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RESEARCH ARTICLE

Developing Novel Tools for Bioethics Education: ACECS and the Visual Analytics Dashboard

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Abstract

The translation of bedside experience to pedagogical content presents a unique challenge for the field of bioethics. The contributions are multidisciplinary, the practices are heterogeneous, and the work product is characteristically nuanced. While academic bioethics education programs have proliferated, developing content and pedagogy sufficient to teach clinical ethics effectively remains a longstanding challenge. The authors identify three reasons why progress towards this goal has been slow. First, there is a lack of robust, empirical knowledge for education focused on praxis. Second, the methods employed in academic education tend to focus on traditional didactic approaches rather than engendering competency through interaction and practice—the principle means by which clinical ethicists work. Third, the data practitioners have captured has not been presented in a medium educators and students can most meaningfully interact with.

In this paper, the authors describe a novel pedagogical tool: the Armstrong Clinical Ethics Coding System (ACECS) and interactive visual analytics dashboard. Together, these components comprise an educational platform that utilizes the empirical data collected by the institution's ethics service. The tool offers four advantages. First, it aids with the identification of ethical issues that present during a consultation at that specific institution or medical unit by making use of a *lingua franca* comprehensible to both ethicists and non-ethicists. Second, content is centered on issue frequency, type, and relation to other issues. Iterating through cases, requestors, or hospital units allows one to understand cases typologically and through metanarratives that reveal relationships and subtle patterns. Third, the use of interactive data visualizations and data storytelling aids comprehension and retention. Fourth, the process of using the system necessitates understanding the manifold ways each case can be understood, accommodating a wide range of perspectives and ethical lenses, enhancing case analysis and self-reflection conducive to life-long learning.

Keywords: ACECS; bioethics; clinical ethics; data visualization; empirical knowledge

Introduction

The translation of bedside experience to pedagogical content presents a unique challenge in bioethics. The contributions are multidisciplinary, the practices are heterogeneous, and the work product is characteristically nuanced. Developing educational content sufficient to teach clinical ethics effectively has thus been a longstanding challenge.[1,2,3,4] There are at least two reasons for this academic-clinical divide. First, while individual clinical ethics consult services have advanced the use of data,[5,6,7,8] there have long been, and continue to be, calls for standardized reporting.[9,10,11,12] As we have argued previously, detailed knowledge about what issues present, how often, with what variation, and how they relate to one another is neither well understood nor available for study.[13] While one multisystem study has been conducted,[14] there remains a lack of robust, systematic, evidence-based empirical

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knowledge about what occurs in different types of hospitals, hospitals in different geographic regions, as well as in other care settings.[15,16,17]

These are not merely epistemic concerns. Scott Halpern identified unfounded bioethical assumptions that were later repudiated by empirical work nearly 20 years ago,[18] and a lack of data continues to be a major barrier in education.[19] This stems at least in part from a lack of consensus regarding standardization in clinical ethics.[20,21,22,23] As a downstream effect, Becket Gremmels identified a lack of criteria and standards for education as an unresolved problem in his proposed pipeline for clinical ethicist training.[24] Sandra Spencer and colleagues investigated resident education and concluded, "Few bioethics curricula at the graduate medical education level are evidence-based or comprehensive."[25] Without a shared, systematic way to manage and analyze data, it can be difficult to scale talent and expertise through education and clinical practice. This leaves educational programs frequently unable to draw on a strong, empirical basis to support theoretical and policy work, and the profession unable to develop an epidemiology of ethical issues with which to prepare aspiring clinical ethicists and educate other healthcare professionals.[26]

Second, a number of authors have pointed out a traditional didactic pedagogy is not aligned with the task of teaching and understanding the complexity that occurs at the bedside. Spencer and colleagues acknowledge the lack of clear linkage between the module training they developed (based on the four-box method) and mastery of the skills and attitudes that lead to clinical competence. Jason Keune and Erica Salter note the Core Competencies advise that "process and interpersonal skills" are "acquired primarily by 'doing'… and there is no substitute for the role of experience."[27] Keune and Salter argue experiential learning is needed to address the challenge of teaching doctoral-level healthcare ethics,[28] a longstanding concern in the field.[29] Alberto Giubilini and colleagues' recent review identified the application of ethical knowledge and critical thinking to clinical practice among the top shortcomings with medical school ethics curricula,[30] paralleling one of the primary critiques of the Healthcare Ethics Consultant Certified (HEC-C) project. A limited number of multiple-choice questions cannot capture the breadth of basic issues a clinical ethicist must understand and contend with, nor is it able to address the challenge of connecting traditional pedagogical approaches to the process of conducting an ethics consult.[31]

Our approach to both consultation documentation and education focuses on advancing bioethics education by integrating the theoretical "what" with an empirical "how." The tool we present assists in developing skills in three primary domains: identification of ethical issues, reasoning through those issues, and constructing justifiable recommendations. This paper will focus on questions concerning how this robust classificatory scheme can be foundational to both learning and practicing clinical ethics, useful for the education of multidisciplinary participants working in clinical settings, and aid the necessary growth and lifelong learning of clinical ethicists. Each component of the system will be described along with examples of how it is used for education.

Identifying pertinent consult information

Many practicing ethicists have found it useful to describe and characterize the activities of their consult services in an attempt to categorize the breadth of clinical ethics activities.[32,33,34,35,36] Subsequent to the Integrated Ethics approach,[37] in 2011, the American Society for Bioethics and Humanities (ASBH) recommended over 20 data points be recorded in a consult service's internal records.[38] Numerous ethics programs have developed some form of database to track consults, though several authors have identified significant heterogeneity among the approaches to which data to capture and how to use or compare that data.[39,40] In his survey of clinical ethics informatics, John Frye noted that at least 75% of databases include a patient's name, record number, age, location, and diagnosis; the position and concerns of the consult initiator, the date the consult began, and when the ethics consultant(s) responded.[41] A recent systematic review found 27 different typologies being used to characterize clinical ethics consultations.[42] Despite the tremendous work programs have invested in their databases, there continues to be debate over what constitutes key data, how to capture it, and how that data would be used other than for pure research purposes.[43]

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Similar to Frye's findings, our program captures basic demographic data such as name, age, gender, medical record number, patient unit, requestor, and various dates. Ethicists also track the length of time between patient admission and consult request and use a free-text box to document a narrative on how the case progresses over time that is also used for hand offs. For research or future potential, the service also collects some ancillary demographics including race, language, religion, and zip code, though these have not yet been shown to provide identifiable patterns or relationships. There may be promise in these areas pending further development of our database or through comparisons with other institutions. Finally, the cases are coded in a standardized form with the Armstrong Clinical Ethics Coding System (ACECS, See Figure 1). This data is then integrated into a data model that we can interact with through the visual analytics dashboard (See Figure 2). This allows the data to be quickly explored, filtered, combined, and analyzed. These tools are the work products of the authors: ACECS was developed by KA and the dashboard was developed by SLT.

We use ACECS to code individual ethics consults, which involves six alphanumerical categories that capture critical dimensions of the consult. As we recently argued in "Telling Stories with Data," the set of codes is used by the ethicist to tell the story of the case, as best as possible, with elements that are conducive to discrete analysis.[44] The first three codes describe: (1) the kind of consult (conflict, values clarification, answer question, etc.), (2) who was involved, and (3) the level of complexity. The next three data points are ACECS issue codes (See Appendix 1, ACECS Coding Sheet). The issue codes are loosely organized into nine groupings which roughly reflect categories of issues ethicists commonly confront, and any code can be used from anywhere in any combination. This ordering aids in quick identification and the nonspecialized language used facilitates discussions with persons who have little to no experience in clinical ethics.

The strength of the ACECS documentation comes from its developing narrative structure: rather than single, discrete codes that are used individually to code a case, ACECS codes are used in sets of three, with each modifying the others.[45,46] This was felt necessary to better understand the particular issue at hand as an instance involving not just one issue, but generally several in tension with one another. Roughly characterizing a case by a single issue such as "end-of-life" does not provide enough information for handoff to another ethicist, informative data analysis, or clinical education.

Consider, for example, that the issue of "Refusal of Recommended Treatment or Testing" has one meaning when combined with "Decisional Capacity" and another when combined with "Religion and Culture." In the first instance, the ethical issue of refusing treatment by a patient where there is also a concern about the patient's decisional capacity suggests a certain set of questions such as how capacity was assessed, is capacity fluctuating, where is the capacity threshold to overrule the patient's refusal, and how best to discern the patient's wishes. In the second instance, the ethical concern regarding refusing treatment is in tension with the patient's freedom or autonomy rights. While adult patients with the capacity are free to refuse treatment based on their personal values and beliefs, different questions arise such as will this refusal result in adverse lifelong consequences, have alternatives been pursued, is the patient fully informed, or is there outside influence from family or the community to make a decision the patient may not fully endorse. Using the ACECS typology in this way allows learners and providers to develop an understanding of how a seemingly basic issue such as treatment refusal can require very different ethical analyses depending on other contributing factors.

The example above compared two issue codes, but ACECS uses three to form a code "triad" that tells the story of the case.[47] This triangulation of three codes to characterize the consult can lead to robust discussions regarding the reasoning and justification behind which elements of the consult were most important.[48] A completed set of ACECS codes looks like the following:

A database of ethics consults that includes ACECS codes and related information forms a model of a given practice environment. In this way, educational materials remain sensitive to the setting in which the data was collected, whether one is in a rural access hospital or an academic medical center[49] and can incorporate specific institutional missions and goals.

Data interaction and visual analytics dashboard

Most published analyses of clinical ethics consult data have been either single or case series studies or studies that make use of discrete issue codes.[50,51,52,53] While this format has been foundational for the

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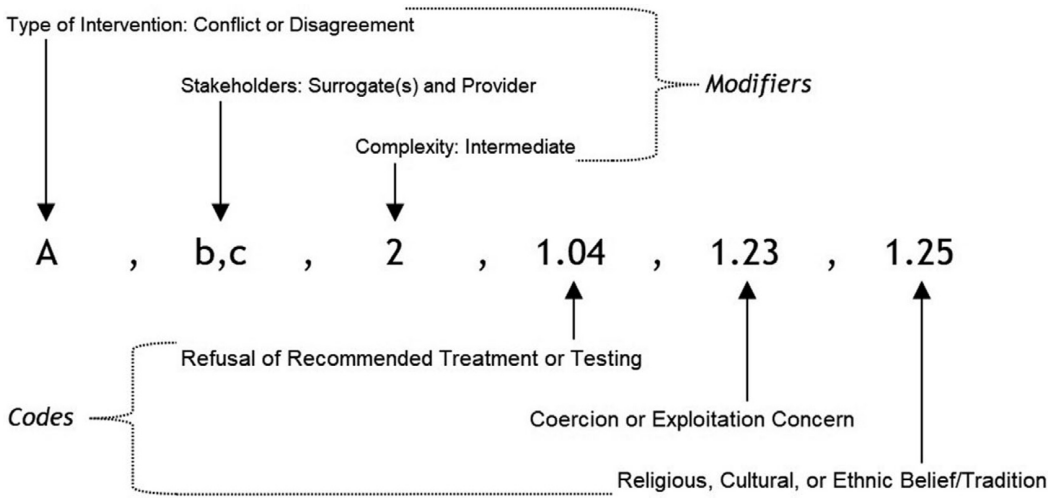


Figure 1. ACECS code set syntax.

field, it lacks the means to convey the kinds of nuanced relationships noted in the previous example about refusal of treatment. We believe that single-issue coding of ethics consults is not sufficient to characterize ethics consults or draw conclusions about those issues, and something like the ACECS multicode approach is necessary. In addition to more accurate characterizations, the breadth of descriptive elements in the taxonomy helps avoid the "weaponization" of a few, well-known principles over other equally valid viewpoints that Autumn Fiester has warned about.[54] However, any means to characterize that kind of complexity produces data sets that are exceedingly complex—perhaps even impenetrable without advanced forms of data analysis.[55]

Rich characterizations that capture more than single-issue descriptions of ethics consults must therefore be conveyed through a medium that optimizes the learner's or users' attention and ability to comprehend. We have argued elsewhere that data visualizations and data storytelling enhance these attributes by bringing one's visual processing power to what is otherwise a large volume of abstract information.[56] The visual analytics dashboard enables analysis of complex sets of relationships by displaying visual representations of data—graphs, charts, and information graphics—that stand in relation to one another. The dashboard facilitates comprehension through real-time interaction with the data. When we use the ACECS taxonomy to discuss cases, we can interact with large numbers of code permutations and related analyses. In doing so, prevalences, permutations, and relationships that exist amidst that complexity become visible.[57,58]

While this approach is relatively new, a recent study by Joanna Sleigh and colleagues found an interactive visual format better-supported learners' understanding, acquisition, and application of knowledge and provided "an overall better episodic and remembered user experience when compared with text-only approaches."[59] The display can be tailored to different audiences and for different purposes. Figure 2 provides a sense of the different forms the data visualizations can take. These visualizations allow us to track where consults come from, the frequency with which different stakeholders call consults, what issues are present in different units or providers, trends in when consults are requested, and how complex the case was in relation to the ethical issues involved. For example, when the service first started 7 years ago, the average day of hospitalization on which the ethics consult was placed was 52 days after admission, and nearly all cases involved conflict. Today, 27% of consults are placed on day 1 of hospitalization, reflecting an increased ability on the part of learners to spot and refer to ethical issues before conflict arises. The data regarding the day of consult and level of complexity has been central to decisions about what units or provider groups to target education regarding "what is an ethical issue?" and "when should I call a consult?"

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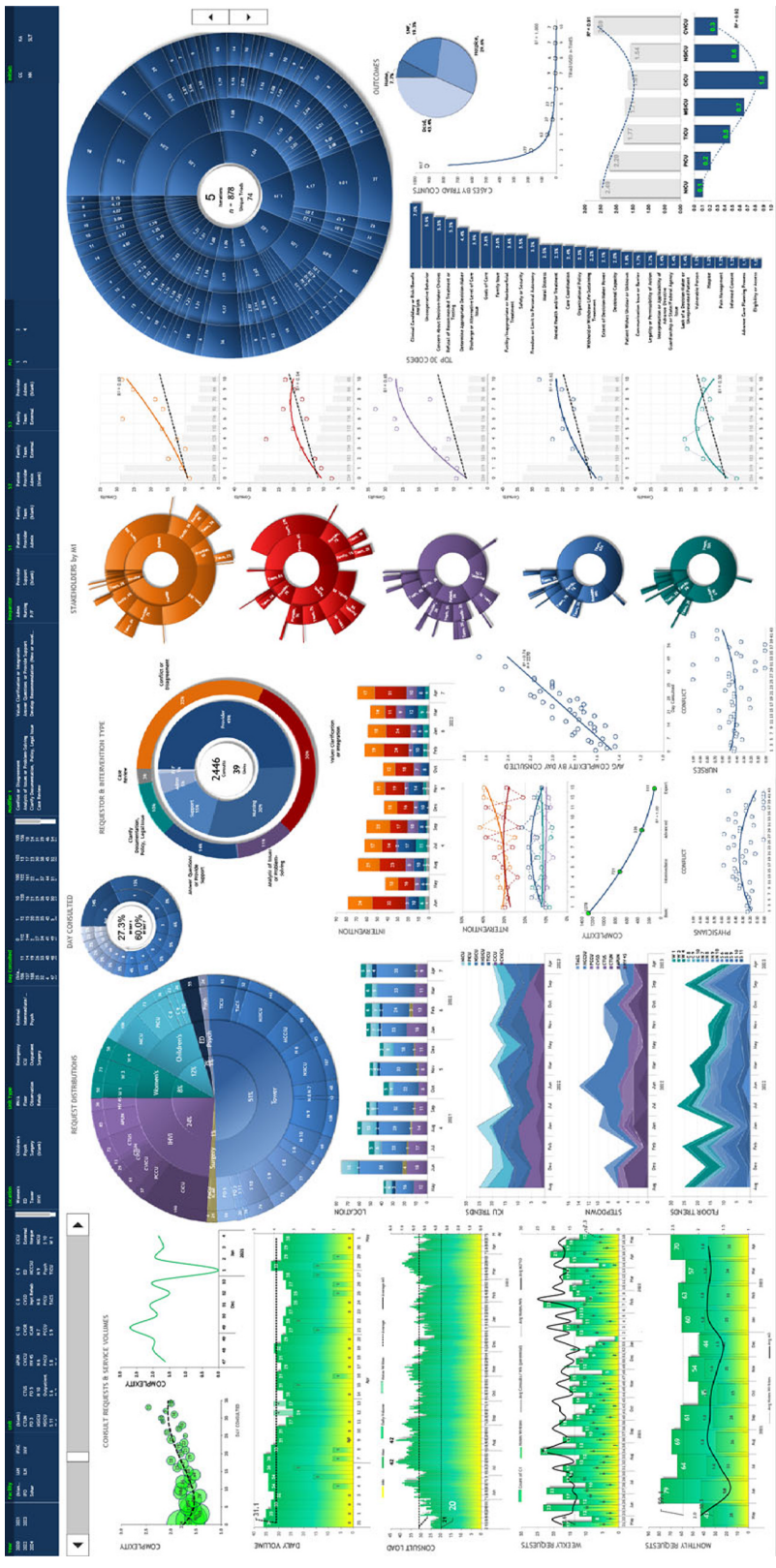


Figure 2. Our visual analytics dashboard.

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The dashboard displays the following relationships that we have found to be particularly useful:

- LEFT (lime green): case complexity by day consulted and recent trending (top); daily consult request volumes, ongoing case load, weekly consult requests (middle); monthly consult requests (bottom). Black lines are average complexity trends.
- CENTER-LEFT (purple, blue, green: location of requests by hospital and unit (top); timing of consult requests (top); volume trends by hospital (middle), by unit type, and by unit (bottom)
- CENTER (orange, red, purple, navy, green, grey): type of ethics intervention and requestor role (top); type of ethics intervention trends, complexity overall, and complexity by day consulted (middle); rates of consults involving conflict with providers (left) and nursing (right) by day consulted (bottom)
- CENTER-RIGHT (orange, red, purple, navy, green, grey): stakeholder breakdown by type of intervention (left); consult volumes by type of ethics intervention with trends (right)
- RIGHT (blue): ACECS code triad prevalences and permutations (top); codes by percentage rank; discharge disposition (middle); Consult-Bed Ratio of all ICUs by average aggregate complexity (bottom)

Scalable education

The charts, graphs, and other information graphics drawn from the dashboard are highly scalable to a variety of learning environments and target audiences. Initially, the data were targeted for presentations to administrators who appreciated ethics but could not describe what it is that the clinical ethicists were doing or why additional staffing was necessary. The visualizations allowed dense information to be communicated in an accessible manner. We can look at the level of consult complexity to assess whether we are catching issues at the "ask questions" or "integrate values" stages, or only at the conflict stages, and explore the specific types of issues appearing on each unit. Drilling down, visualizations can show the types of issues physicians requested assistance for (with a "what is permissible?" pattern), versus the types of issues that nurses were calling consults for (with a "how do I address this?" pattern). This data becomes the core of preventative ethics initiatives, and interventions can be measured for quality and outcomes by examining subsequent consult request data.

Data-informed preventative ethics strategies moved to unit-level education for physicians and staff to directly address the most common issues being encountered in specific areas, and the red flags to look for early in the patient's stay. Education could be distilled into 15-minute weekly issue-specific discussions in the break room or expanded into formal 30-, 60- or 90-minute inservices or grand rounds. Initially, the visual data was particularly helpful in demonstrating that a provider was not alone in recognizing the difficulty of certain issues. Subsequently, providers more readily requested consults and educational sessions because they better understood how the ethics consult service could directly assist with the issues they were frequently seeing. With medical students, residents and other learners who shadowed with the ethics service, the ACECS codes gave them an accessible language to begin speaking about cases, validated their concerns about certain issues they had seen, and the visualizations provided a rich contextual introduction to the breadth of issues they would encounter during their time at this facility. Finally, and perhaps more importantly, the system allows the Ethics team to robustly discuss and analyze both cases and approaches, facilitating team calibration and self-reflection.

Medical students and residents

Generally, a foundational step with medical learners of all disciplines is to dissuade them from thinking the discipline of Ethics is abstract, processless opining not relevant to the bedside. Often learners initially tell us they think ethical issues are rare or are clearly settled by the law. However, "patients have the right to refuse treatment" ignores the difficulties encountered in its application to specific circumstances with confounding factors. Students learn that Ethics is not simply "what does the law say?" but involves the

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Figure 3. Heat map.

complexity of applying the law in nonideal circumstances—such as when the patient lacks a decision-maker. Using ACECS to introduce learners to the ethics consult service allows them to better understand the everyday issues encountered at the bedside that contribute to, or complicate, the ethical analysis. An ACECS heat map (Figure 3) where formal ethics consult issues are marked in red at the end of each year, reveals the breadth of issues faced by clinicians every day across every unit in the hospital, thereby demystifying and normalizing the practice of ethics consultation. We have found this lowers the threshold on when to call a consult and increases comfort in consulting in a wider array of cases.

Yearly heat maps illustrate how institution-specific issues might change over time, tracking the development of the institutional ethics environment. Not incidentally, these are the same reasons we have found various permutations of the heat map extremely helpful in communicating with administrators and colleagues from other institutions. The immediacy with which a learner can comprehend the scope of issues at one institution versus another is a critical missing factor in clinical ethics education. As the heat map in Figure 3 illustrates, our institution does not have an assistive reproduction program, our staff are not part of a union, and our program limits itself to direct patient care, with research ethics managed elsewhere in the organization.

ACECS was designed to form a core foundational language for discussions that avoid ethics-specific language or reduction to the limited principles of ethics most learners have been briefly exposed to.[60] This allows learners to more readily identify issues they encounter and "see" the issue has ethical permutations. For example, a patient who does not cooperate with care and threatens staff may be seen as a strictly "call security" issue, while ethics consults often uncover more nuanced reasoning and even coercive provocations. The use of 3 codes requires the learner to ask further questions—this is an uncooperative patient, but what are the other 2 codes? This investigation calls for the learner or user to identify contributing factors. In other cases, issues such as moral distress, unprofessionalism, or a surrogate's decision to override the patient's previously known wishes may not be identified when

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using the four principles most learners have been exposed to. ACECS allows trainees to give language to issues that "seemed wrong in the pit of my stomach, but everyone else was just moving along." Once cases are identified ethics education moves to what constitutes relevant information, and why what may appear to be the same issue in different cases can require very different ethical analyses and perspectives.

After medical students and residents who rotate with the ethics consult service have shadowed a consult, we prompt them to "code" the case. Selecting which codes to use invites a discussion: why this code and not that one? We walk students through the process of coding to help them develop an understanding of the similarities and differences between ethics consults: what was the case about? What issues were present? Working through the process of choosing codes allows learners to consider the relative importance of different aspects of the consult, deepening familiarity with how issues impact the case overall. "Refusal of Recommended Treatment or Testing" involves a different set of concerns when paired with "Decisional Capacity," "Mental Health," or "Uncooperative Behavior."

Thinking through which codes most accurately characterize the consult requires the learner to discern which elements of the case are most salient, and why. This process of discernment involves considering a range of possibilities and narrowing down the codes to the set that fits the situation best. This mapping of experience onto a common lexicon increases learners' ethical sensitivity to the details and borders of individual issues and improves the consistency from case to case. Notably, this process focuses on what one study found to be the three most appreciated aspects of bioethics education: increased discussion, helpful educational materials, and cases.[61]

Invited educational sessions

The system allows us to examine what kinds of cases the service typically sees on a particular unit so we tailor education accordingly. Figure 4A shows NICU consults over a 21-month period. Moral distress and goals of care are the most prominent issues. Based on this, we developed and implemented weekly interdisciplinary ethics case reviews. By looking at a unit's heat map at different times, we can monitor changes in consult requests after an intervention is implemented. Figure 4B shows NICU consults over the 21-month period after the intervention began. Note several changes: consults involving moral distress decreased from 17 to eight and questioning decision-maker choices increased from seven to 12. Also note that 18 goals of care consults occurred in the first period, but only six in the second period. This appears to be a result of team members getting better at managing difficult goals of care conversations internally and requesting consults for more nuanced concerns. Figure 4B shows a lower number of overall consults but a larger number of different ethical issues. This can be measured as a ratio: the number of different ACECS codes divided by the number of consults. The figures show 0.61 issues per consult in the first period and 0.81 in the second, a substantial increase in variation.

Caption: Figures 4A and 4B show the frequency with which each ACECS code is used in two different time periods. The more intense the color, the more frequently it has been used to code a consult. The number of times a given code has been used is shown in the colored box left of the code description. Codes not used at all are greyed out and have no color.

Similarly, the dashboard allowed us to see consults involving the use of behavioral contracts and patients leaving Against Medical Advice (AMA) started increasing after the pandemic. We used it to identify the most affected hospital units and developed a packet of information tailored to their specific needs. We used that information to do 20 minute "coffee talk" discussions in break rooms on different shifts, allowing us to address specific questions and offer advice. Bringing this information to the institutional ethics committees allowed us to push out that information to many different areas of the hospital.

Rounds and grand rounds

The dashboard can output a list of the top 10, 20, or 30 issues at the touch of a button; what are we seeing, how often, and the most affected locations can provide insights into issues, both broad and specific, that

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NICU — Consults: 59 Codes: 36 — 0.61

Code	No.	Description
1.00		TREATMENT DECISION-MAKING
1.01		Decisional Capacity
1.02	3	Informed Consent
1.03	18	Goals of Care
1.04	4	Refusal of Recommended Treatment or Testing
1.05	13	Clinical Candidacy or Risk/Benefit Analysis
1.06	5	Communication Issue or Barrier
1.07	2	Mental Health and/or Treatment
1.08	3	Discharge or Alternative Level of Care Issue
1.09		Pain Management
1.10		Genetics and Genetic Testing
1.11		Preventative Intervention
1.12		Complementary, Integrative, Alternative Medicine
1.13		Body Image, Alteration, or Modification
1.14		Cognitive Enhancement
1.15		Novel, Innovative, or Experimental Intervention
1.16		Freedom or Limit to Personal Autonomy
1.17		Non-Adherence to Treatment or Care Plan
1.18	1	Substance Use
1.19	7	Uncooperative Behavior
1.20	1	Vulnerable Person
1.21	6	Family Issue
1.22		Discrimination Concern
1.23		Coercion or Exploitation Concern
1.24		Age Appropriate Participation of Adolescent/Child
1.25	1	Religious, Cultural, or Ethnic Belief/Tradition
1.99		Other
2.00		SUBSTITUTE DECISION-MAKING
2.01		Determine Appropriate Decision-Maker
2.02		Patient Wishes Unclear or Unknown
2.03	3	Extent of Decision-Maker Power
2.04	7	Concern About Decision-Maker Choices
2.05		Remove or Replace Decision-Maker
2.06		Lack of a Decision-Maker or Unbefriended Patient
2.07	1	Guardianship or State/Federal Agency Issue
2.08	4	EMTALA, CAPTA, or Other Legally Required Care
2.09	7	Proxy Decision-Making for a Minor
2.10		Assent of Patient
2.11		Involuntary Treatment
2.12		Emergency Consent
2.13		Create, Change, Void Advance Directive
2.14		Advance Care Planning Process
2.15		Interpretation or Applicability of Advance Directive
2.16		Advance Directive - Patient Wishes not Followed
3.00		END-OF-LIFE
3.01	3	Resuscitation for Full Arrest
3.02		Resuscitation Pre-Arrest Emergency/for Procedure
3.03	6	Withhold or Withdraw Life-Sustaining Treatment
3.04	1	Artificial Nutrition or Hydration
3.05		Palliative Care/Symptom Management
3.06		Hospice
3.07		Palliative Sedation
3.08		Assisted Suicide/Physician Aid in Dying
3.09		Euthanasia
3.10	8	Futility/Inappropriate or Nonbeneficial Treatment
3.11		Organ and Tissue Donation or Receipt
4.00		PROFESSIONALISM
4.01	6	Care Coordination
4.02		Confidentiality/Privacy/HIPAA
4.03		Information Disclosure/Request Not to Disclose
4.04		Abuse, Neglect, or Mandatory Reporting
4.05	17	Moral Distress
4.06		Conscientious Objection
4.07		Paternalism or Moral Bias
4.08		Conflict of Interest
4.09		Preferential Treatment
4.10	1	Inappropriate or Impaired Behavior or Actions
4.11		Treatment of Self or Family Members
4.12		Training or Education Issue
4.13		Medical Error or Adverse Event
4.14		Refusal to Accept or Treat New Patient
4.15		Dismiss Patient from Practice
4.16	1	Potential Harm to Others or 3rd Party Notification
4.17	3	Safety or Security
4.18		Advocacy, Social Responsibility, or Stewardship
4.19	2	Legality or Permissibility of Action
5.00		REPRODUCTION
5.01		Sexuality or Sexual Health
5.02		Contraception
5.03	1	Pregnancy or Prenatal Care
5.04		Birth or Mode of Delivery
5.05	1	Fetal Testing or Treatment
5.06		Maternal-Fetal Conflict
5.07		Termination of Pregnancy
5.08		Sterilization
5.09		Surrogacy or Gestational Carrier Issue
5.10		Custody Issue
5.11		Gamete Donation or Retrieval
5.12		Assisted Fertility or Reproductive Technology
5.13		Embryo Research, Adoption, or Destruction
5.14		PVS or Post-Mortem Pregnancy
5.15		Gender Issue
6.00		DEATH AND POST-MORTEM
6.01	3	Brain Death
6.02		Autopsy
6.03		Visitation or Location of Body After Death
6.04		Participation in Learning Exercise
6.05		Anatomical Donation
6.06		Release of Body/Disposition of Remains
6.07		Coroner/Medical Examiner/Other Gov't Service
6.08		Bereavement Counseling
6.09		Memorialization (hair, footprints, photos, etc.)
7.00		RESOURCE ALLOCATION
7.01		Cost
7.02		Availability
7.03		Staffing or Expertise
7.04		Insurance
7.05	1	Eligibility or Access
7.06		Emergency Prioritization
7.07		Medical Tourism
7.08		Bribery or Corruption
7.09		Human Rights
8.00		RESEARCH
8.01		Clinical Study Design
8.02		Clinical Study Conduct
8.03		Independent or Institutional Review
8.04		Therapeutic Misconception
8.05		Biobanking or Tissue Sampling
8.06		Funding or Compensation
8.07		Compassionate or Emergency Use
8.08		Device or Drug Development or Approval
8.09		Authorship, Presentation, or Publication Issue
8.10		Intellectual Property or Commercialization Issue
9.00		ORGANIZATIONAL ETHICS
9.01	4	Organizational Policy
9.02		Institutional Mission and Goals
9.03		Structure and Hierarchy
9.04		Organizational Climate
9.05		Procedural Fairness or Justice Issue
9.06		Risk Management
9.07		Financial Management
9.08		Human Resources
9.09		Public Relations, Marketing, or Social Media
9.10		Industry or Insurance Relationships
9.11		Union or Labor Relationships
9.12		Data Collection and Use
9.13		Image, Recording, or Film Management
9.14		Health Information Management (HIM)

Figure 4A. Reasons for ethics consults in the NICU prior to initiation of ethics rounds.

persist or increase across the health system. By focusing rounds in such a manner, we can provide more thorough education on the theories behind certain rights or policies and we can illustrate the work through real cases we have used the dashboard to identify. The goal in doing so is decreasing the "re-work" phenomenon, wherein very similar situations across an institution get very different treatment based on who ends up handling the issue. By teaching others how to correctly identify the issue and appropriately address it, the consult service can improve the moral climate of the institution. Over time, the use of the database and dashboard allows us to target education to improve it further, always drawing on the close linkage between what is occurring at the bedside and the educational content presented to others.

Education for physician leaders

Physicians have shown strong interest in learning how to identify ethical issues early to decrease delays. For example, education for hospitalists on the intricacies of the state statutes on substitute decision-making and its associated required documentation allows physicians to reduce conflict by asking one or two questions regarding wishes for an agent during intake. The use of actual cases, which at times are

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NICU — Consults: 47 — Codes: 38 — 0.81

Code	No.	Description
1.00		TREATMENT DECISION-MAKING
1.01		Decisional Capacity
1.02		Informed Consent
1.03	6	Goals of Care
1.04	7	Refusal of Recommended Treatment or Testing
1.05	12	Clinical Candidacy or Risk/Benefit Analysis
1.06	2	Communication Issue or Barrier
1.07	2	Mental Health and/or Treatment
1.08	4	Discharge or Alternative Level of Care Issue
1.09		Pain Management
1.10	7	Genetics and Genetic Testing
1.11		Preventative Intervention
1.12	1	Complementary, Integrative, Alternative Medicine
1.13		Body Image, Alteration, or Modification
1.14		Cognitive Enhancement
1.15		Novel, Innovative, or Experimental Intervention
1.16		Freedom or Limit to Personal Autonomy
1.17	1	Non-Adherence to Treatment or Care Plan
1.18	2	Substance Use
1.19	4	Uncooperative Behavior
1.20	1	Vulnerable Person
1.21	3	Family Issue
1.22		Discrimination Concern
1.23	1	Coercion or Exploitation Concern
1.24		Age Appropriate Participation of Adolescent/Child
1.25		Religious, Cultural, or Ethnic Belief/Tradition
1.99		Other
2.00		SUBSTITUTE DECISION-MAKING
2.01	2	Determine Appropriate Decision-Maker
2.02	1	Patient Wishes Unclear or Unknown
2.03	4	Extent of Decision-Maker Power
2.04	12	Concern About Decision-Maker Choices
2.05	1	Remove or Replace Decision-Maker
2.06		Lack of a Decision-Maker or Unbefriended Patient
2.07		Guardianship or State/Federal Agency Issue
2.08	2	EMTALA, CAPTA, or Other Legally Required Care
2.09	6	Proxy Decision-Making for a Minor
2.10		Assent of Patient
2.11		Involuntary Treatment
2.12		Emergency Consent
2.13	1	Create, Change, Void Advance Directive
2.14	1	Advance Care Planning Process
2.15		Interpretation or Applicability of Advance Directive
2.16		Advance Directive - Patient Wishes not Followed

Code	No.	Description
3.00	1	END-OF-LIFE
3.01		Resuscitation for Full Arrest
3.02		Resuscitation Pre-Arrest Emergency/for Procedure
3.03	8	Withhold or Withdraw Life-Sustaining Treatment
3.04	1	Artificial Nutrition or Hydration
3.05		Palliative Care/Symptom Management
3.06	1	Hospice
3.07		Palliative Sedation
3.08		Assisted Suicide/Physician Aid in Dying
3.09	1	Euthanasia
3.10	7	Futility/Inappropriate or Nonbeneficial Treatment
3.11		Organ and Tissue Donation or Receipt
4.00		PROFESSIONALISM
4.01	5	Care Coordination
4.02		Confidentiality/Privacy/HIPAA
4.03		Information Disclosure/Request Not to Disclose
4.04		Abuse, Neglect, or Mandatory Reporting
4.05	8	Moral Distress
4.06		Conscientious Objection
4.07	1	Paternalism or Moral Bias
4.08		Conflict of Interest
4.09		Preferential Treatment
4.10		Inappropriate or Impaired Behavior or Actions
4.11		Treatment of Self or Family Members
4.12		Training or Education Issue
4.13	1	Medical Error or Adverse Event
4.14		Refusal to Accept or Treat New Patient
4.15		Dismiss Patient from Practice
4.16		Potential Harm to Others or 3rd Party Notification
4.17	5	Safety or Security
4.18		Advocacy, Social Responsibility, or Stewardship
4.19	2	Legality or Permissibility of Action
5.00		REPRODUCTION
5.01		Sexuality or Sexual Health
5.02		Contraception
5.03		Pregnancy or Prenatal Care
5.04	1	Birth or Mode of Delivery
5.05	1	Fetal Testing or Treatment
5.06		Maternal-Fetal Conflict
5.07		Termination of Pregnancy
5.08		Sterilization
5.09		Surrogacy or Gestational Carrier Issue
5.10		Custody Issue
5.11		Gamete Donation or Retrieval
5.12		Assisted Fertility or Reproductive Technology
5.13		Embryo Research, Adoption, or Destruction
5.14		PVS or Post-Mortem Pregnancy
5.15		Gender Issue

Code	No.	Description
6.00		DEATH AND POST-MORTEM
6.01		Brain Death
6.02		Autopsy
6.03		Visitation or Location of Body After Death
6.04		Participation in Learning Exercise
6.05		Anatomical Donation
6.06		Release of Body/Disposition of Remains
6.07		Coroner/Medical Examiner/Other Gov't Service
6.08		Bereavement Counseling
6.09		Memorialization (hair, footprints, photos, etc.)
7.00		RESOURCE ALLOCATION
7.01		Cost
7.02		Availability
7.03		Staffing or Expertise
7.04		Insurance
7.05		Eligibility or Access
7.06		Emergency Prioritization
7.07		Medical Tourism
7.08		Bribery or Corruption
7.09		Human Rights
8.00		RESEARCH
8.01		Clinical Study Design
8.02		Clinical Study Conduct
8.03		Independent or Institutional Review
8.04		Therapeutic Misconception
8.05		Biobanking or Tissue Sampling
8.06		Funding or Compensation
8.07		Compassionate or Emergency Use
8.08		Device or Drug Development or Approval
8.09		Authorship, Presentation, or Publication Issue
8.10		Intellectual Property or Commercialization Issue
9.00		ORGANIZATIONAL ETHICS
9.01	3	Organizational Policy
9.02		Institutional Mission and Goals
9.03		Structure and Hierarchy
9.04		Organizational Climate
9.05		Procedural Fairness or Justice Issue
9.06		Risk Management
9.07		Financial Management
9.08		Human Resources
9.09		Public Relations, Marketing, or Social Media
9.10		Industry or Insurance Relationships
9.11		Union or Labor Relationships
9.12		Data Collection and Use
9.13		Image, Recording, or Film Management
9.14		Health Information Management (HIM)

Figure 4B. Reasons for ethics consults in the NICU post initiation of ethics rounds.

messy or present unique barriers, helps concretize the importance of asking these types of questions. Figure 5 illustrates that, on average, ethics consults become more complex the later the consult is requested in the patient's hospitalization. Disseminating such knowledge among physicians and physician groups during team meetings improves their understanding of causes and effects, improves patient care, and expedites issue resolution. Among our intensive care units (ICUs), we have found that units that consult us more often (those that have a higher consult-to-bed ratio) have a lower average complexity than units that consult us less frequently.[62]

Ethics trainees/fellows

A critical element in any clinical ethicist's education is progressing from analyzing an abstract *concept* to addressing a contextualized *problem*. Figure 6 shows the 30 most-used codes among our dataset. This list forms a roadmap of the frequency with which issues are present in a given hospital, set of hospitals, or health system. In this example, these top 30 issues (in a myriad of permutations) account for over 80% of the issues that present to the service. This allows the ethics program to focus mentoring and educational

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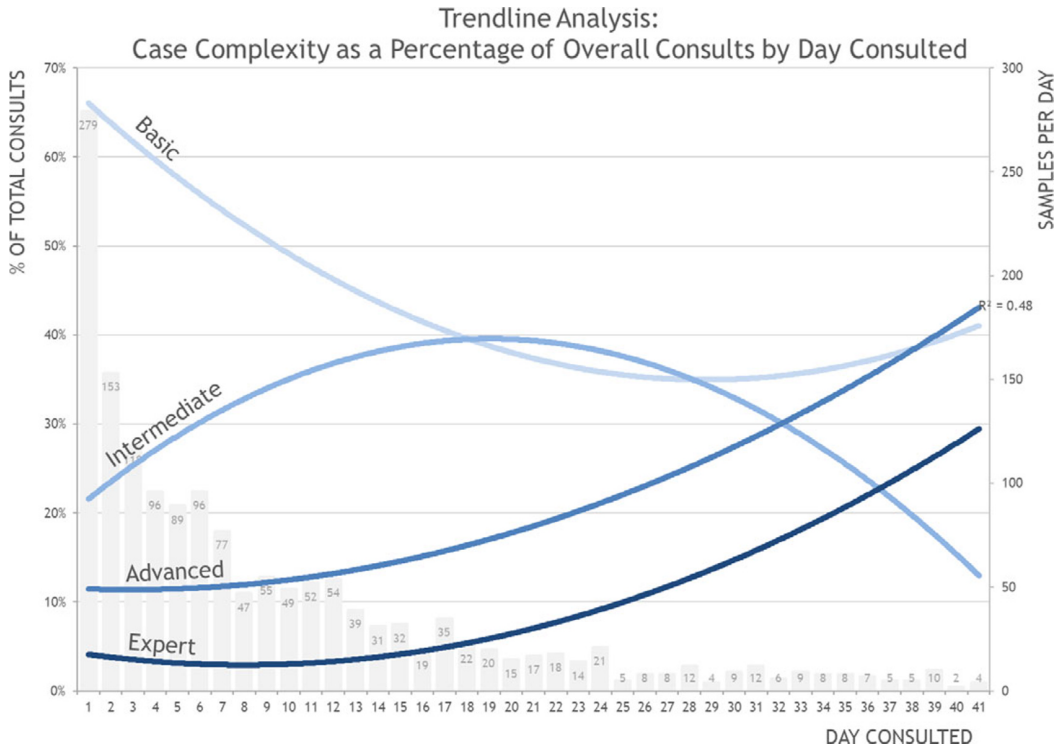


Figure 5. Changes in averages of case complexity by day consulted.

efforts on the knowledge and skills the trainee will need in order to address the issues that will be most commonly seen in practice.

It also allows the program to track which issues the trainee has seen and review the recommendations for accuracy or to engage in discussion why the learner did or did not do X. It also allows fellow program members to intentionally accompany a trainee on a consult where the issue is more rare or complex, requiring some historical knowledge of resources that are not utilized in a typical consultation.

Consider the potential ethical questions involved with "Determine Appropriate Decision-Maker," number five on the list in Figure 6, one of the most frequently seen issues. There are many possibilities for the form a consult can take, but which are most important to teach? For example, "Decisional Capacity" is a concept, whereas "Decisional Capacity" and "Refusal of Recommended Treatment or Testing" is a *problem*: a patient is refusing and there is a question about the patient's capacity. If we add to those two issues, "Substance use" we have contextualized discrete abstractions in relation to other concepts.

It is possible to further investigate the permutations that occur most frequently, as shown in Figure 7. Cases involving "Determining the Appropriate Decision-Maker" and "Interpretation of Advance Directive" are commonly combined with questions about advance directives not being honored, the legal permissibility of action, and the withholding or withdrawal of treatment. These data provide an empirical basis for even more specific educational focus, for example, on the laws, practices, and ethical principles surrounding the respective authority of surrogate decision-makers and advance directives when it comes to withholding or withdrawing life-sustaining treatment.

Exploring issues in relation to the frequency of the permutations in which they present prepares students for the complexity of ethics consultation in practice. In addition to generating lists of related issues, we can display the frequency of respective permutations as well. Examples of case permutations involving "Freedom or limits to personal autonomy" are shown in Figure 8.

Notably, of the 58 cases shown, the most common pairing with "Freedom or limit to personal autonomy" is "Family issue." This generally means an intra-family issue and tells us the most common

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Rank	Description	%
1	Clinical Candidacy or Risk/Benefit Analysis	7.0%
2	Uncooperative Behavior	5.9%
3	Concern About Decision-Maker Choices	5.5%
4	Refusal of Recommended Treatment or Testing	5.3%
5	Determine Appropriate Decision-Maker	4.4%
6	Discharge or Alternative Level of Care Issue	3.9%
7	Goals of Care	3.8%
8	Family Issue	3.6%
9	Futility/Inappropriate or Nonbeneficial Treatment	3.6%
10	Safety or Security	3.5%
11	Freedom or Limit to Personal Autonomy	3.2%
12	Moral Distress	2.5%
13	Mental Health and/or Treatment	2.5%
14	Care Coordination	2.4%
15	Organizational Policy	2.3%
16	Withhold or Withdraw Life-Sustaining Treatment	2.2%
17	Extent of Decision-Maker Power	2.1%
18	Decisional Capacity	2.0%
19	Patient Wishes Unclear or Unknown	1.8%
20	Communication Issue or Barrier	1.7%
21	Legality or Permissibility of Action	1.7%
22	Interpretation or Applicability of Advance Directive	1.4%
23	Guardianship or State/Federal Agency Issue	1.4%
24	Lack of a Decision-Maker or Unrepresented Patient	1.4%
25	Vulnerable Person	1.2%
26	Hospice	1.2%
27	Pain Management	1.2%
28	Informed Consent	1.2%
29	Advance Care Planning Process	1.1%
30	Eligibility or Access	1.0%
		81.9%

Figure 6. Top 30 issues.

concern involving limits to a patient's freedom or personal autonomy for which consults are sought arise not from a physician's actions, but from the actions of the patient's own family members. Investigating further, we find that of the 14 cases involving family issues, six involved hospice, as shown in Figure 9.

The ethicist/trainee can then look up these cases and compare and contrast the accompanying case narratives of all cases coded with that triad to better understand the range of presentation seen at the bedside. Three of the narratives of the hospice cases are as follows.

Case 1

Codes: values, patient-family, basic.

Ethics was consulted regarding 61-year-old female patient with metastatic rectal cancer who accepted hospice, but her family wants surgical options and for the patient to remain in the hospital. Ethicist followed up with the patient, who asked for assistance in helping her family accept her decision. She explained it was very important to her to scatter her mother's ashes on the waterfront near the family home

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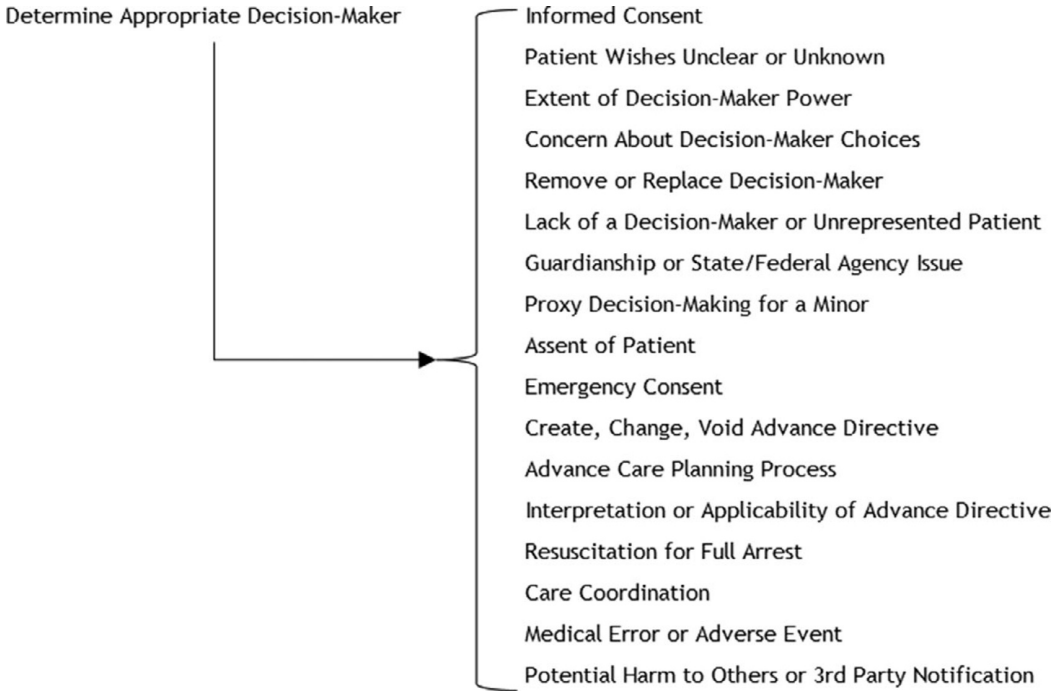


Figure 7. Common permutations of issues involving Determine Appropriate Decision-Maker.

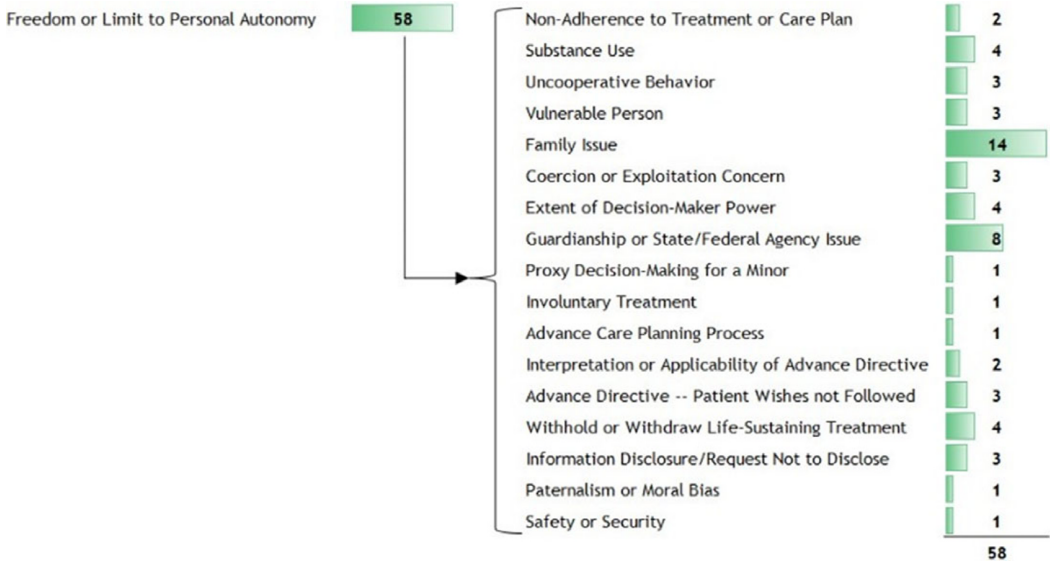


Figure 8. Investigating permutations of issues involving Freedom or Limit to Personal Autonomy.

before she died. Ethicist then met with the patient and family and helped to create space for the patient to share her feelings about her choice. The ethicist explained the family's role in decision-making would be to put themselves in her shoes and carry out her wishes—which may differ from theirs. After further discussion, family accepted patient's wish to transition to home hospice.

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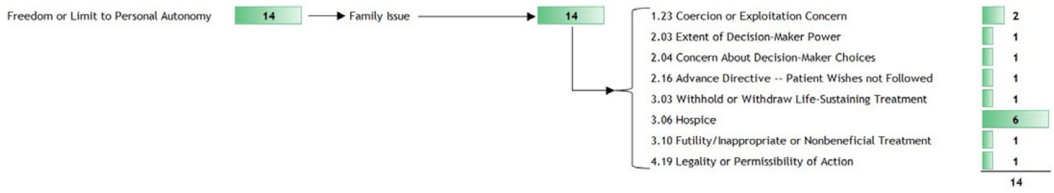


Figure 9. Investigating permutations of issues involving Freedom or Limit to Personal Autonomy and Family Issues.

Case 2
Codes: values, patient-family, intermediate.
Ethics was consulted about an 80-year-old male patient who wanted hospice care at home after a long battle with cancer, now further metastasized. While drowsy and slipping in and out of consciousness, the patient was fully capacitated. Despite making his wishes clear, his wife told the medical team she had the healthcare Power of Attorney (POA) and would be making the decisions. She wanted further curative therapy, saying he would too if he wasn't so worn down. Through discussions it became clear the wife feared taking him home, worrying she could not manage his care. She insisted he go to a facility, but he did not want to; he wanted to die at home, not surrounded by strangers. Ethicist facilitated discussions with wife, explaining that as it was the patient's home too, she could not refuse him re-entry. While still fearful of being overwhelmed, wife agreed to work with the team. Focus then turned to resolving logistical challenges and getting the patient home with as much support for the couple as could be arranged.

Case 3
Codes: conflict, patient-family-team, advanced.
Ethics was consulted for a concern that the decisions of a 75-year-old male patient were not being respected by the patient's large family. Per the nursing report, the patient had capacity and had explained to his family that he did not want further curative options; he wanted to focus on his comfort. The family would agree with him in private, but when in the presence of the medical team they would talk over him, insisting on more treatment options and demanding a variety of consults. Privately, the patient shared his fear that he had no choice in the matter. The nursing team became very distressed that the wishes of this patient were being countermanded. Ethics met with the patient, who expressed his desire for comfort care but questioned if it was worth upsetting his family. Ethicist met with the team to organize a meeting in which the patient's voice remained front and center. Family became very upset and challenged the patient's capacity to choose hospice. Ethicist and team explained that capacity was a clinical determination, and the authority to decide rested with the patient. In the face of this conflict, the patient became more withdrawn and, according to the nursing team, fearful of speaking up. Family became hostile towards the team, and stymied efforts to arrange discharge home with hospice, requiring further work by ethicist. Several more meetings were required to make suitable arrangements.

The system allows more senior ethicists to walk clinical ethics trainees or fellows through sets of cases with similar features, linking the abstract theory or mid-level principles of traditional bioethics education to the messy reality of clinical practice; of what occurred in the case, what is important, and why? How should those facts affect the recommendation? Rather than composite cases, students are able to review actual cases in the full range of variation and uniqueness that a service has documented. This tight linkage between the service's consult history and the education of students and trainees provides excellent preparation for the varied practice encountered when doing this work.

Principles and applications for ourselves and others

Two final uses of the system bear mention. First, some authors have pointed out that the traditional approach has obscured the conceptual discomfiture that may occur between principles and their application.[63] Moving from high-level to mid-level principles, or from any abstractions to practice

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involves interpretations that are often not (if ever) value-free, and sometimes even mistaken. Authors Karel-Bart Ceile and John Paris argue that a misunderstanding of Respect for Persons has resulted in "the ethical obligation shift[ing] to the one providing "proxy" consent."[64] The high rates of "Family Issue" in Figures 8 and 9 show that what theory describes as a "shift" is often in practice a tension; patients disagree with their surrogates in ethically important ways.

How a clinical ethicist looks at a case affects what one thinks is important; if one looks at issues from the vantagepoint of theory alone, one may miss ethically important perspectives. Our team routinely "calibrates" with one another to broaden the lenses we each bring to our work. The shared common language ACECS codes offer allows ethicists to compare notes with one another, checking self-reflection and ethical justification, as well as one's colleagues' thinking—often expanding it for all. It is not uncommon that the ethicist coding the case will initially code it differently than other ethicist colleagues who are only hearing the story. This allows for a more robust discussion, with the consulting ethicist identifying and bringing forward more important details, while colleagues can bring forward more options based on differing experiential backgrounds.

This sort of calibration enhances the ability of the consult service to be more morally sensitive to different perspectives and interpretations while also being more consistent in treating like cases similarly and improving inter-rater reliability. While the service strives for high degree of inter-rater reliability, it also recognizes the experience of each ethicist may be different given the level of experience with a particular type of consult (more experience with complex cases expands the knowledge base of available options). Similarly, the concerns put forward may be different based on past relationships with the stakeholders. For example, a physician who has worked extensively with one ethicist may be presented with moral distress, such as "I've tried everything and they just won't work with us!" while a different ethicist may elicit only "the family is struggling to decide on next steps." The second scenario may (or may not) focus as much on the moral distress of the team if a resolution quickly occurs.

Conclusion

Whereas bioethics education traditionally abstracts from individual cases to general lenses or schools of thought, ACECS and the visual analytics dashboard expose students and trainees to the complexity that occurs at the bedside. This approach allows learners to develop greater facility in critically thinking through the miasma of value considerations and interpersonal interactions and provides a framework for categorizing and understanding the issues involved. If a code triad does not seem quite right, the learner can explore other cases with that triad; are there salient difference between the cases? And if so, what are they? And for practicing ethicists, dialogue with colleagues allows one to challenge traditional ways of thinking and look at situations anew.

Beyond the practicality and effectiveness of this approach, there is an ethical motivation to tether bioethics education more closely to what occurs at the bedside. Drawing directly from an aggregate of real cases is not just epistemically advantageous, but ethically preferable.[65] The moral authority of experience is usually understood on the level of the individual; a person may have an epistemic advantage by virtue of experience.[66] Collections of experience can carry a similar weight. In a field that experiences rapidly changing norms, the close linkage between what is experienced at the bedside and what is taught lessens the chance that edified knowledge loses the epistemic validity on which it is premised.

Specifically with regard to the education of clinical ethicists, a survey approach to the subject matter is not sufficient to engender a deep understanding of the issues that arise at the bedside. On this point Paul Root Wolpe has argued that:

> It is a disservice to students, I believe, to offer a doctorate that does not provide them with the expertise to confront the serious and complex problems that bioethics offers. Disciplinary expertise is not primarily information about bioethical issues, or education about the myriad ways others approach bioethical problems; both are valuable, and both are lifelong responsibilities of a serious scholar. Rather, as one embarks on a disciplinary apprenticeship, the responsibility of the mentor is

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to transmit methodological sophistication and the guild knowledge that characterizes any mature discipline.[67]

The system presented here is, we propose, one way to advance towards that goal. Others may find different typologies that better fit their particular circumstances and different ways to make data meaningful and accessible. We hope the information presented here will be of use to others doing this work and lead to further improvements in bioethics education.

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