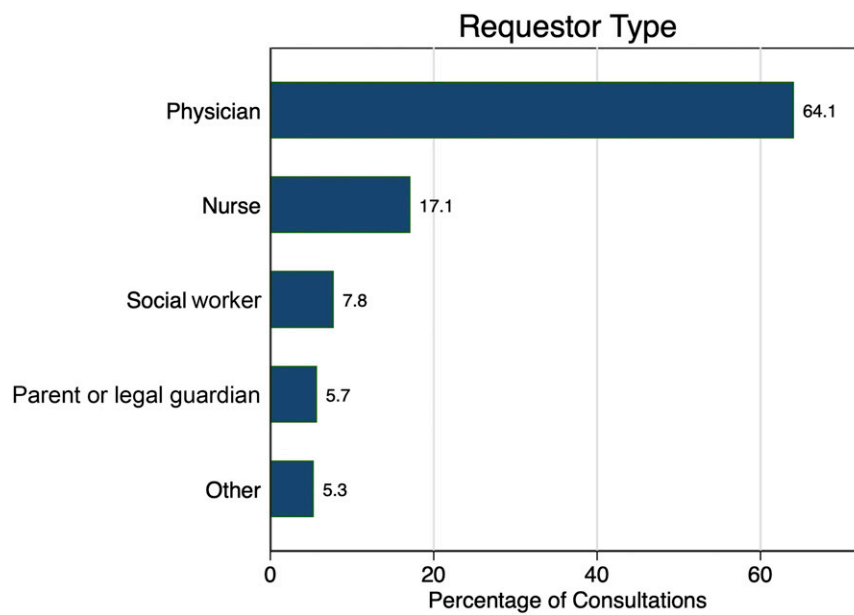


Supplemental Information



SUPPLEMENTAL FIGURE 5

Percentage of 245 ethics consultations from 2013 to 2018 by requestor type.

SUPPLEMENTAL TABLE 3 Core Problematic Issues

Category	Definition	Case Example
Adherence issue or refusal of treatment	Cases related to adherence to or refusal of recommended treatment by patients or parents.	Adolescent patient's inconsistent adherence to medication plan and other therapies raises questions about listing for transplant.
Confidentiality	Cases that raise questions about confidentiality of patient or parent information.	Patient's mother does not want to disclose patient's newly discovered HIV-positive status to patient's father.
Consent or assent	Cases related to informed consent or assent, including issues related to consent for innovative treatment.	Patient's parents retain parental rights but patient is in foster care. Do parents need to consent to treatment?
Decision-making/surrogate question/capacity	Cases related to patient or parent decision-making, including questions about identifying the appropriate surrogate decision-maker as well as questions about capacity to make medical decisions.	Adult patient with anorexia is refusing feeds: team is questioning her capacity to refuse treatment. She has not named a surrogate decision-maker.
Determination of brain death	Cases related to the diagnosis of death by neurologic criteria.	Mother of patient who has met criteria for determination of death by neurologic criteria is refusing withdrawal of technology.
Disposition or transition	Cases that raise issues regarding difficult discharge or disposition, or transition to adult care settings.	Parents wish to take their medically complex, technology-dependent child home, but home nursing is not available in their area. Question of safety of discharge versus wishes of the family.
Intensity of treatment or treatment limitation	Cases related to the escalation or de-escalation of treatment.	Parents of 10-y-old boy with incurable metastatic cancer want "everything done" to prolong his life. Some staff feel like he is suffering and that continued invasive and painful treatments are unethical.
Moral distress	Cases in which staff have identified feelings of moral distress.	Any consult in which staff are distressed about not being able to do what they perceive to be the right thing.
Organ donation	Cases related to organ donation, including questions related to donation after circulatory death.	Any consult involving organ donation.
Patient safety	Cases related to patient safety, including managing difficult patient behaviors and potential use of restraints.	Patient with severe mental illness requires mechanical restraints for all care to protect himself and staff from harm.
Policy issue	Cases that raise questions about a particular hospital policy.	An outpatient medical team wants to "adopt a family" for the holidays from their clinic population.
Potential medical neglect	Cases that include considerations of medical neglect or abuse or question the involvement of child protective services.	Parents of a patient with renal failure insist on using alternative therapies with no known medical benefit.
Religious objection	Cases in which a patient or parent expresses an objection to a treatment plan based on a religious conviction.	Parents who are Jehovah's witnesses are refusing blood transfusion for their daughter.
Requests for care outside the standard	Cases in which a patient or parent requests a treatment or intervention that is not part of the standard of care.	Parents request the use of an alternative treatment that they read about on the Internet.
Therapeutic relationships and professional boundaries	Cases related to professional boundaries including topics such as gift giving and receiving, social media, responding to patient deaths.	A nurse in the NICU wishes to adopt one of her patients who is in foster care.
Withholding or withdrawal of life-sustaining treatment	Cases related to the noninitiation or withdrawal of life-sustaining technologies such as mechanical ventilation, ECMO, VAD, or artificially routed nutrition and hydration.	Adolescent patient with a VAD, who is no longer a candidate for heart transplant, now wishes to turn off the VAD.

ECMO, extracorporeal membrane oxygenation; VAD, ventricular assist device.

SUPPLEMENTAL TABLE 4 Pertinent Ethical Considerations

Category	Definition	Case Examples
Autonomy and decision-making	Cases in which the decision-making of a patient or parent is in question, or when there is disagreement or doubt about the ability or legitimacy of decision-making.	Parent of a patient exhibits symptoms of substance abuse that appear to impair his decision-making ability.
Benefits versus burdens of treatment	Cases in which questions arise regarding the potential benefits and harms of a particular treatment plan.	Team wishes to implement an invasive innovative treatment in a patient with an otherwise incurable condition, in which the benefits of the innovative treatment are unknown.
Best interest	Cases in which the ethical analysis hinges on whether a particular course of action is in the best interest of the child.	Any consult in which the consultant needs to weigh the potential benefits and harms of a treatment in question.
Distribution of scarce resources	Cases in which stewardship of resources is the central concern.	Heart transplant team is in conflict regarding transplant listing for a patient whose family has been noncompliant with clinic visits.
Futility	Cases in which "futility" is mentioned as a reason for wishing to discontinue treatment.	Medical team believes that future treatment of a child with devastating neurologic injury is futile.
Preferential treatment or favoritism	Cases in which staff are seen to be providing special treatment to a particular patient or family.	Staff are proposing to hold a baby shower on the unit for the mother of a long-term patient who they have become close to.
Professional boundaries	Cases in which concerns are expressed regarding boundary crossings or violations.	A unit is considering using patient's parent's restaurant to supply staff lunches.
Truth-telling	Cases involving requests to withhold information from patients or other stakeholders.	Parents of a 14-y-old patient recently diagnosed with leukemia do not want the team to use the word "cancer" when speaking with the patient.

SUPPLEMENTAL TABLE 5 Additional Demographic Characteristics of Patients, *N* = 218

Category	<i>n</i> (%)
Language	
English	187 (85.78)
Arabic	9 (4.13)
Spanish	7 (3.21)
Other	6 (2.75)
Chinese	2 (0.92)
French	1 (0.46)
Missing	6 (2.75)
Religion	
Christian: nondenominational	50 (22.91)
Catholic	36 (16.51)
None	26 (11.93)
Muslim	17 (7.80)
Unknown	16 (7.34)
Baptist	9 (4.13)
Roman Catholic	8 (3.67)
Other	8 (3.67)
Jehovah's Witness	7 (3.21)
Jewish	6 (2.75)
Lutheran	5 (2.29)
Hindu	4 (1.83)
Jewish: Hasidic or Orthodox	4 (1.83)
Atheist	2 (0.92)
Episcopal	2 (0.92)
Methodist	2 (0.92)
Pentecostal	2 (0.92)
Protestant	2 (0.92)
Amish	1 (0.46)
Buddhist	1 (0.46)
Christian Scientist	1 (0.46)
Evangelical	1 (0.46)
Greek Orthodox	1 (0.46)
Orthodox	1 (0.46)
Presbyterian	1 (0.46)
Seventh Day Adventist	1 (0.46)
Missing	4 (1.83)