clearly define a process for communicating the opinions and conclusions of the meeting, and one person should be clearly identified to carry out this task.

One suggestion from respondents was that the attending physician lead the consultation, rather than a HEC member. The pros and cons of this suggestion need to be discussed by the HEC.

Physical environment issues (e.g., room size, comfortable chairs, and group size) need to be addressed by the HEC and determined on a case-by-case basis.

The request of one staff respondent that the Committee avoid making staff feel like "they are on trial or on the witness stand" should be evaluated. A "courtroom" atmosphere seems counterproductive to the purposes of ethics consultations.

What was Learned About Improving the Evaluation Process

Because this assessment was the first attempt to solicit feedback from HEC consultation participants, all cases before April 1992 were included. Some cases dated to 1985. Responses of the participants indicate that this is too long to recall the kind of detail requested. It was recommended that staff be surveyed regularly within a month of the consultation and family members after six months, unless the circumstances of the case indicate six months to be inappropriate. Results can be summarized annually or biannually, depending on the volume of consultations.

As a result of this survey, the two questionnaires should be critiqued and revised if necessary. The tracking form developed by the Department of Bioethics should be completed immediately after each Committee consultation. Such data would allow participants' perceptions to be compared with the "reality" of the cases. The form should be expanded to include the name, address, and phone number of each participant; the location where the consultation was held; and who was responsible for sharing the recommendation with the family members and other participants.

Conclusion

The CCF HEC reviewed the report and appointed a task force to develop a more detailed protocol based on the findings. The Committee concluded that the process of obtaining feedback was valuable and will contribute to improving the quality of future consultations.

FAMILY ASSESSMENT ETHICS COMMITTEE CONSULTATION

In 199 you took part in a formal Cleveland Clinic Ethics Committee consultation regarding the care of your family member _____, a Cleveland Clinic patient. Please answer the following questions as they apply to that particular Ethics Committee consultation.

1. What is your relationship to the person whose medical problem was being reviewed?

   [ ] Patient's spouse [ ] Patient's child
   [ ] Patient's parent [ ] Patient's friend
   [ ] Patient's sibling [ ] Other_____

2. At whose request was this Ethics Committee consultation held?

   [ ] Patient's family [ ] Attending Physician
   [ ] Don't know [ ] Other (Please specify who)

3. Do you feel you had an accurate understanding of the purpose of the Ethics Committee Consultation before the session began?

   [ ] Yes [ ] No

4. Ultimately, what do you feel was the purpose of the session?

5. Were you introduced to all of the participants?

   [ ] Yes [ ] No

6. In your opinion were the appropriate individuals included in the discussion?

   [ ] Yes [ ] No

   If "No" a. Who should have been included who was not?

b. Who was there who should not have been?

7. Did you understand the reason why each individual was present?

[ ] Yes [ ] No

8. Were there too many people present?

[ ] Yes [ ] No

9. Do you feel you were given enough time to present your views?

[ ] Yes [ ] No

10. Could you have spoken privately with a Ethics Committee member if you had wanted to?

[ ] Yes [ ] No

11. How was the final recommendation shared with you?

12. Would you have liked the committee's recommendation to have been shared with you in a different manner? Please explain.

13. Were you in agreement with the final recommendation?

[ ] Yes [ ] No

If "NO" - Was it difficult for you to understand why that recommendation was given? Please explain.

14. How appropirate was the setting of the room where the session took place?

a. Size [ ] Too large [ ] Too small [ ] Just right
b. Location [ ] Convenient [ ] Inconvenient
c. Seating [ ] Comfortable [ ] Uncomfortable

15. Was the time of the session convenient for you?

[ ] Yes [ ] No (Please explain)

16. In general, how satisfied were you with the process of the Ethics Committee consultation?

[ ] Very Satisfied [ ] Somewhat Satisfied
[ ] Somewhat Dissatisfied [ ] Very Dissatisfied

17. What suggestions would you make to improve the general process of conducting a formal Ethics Committee consultation?

STAFF ASSESSMENT ETHICS COMMITTEE CONSULTATION

In 199 you took part in a formal Cleveland Clinic Ethics Committee consultation regarding the care of _____, a Cleveland Clinic patient. Please answer the following questions as they apply to that particular Ethics Committee consultation.

1. In what capacity were you involved in this case?

[ ]	Attending physician	[ ]	Social worker
[ ]	Nurse	[ ]	Clergy
[ ]	Resident or fellow	[ ]	Psychiatric consultant
[ ]	Other	[ ]	Observer only

(Please expalin:_____)

2. At whose request was this Ethics Committee consultation held?

[ ]	Patient's family	[ ]	Attending Physician
[ ]	Don't know	[ ]	Other (Please specify who)

3. Do you feel you had an accurate understanding of the purpose of the Ethics Committee consultation before the session began?

[ ] Yes [ ] No

4. Ultimately, what do you feel was the purpose of the session?

5. Were you introduced to all of the participants?

[ ] Yes [ ] No

6. Did you understand the reason why each participant was present?

[ ] Yes [ ] No

7. In your opinion were the appropriate individuals included in the session?

[ ] Yes [ ] No

If "No" a. Who should have been included who was not?

b. Who was present who should not have been?

8. Would you have liked to have played a larger role in the consultation process?

[ ] Yes [ ] No [ ] Not applicable

9. Do you feel you were given enough time to present your views?

[ ] Yes [ ] No

10. How was the final recommendation shared with the patient's family?

Would you have done anything differently in sharing the final recommendation with the family?

11. Were you in agreement with the final recommendation?

[ ] Yes [ ] No

If "NO" - Was it difficult for you to comprehend why that decision was reached? Please explain.

12. How appropirate was the setting of the room where the session took place?

a. Size [ ] Too large [ ] Too small [ ] Just right
b. Location [ ] Convenient [ ] Inconvenient
c. Seating [ ] Comfortable [ ] Uncomfortable

13. Do you feel that being present at this particular Ethics Committee consultation helped you address future patient management issues?

[ ] Yes, a lot [ ] Yes, somewhat [ ] No, not at all

14. In general, how satisfied were you with the process of the Ethics Committee consultation?

[ ] Very Satisfied [ ] Somewhat Satisfied
[ ] Somewhat Dissatisfied [ ] Very Dissatisfied

15. What suggestions would you make to improve the general process of conducting a formal Ethics Committee consultation?