Empiric Studies of Ethics Consultation:
How Do the Data Inform Our Practice?

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Harvard Bioethics Course
Harvard Medical School
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Objectives of the Talk

• Review the published research done on ethics consultation

• Identify what conclusions we may draw from this body of work
  – How ought these data impact our consultations?
  – What are the limitations of research of this kind?

• Identify strategies to close the gaps in our data
What is in the Medical Literature?

• Opinions of individuals or groups
  – Sometimes based on institutional experience

• Policy statements and guidelines from professional groups

• **Empiric research** (today’s focus)
  – Outcomes
    • Physician
    • Patient
  – Descriptive/Evaluative
Studies Looking at the Outcomes of Ethics Consultation:

The Physician Perspective
An ethics consultation service in a teaching hospital: Utilization and evaluation

JAMA 260(6): 1988
LaPuma J, Stocking CB, Silverstein MD, DiMartini A, Siegler M.

- Retrospective review of 51 ethics consultations in a single teaching hospital

- Majority (96%) of physicians would request a consultation again in the future

- Requesting physicians (71%) found consult “very important” for:
  - Managing patient care
  - Clarifying ethical issues
• Survey of 600 randomly selected internists
  – >20% of their time in patient care
  – >1 year in practice

• Quantitative and qualitative methods
  – Majority (90%) report encountering an ethical dilemma recently
  – 82% had requested ethics consult
  – Ethical dilemmas involved
    • Justice
    • Patient autonomy
    • End-of-life issues
    • Conflicts among parties
DuVal et al, Results

- General internists, oncologists, and critical care specialists participated in 1.4, 1.3, and 4.1 consultations in the preceding 2 years, respectively.

- Physicians with less ethics training requested fewer consults:
  - Learning for the future (72%)
  - Likely to request a consultation again (86%)
DuVal et al, Results

• Positive outcome
  – Learning for the future (72%)
  – Likely to request a consultation again (86%)

• Negative (41%)
  – Too time consuming
  – Makes situation worse
  – Consultants unqualified
Conclusions and Questions Raised

• Physicians usually learn from consultation
  – We still lack specifics as to how or why
• Negatives may include time, usefulness, credentials of consultants
• What factors affect whether a given clinician requests a consult?
• Process of the consult not explicitly addressed in study questions or design
Studies Looking at the Outcomes of Ethics Consultation:

The Patient Perspective
Surveyed physicians, nurses, patients, and family members, 20 ethics consultations
- Rate helpfulness of the consultation

Physicians and nurses overwhelmingly rated consultation as helpful (>95%)

Patients and family members found the consult less helpful (65%)

Lack of communication between patient and clinical team cited as reason for unhelpfulness
• Conducted interviews with patients or surrogates, ethics consultation within last year (N=56)

• High satisfaction (77%) with decisions made

• Consultation reported as detrimental for only 4%

• Small majority (57%) found consultation helpful overall
Orr et al, Results

Ethics consultation found to be helpful in 7 major ways:

- Increased clinical clarity
- Increased moral or legal clarity
- Motivation to do what they believe is right
- Implementation of decision
- Facilitate decision-making process
- Interpretation of technical language
- Consolation and support
• Studied 551 patients in adult ICU’s in seven U.S. hospitals
  – All had value-related treatment conflicts during care
  – Randomly assigned to be offered ethics consultation or standard care

• Mortality rates did not differ between groups

• Ethics consultation led to shorter hospital and ICU stays and decreased use of life-sustaining treatment in patients who did not survive to discharge
Figure 3. Responses to the Follow-up Interviews Seeking Subjective Evaluations of the Ethics Consultation by Health Care Professionals and Patients/Surrogates

Patient/Surrogate Interview Responses (n = 108)

- Consultation Was Helpful
- Stressful
- Informative
- Supportive
- Fair
- Respectful of Values
- Consult Helped in Identifying
- Analyzing
- Resolving
- Educating
- Presenting Views
- Would Seek Consult Again
- Would Recommend to Others

Health Care Professional Interview Responses (n = 272)

- Consultation Was Helpful
- Stressful
- Informative
- Supportive
- Fair
- Respectful of Values
- Consult Helped in Identifying
- Analyzing
- Resolving
- Educating
- Presenting Views
- Would Seek Consult Again
- Would Recommend to Others

Likert scores are the following: 1, strongly disagree; 2, disagree; 3, neutral; 4, agree; and 5, strongly agree. Boxes indicate 25th and 75th percentile range.
To evaluate the effectiveness of health care ethics consultation based on the goals of health care ethics consultation
Chen YY et al. BMC Med Ethics. 2014 Jan; 15:1

• Study in 3 surgical ICU at university hospital in Taiwan
• 62 patients with conflict regarding values randomly assigned to receive ethics consult or not
  – 3 year study
• Patients in ethics consult group had shorter length of stay, easier time achieving goals of care
Ethics consultation is not standardized

- **Structure**
  - Organization of consult service
  - Qualifications and quality of the consultants

- **Process**
  - Example: facilitative vs. authoritative
  - Meeting participants

- Huge variety in the type of consultations requested

- Blinding absent
Assessing clinical ethics consultation processes and outcomes.
Batten J. Med Law 2013 Jun; 32(2)

• The outcomes most commonly assessed are not the right git
  – Healthcare cost
  – ICU based indicators
  – User satisfaction

• Not in the ethics consultant’s control

• Process indicators more useful as markers of quality

- 23-item checklist developed through literature review, iterative revising from expert group
- 6 month pilot phase followed by survey of ethics consultants using the checklist
- Checklist viewed as helpful by 2/3 of sample, especially among novices
  – Experts found it most helpful for training
Conclusions and Questions Raised

• Consultation may improve objective patient outcomes such as ICU stay, use of life-sustaining therapies, cost

• Patients and surrogates found consultation less helpful than physicians
  – Not thoroughly explained

• Nature of the exposure
  – Systematic review and RCT limited by lack of information about consult methodology
  – Different than empiric work done in other settings
Research on Ethics Consultation: The Nursing Point of View
The Courage to Stand Up: the Cultural Politics of Nurses’ Access to Ethics Consultation
Elisa Gordon and Ann Hamric J Clin Eth 2006; 17(3): 231-52

- Healthcare has hierarchical structure
- Even when technically permitted, nurses may not request consults as frequently
- Survey of nearly 900 inpatient nurses with semi-structured interviews
- Most nurses knew about ethics consultation but only 25% knew how to make a request
- While 8% had requested a consult, 15% had wanted to but did not. Latter group experiencing more regret
- Nurses who requested consult suffered consequences in 25% of cases
Physicians' and nurses' expectations and objections toward a clinical ethics committee
Jansky M et al. Nursing Ethics. 2013 Nov; 20(7):771-83

- 101 physicians and nurses at an academic hospital
- Nurses perceive ethical dilemmas as less important to physicians than to nurses
- Nurses feared ethics consultation would not impact practice
- Nurses reported talking about ethical issues mostly in their own professional group
Descriptive/Evaluative Studies
Ethics Consultation in United States Hospitals: A National Survey

Ellen Fox, National Center for Ethics in Health Care, Department of Veterans Affairs
Sarah Myers, Division of Health Policy & Clinical Effectiveness, Cincinnati Children’s Hospital Medical Center
Robert A. Pearlman, National Center for Ethics in Health Care, Department of Veterans Affairs; VA Puget Sound Health Care System; and University of Washington
A National Survey

- Aimed to describe how ethics consultation practiced in U.S. general hospitals
- Surveyed a random sample of U.S. general hospitals
  - Prevalence of consultations
  - Who performs the consultation and how are they trained
  - How ethics consultation services function
- Random sample of 600 (12%) hospitals
Fox et al, Results

• Ethics consultation services very prevalent (81%)

• Median number of consultations in last year = 3
  – Range 0-300
  – 22% reported no consults in last year

• Consultants
  – Usually work as small team (68%)
  – Rarely receive salary support (16%)
  – 90% Caucasian, 54% female
  – 34% physician, 31% nurse, 11% social work, 10% chaplain, 9% administrator
  – Learn ethics through direct supervision (41%) or independently (45%)
  – Few (5%) had graduate training or fellowship in ethics
Almost all (95%) respondents reported that anyone could request a consultation.

Consultants “usually” or “always” (%):
- Had discussions with individual clinicians (92)
- Spoke with patient/proxy individually (78)
- Gathered information from patient’s chart (87)

Consultants less consistently (%):
- Had discussions with full clinical team (67)
- Spoke with patient or proxy during group meetings (29-48)
- Gathered information directly from patient (54)

Consultants participated throughout patient’s stay in 13% cases and 72% had no evaluation process for the consultation.
### Table 3. Reported Goals of Ethics Consultation

<table>
<thead>
<tr>
<th>Explicit Goal</th>
<th>Primary Goal (%)</th>
<th>Secondary Goal (%)</th>
<th>Not an Explicit Goal (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intervening to protect patient rights</td>
<td>94</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Resolving real or imagined conflicts</td>
<td>77</td>
<td>22</td>
<td>1</td>
</tr>
<tr>
<td>Changing patient care to improve quality</td>
<td>75</td>
<td>19</td>
<td>6</td>
</tr>
<tr>
<td>Increasing patient/family satisfaction</td>
<td>68</td>
<td>26</td>
<td>6</td>
</tr>
<tr>
<td>Educating staff about ethical issues</td>
<td>59</td>
<td>37</td>
<td>4</td>
</tr>
<tr>
<td>Preventing ethical problems in the future</td>
<td>59</td>
<td>36</td>
<td>5</td>
</tr>
<tr>
<td>Meeting a perceived need of staff</td>
<td>50</td>
<td>35</td>
<td>14</td>
</tr>
<tr>
<td>Providing moral support to staff</td>
<td>47</td>
<td>47</td>
<td>6</td>
</tr>
<tr>
<td>Suspending unwanted or wasteful treatments</td>
<td>41</td>
<td>40</td>
<td>19</td>
</tr>
<tr>
<td>Reducing the risk of legal liability</td>
<td>40</td>
<td>49</td>
<td>11</td>
</tr>
</tbody>
</table>

### Table 5. Actions Recommended in Ethics Consultation: Percentage of Ethics Consultation Services Reporting Various Frequencies of Three Different End Results.

<table>
<thead>
<tr>
<th>End Result</th>
<th>Frequency with Which Each End Result Occurred, %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 % of the time</td>
</tr>
<tr>
<td>Recommend a best course of action</td>
<td>25</td>
</tr>
<tr>
<td>Specify a range of acceptable actions</td>
<td>22</td>
</tr>
<tr>
<td>Make no specific recommendation</td>
<td>65</td>
</tr>
</tbody>
</table>
Fox et al, Conclusions

• Ethics consultation service is a routine part of U.S. healthcare

• However, consultations may be infrequent

• Most ethics consultants are clinicians
  – Formal training is very rare
  – Nearly half learn unsupervised

• Heterogeneous goals and practices
  – Interactions with the patient
  – Whether specific actions were recommended
Ethics Consultation in Children's Hospitals: Results From a Survey of Pediatric Clinical Ethicists

Jennifer C. Kesselheim, Judith Johnson and Steven Joffe

Pediatrics 2010;125;742-746
Objectives

• To survey pediatric clinical ethicists in order to:
  
  – Explore their characteristics and the training they receive to fulfill their ethics role
  
  – Describe the institutional support that pediatric ethicists receive for their ethics work
  
  – Determine the policies and methods for ethics consultation within children’s hospitals
Results: Demographics and Professional Time

- Median age 55 years (Range 35-68)
- 19 (58%) male

Allocation of Professional Time (%)

- Patient Care: 48%
- Education: 15%
- Admin: 14%
- Clinical/Org Ethics: 13%
- Ethics Research: 3%
### Results: Training for Ethics Roles

<table>
<thead>
<tr>
<th>Response</th>
<th>N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experience on the job</td>
<td>24 (73)</td>
</tr>
<tr>
<td>Intensive bioethics mini-course</td>
<td>13 (40)</td>
</tr>
<tr>
<td>Mentoring with an experienced ethicist</td>
<td>12 (36)</td>
</tr>
<tr>
<td>Masters degree</td>
<td>11 (33)</td>
</tr>
<tr>
<td>Required reading</td>
<td>8 (24)</td>
</tr>
<tr>
<td>Institutional training</td>
<td>6 (18)</td>
</tr>
<tr>
<td>Ethics fellowship</td>
<td>5 (15)</td>
</tr>
<tr>
<td>Ethics certificate program</td>
<td>4 (12)</td>
</tr>
<tr>
<td>Formal training in mediation</td>
<td>5 (15)</td>
</tr>
<tr>
<td>PhD</td>
<td>4 (12)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (27)</td>
</tr>
<tr>
<td>Task</td>
<td>Never/Rarely N (%)</td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Review consultation with ethics committee</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Meet with &gt;1 member of team</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Notify patient/family of consult</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Follow up with participants for clinical update</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Enter written report into medical record</td>
<td>4 (12)</td>
</tr>
<tr>
<td>Meet with patient/family</td>
<td>3 (9)</td>
</tr>
<tr>
<td>Follow-up with team for feedback</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Provide written report to team</td>
<td>8 (24)</td>
</tr>
<tr>
<td>Provide written report to patient/family</td>
<td>17 (52)</td>
</tr>
<tr>
<td>Include a resident on consultation</td>
<td>15 (46)</td>
</tr>
</tbody>
</table>
Knowledge of Pediatric Ethics: Results of a Survey of Pediatric Ethics Consultants
Kesselheim JC et al. AJOB Emp Bioethics. 2015; 6(4).

• Administered validated knowledge scale to 2 ethicists at 45 free-standing children’s hospitals (N=99)
  – Based on published policy statements
• 73% of ethicists had completed ≥1 formal training modality
• Respondents infrequently received salary support (32%) or had a budget (28%) to support ethics work
Knowledge of Pediatric Ethics: Results of a Survey of Pediatric Ethics Consultants Kesselheim JC et al. AJOB Emp Bioethics. 2015; 6(4).

• The median TREK-P score was 19/23 – IQR 17-21

• 40% scored ≥20, surpassing the threshold of adequate performance proposed in previous work.

• Median scores were significantly higher among ethicists with formal training
High scores (≥20) were significantly more common among ethicists
- receiving salary support (55% vs. 33%, p = 0.04)
- who had formal ethics training (47% vs. 22%, p = 0.02).

Items pertaining to privacy, genetic testing, and assent, were answered incorrectly by >33% of ethicists.
Conclusions

• Majority report training via on the job experience
  – Other methods of formal training far less frequently reported
  – May be increasing, at least in pediatric ethics

• Heterogenous and sometimes inconsistent consultation practices
  – Meeting with patient and family
  – Sharing written report with the team
  – Sharing written report with the patient/family
  – Following up with participants to get feedback
Outcomes of Ethics Consultation as reported by the Ethicists!
Standards for Consultants

• Good ethics consultation requires core competencies: knowledge, skills, character traits can be acquired through many different training strategies

• Second edition of this statement published in 2011

Clinical Ethics Consultation Affairs (CECA)

- Established by ASBH in 2009
- Explore
  - Credentialing of clinical ethics consultants by hospitals
  - Accreditation of ethics consultation training programs
  - Development of a code of ethics
  - Certification of clinical ethics consultants

ASBH Clinical Ethics Consultation Affairs (CECA) Committee www.asbh.org/about/committees.html
Clinical Ethics Consultation Affairs (CECA)

- Initial code of ethics created 2009
  - 8 elements
- Survey distributed in 2011-2012 to solicit feedback (N=293)
- Revised version of the code put forth in 2012
- Second survey in 2013 (N=393)
  - >90% sample endorsed each element of Code.

ASBH Clinical Ethics Consultation Affairs (CECA) Committee [www.asbh.org/about/committees.html](http://www.asbh.org/about/committees.html)
Tarzanian et al. AJOB 2015; 15(5).
Toward Competency-Based Certification of Clinical Ethics Consultants: A Four-Step Process

Martin L. Smith, Richard R. Sharp, Kathryn L. Weise, and Eric Kodish
<table>
<thead>
<tr>
<th>Steps</th>
<th>Intervention</th>
<th>Areas To Be Addressed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td>Written examination</td>
<td>Domains of factual knowledge</td>
</tr>
<tr>
<td>Step 2</td>
<td>Case portfolio</td>
<td>Consultative experience</td>
</tr>
<tr>
<td>Step 3</td>
<td>Case simulations, standardized patients</td>
<td>Interpersonal and communication skills</td>
</tr>
<tr>
<td>Step 4</td>
<td>Oral examination</td>
<td>Integration of skills and knowledge, role identity</td>
</tr>
</tbody>
</table>
Standards for Practice

• Ethics consultation process should adhere to published standards
  – How does lack of specific policies or procedures for doing consults contribute to variation in practice?
  – Why is this variation present? Why do consultants do what they do? How do they decide?
  – Does heterogeneity affect outcomes?
We Have Many Unanswered Questions

• Get into pairs
• Take 5 minutes to generate a new question amenable to research
• Report to group
References


• ASBH Clinical Ethics Consultation Affairs Committee (CECA) www.asbh.org/about/committees.html


References


• Schneiderman LJ et al. Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. JAMA, 2003: 290(9); 1166-72.


• Yen BM, Schneiderman LJ. Impact of pediatric ethics consultation on patients, families, social workers, and physicians. J. Perinatology (1999): 19(5); 373-8.
How should we apply this standard?

– What educational background or skills are needed?

– What is the relationship between volume and competence?

– How might we guarantee, oversee or regulate the competence of clinical ethicists?