Features

Pediatric Ethics Consultations: Identifying Disparities to Inform Future Practice

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ABSTRACT

The COVID-19 pandemic accentuated the presence of significantly worse health outcomes for racial and ethnic minorities and raised public consciousness around systemic inequity. One area that received little attention was potential inequities in requests for ethics consultation services. Ethics consultants provide support, clarify values and preferences, and offer frameworks for decision making when the best way to proceed is not clear. Requests for ethics consultation can reflect disagreement between the stakeholders involved in a patient's care. Disagreements may be rooted in biases that lead to inequitable approaches to resolve conflict. This institutional review board-approved study explored the association between patients' demographics and requests for pediatric ethics consultation.

We conducted a retrospective review of all inpatient pediatric ethics consultations at an academic medical center for a 13-year period. We compared available patients' demographics for each case with inpatient hospital population demographics over the same period. Using Fisher's exact test or chi-squared analysis as appropriate, we found significant differences in key demographics between these two populations. Patients who were the focus of an ethics consultation were more likely to be Black or African-American (Black), and insured by a government payer (for example, Medicaid) compared to the general inpatient population. Our findings highlighted a need to further explore and attend to potential inequities in the utilization of ethics resources and enhanced our efforts to provide equitable ethics consultation services and proactively consider bias that may contribute to conflict in patient care.

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INTRODUCTION

Over the past several decades, there is evidence that racial and ethnic minority groups in the United States suffer worse health outcomes than those who identify as non-Hispanic White.[1] This has become even more apparent since the COVID-19 pandemic, as certain racial and ethnic groups have been at higher risk of death from COVID-19.[2] These findings prompted a closer examination of healthcare disparities and exploration for the presence of inequities.

Ethics consultation is a service provided to patients, families, surrogates, healthcare professionals, and other involved parties to help resolve uncertainty or conflict regarding value-laden concerns that emerge in healthcare.[3] *Value-laden* is a subjective term that acknowledges the personal nature of strongly held beliefs and preferences. Hospitalized pediatric patients are often exposed to complex medical procedures and face uncertain outcomes, contexts where value-laden decision making is required. Recommended treatments may be highly burdensome in life-or-death circumstances. These types of patient care situations are often associated with clinicians' moral distress. While the presence of moral distress does not indicate an ethical infraction or shortcoming, it often triggers ethics consultation because it can create the perception of a potential ethical challenge.[4] Ethics consultations at our institution are conducted by either an ethics fellow and a trained ethics consultant, or by an ethics consultant who engages other members of the ethics consultation service as appropriate via the small-team model. Challenging cases are presented at multidisciplinary biweekly ethics consultation subcommittee meetings for additional input. Consultants document recommendations in the electronic medical record (EMR) in an ethics consultation note and complete a Consultation Summary Sheet (CSS) for each consultation (see figure 1).

Although the practice of ethics consultation is designed to promote a non-biased approach, in these situations the subjective experience and personal value set of the involved parties opens the possibility of bias in requests for ethics consultation. In addition, although patients and families may request an ethics consultation at our institution, the bulk of requestscome from members of the healthcare team, overwhelmingly physicians and nurses, which may exacerbate the potential for bias.

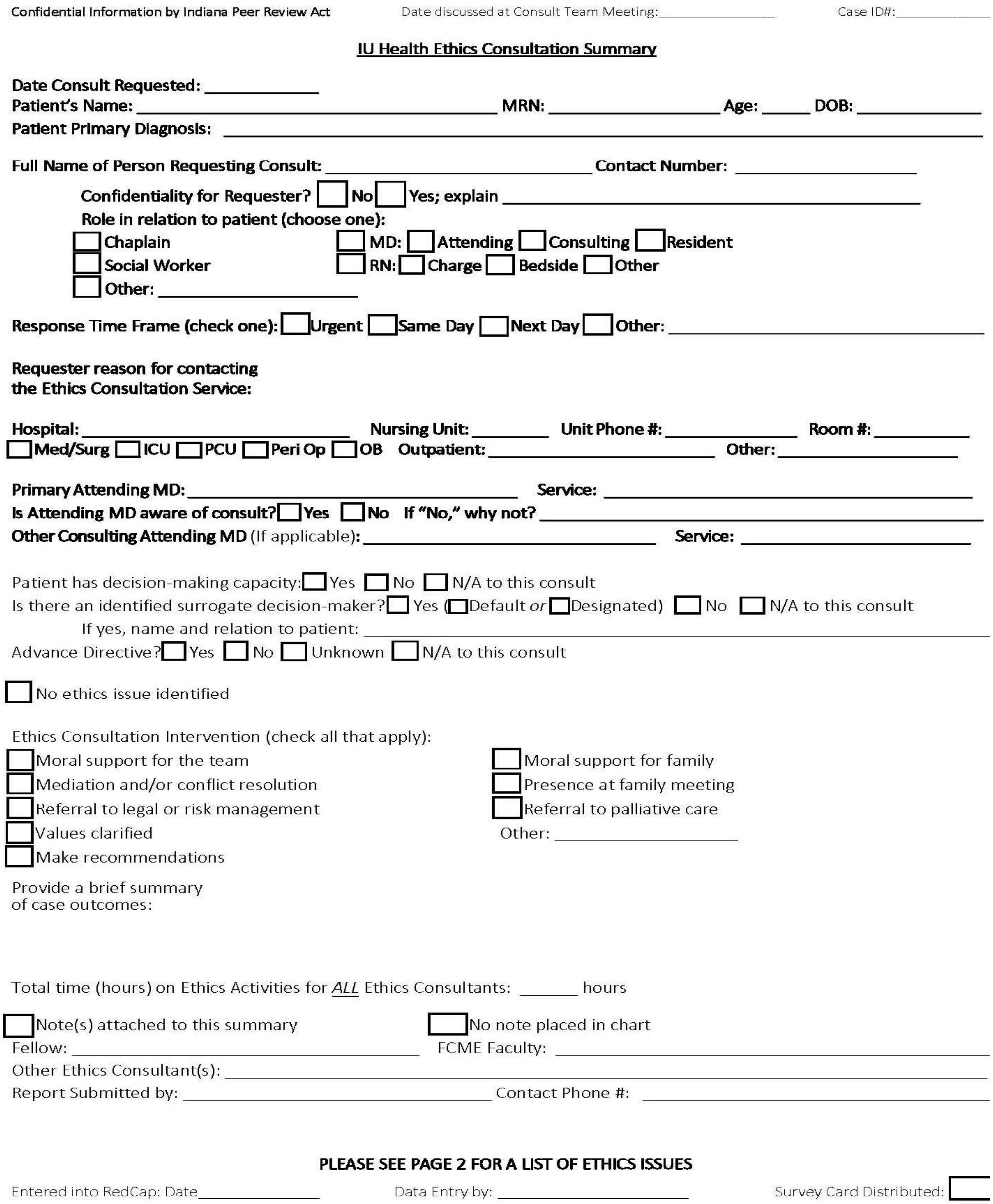
Common ethical issues in pediatric ethics consultations include the best interest of the patient, withholding or withdrawing life-sustaining therapy, providers' moral distress, nonbeneficial treatment (futility), and determinations of code status.[5,6] These also have been identified as circumstances potentially associated with practices that may perpetuate racist or discriminatory behaviors.[7] Healthcare providers may be limited in their ability to see a patient's or family's perspective.[4] Since providers are the most frequent requesters of ethics consultation, it is important to explore whether disparities exist within ethics consultation practice.

Despite the aforementioned renewed commitment to identify and explore healthcare inequities, published research that examines the association of patients' race or ethnicity in pediatric ethics consultation is limited.[6,8] Further, in the ethics consultation studies that have been published, race or ethnicity are not regularly used as study variables, and they are rarely documented.[8] As Wolfe noted, "a bioethicist ignoring race, ethnicity, and gender will fail in moral analysis of these cases."[7] Our examination of our ethics consultation service for evidence of disparities based on race, ethnicity, or other demographic supports our effort to develop quality improvement initiatives to eliminate possible inequities. Failure to recognize disparities may reinforce inequity.

METHODS

We performed a retrospective review of CSSs for all pediatric ethics consults at the quaternary care children's hospital and the Neonatal Intensive Care Units (NICUs) located in the two adult hospitals on our urban academic health center between January of 2008, when our current model of consultation began, and December of 2020. It is noteworthy that historically the CSS did not contain information about patients' or

FIGURE 1. Consultation Summary Sheet



Confidential Information by Indiana Peer Review Act Date discussed at Consult Team Meeting:______________ Case ID#:__________

IU Health Ethics Consultation Summary

Date Consult Requested: ___________
Patient's Name: ____________________________ **MRN:** _____________ **Age:** ____ **DOB:** __________
Patient Primary Diagnosis: ____

Full Name of Person Requesting Consult: ____________________ **Contact Number:** ______________

Confidentiality for Requester? ☐ **No** ☐ **Yes; explain** ______________________________
Role in relation to patient (choose one):
☐ **Chaplain** ☐ **MD:** ☐ **Attending** ☐ **Consulting** ☐ **Resident**
☐ **Social Worker** ☐ **RN:** ☐ **Charge** ☐ **Bedside** ☐ **Other**
☐ **Other:** _______________

Response Time Frame (check one): ☐ **Urgent** ☐ **Same Day** ☐ **Next Day** ☐ **Other:** _______________________

Requester reason for contacting
the Ethics Consultation Service:

Hospital: ___________________ **Nursing Unit:** ______ **Unit Phone #:** __________ **Room #:** _______
☐ **Med/Surg** ☐ **ICU** ☐ **PCU** ☐ **Peri Op** ☐ **OB** **Outpatient:** ______________ **Other:** ___________

Primary Attending MD: ________________________ **Service:** ____________________
Is Attending MD aware of consult? ☐ **Yes** ☐ **No** **If "No," why not?** ________________________
Other Consulting Attending MD (If applicable)**:** ____________________ **Service:** _______________

Patient has decision-making capacity: ☐ Yes ☐ No ☐ N/A to this consult
Is there an identified surrogate decision-maker? ☐ Yes (☐ Default *or* ☐ Designated) ☐ No ☐ N/A to this consult
If yes, name and relation to patient: ______________________________________
Advance Directive? ☐ Yes ☐ No ☐ Unknown ☐ N/A to this consult

☐ No ethics issue identified

Ethics Consultation Intervention (check all that apply):

☐ Moral support for the team
☐ Mediation and/or conflict resolution
☐ Referral to legal or risk management
☐ Values clarified
☐ Make recommendations
☐ Moral support for family
☐ Presence at family meeting
☐ Referral to palliative care
Other: _____________

Provide a brief summary
of case outcomes:

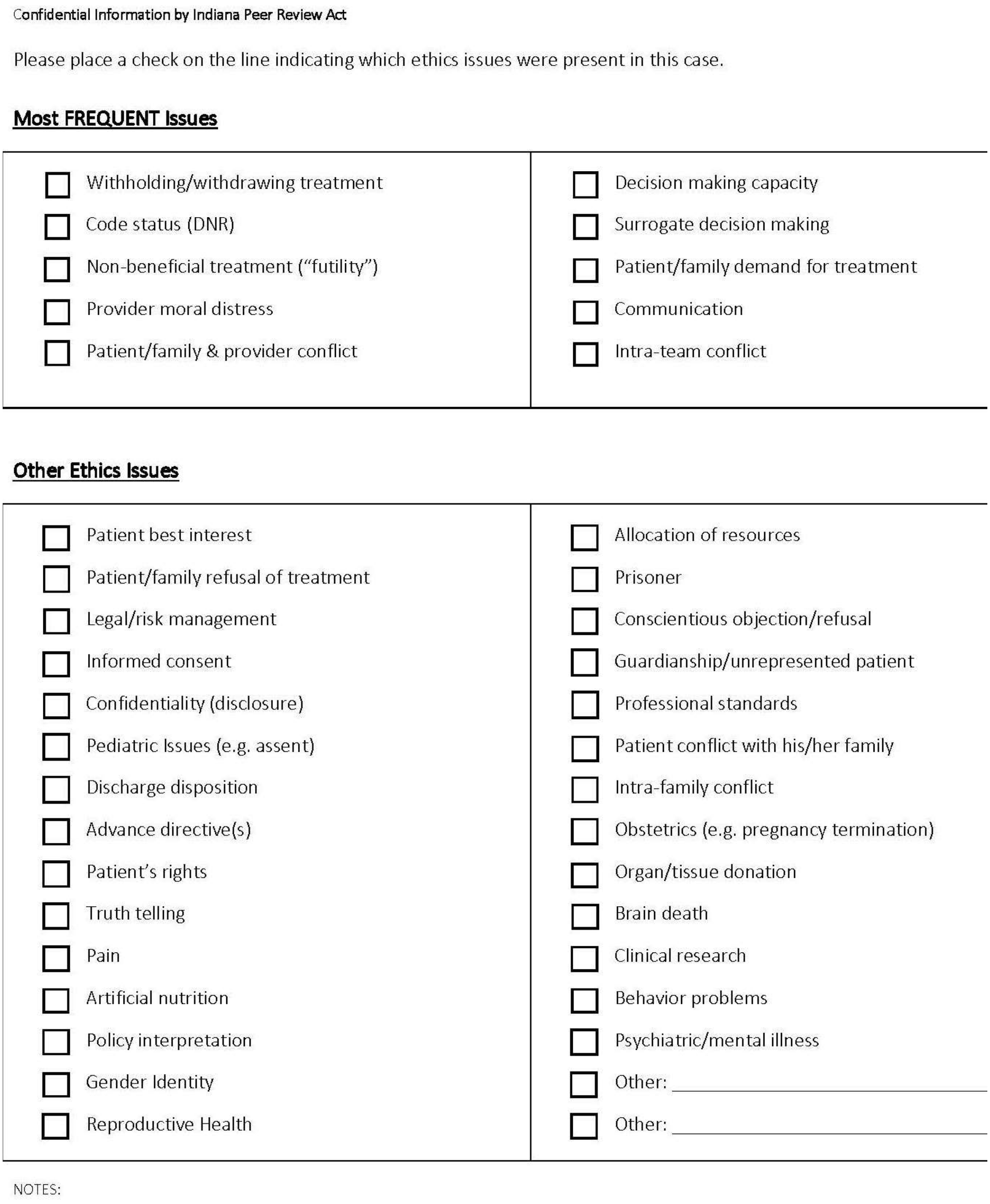
Total time (hours) on Ethics Activities for *ALL* Ethics Consultants: _____ hours

☐ Note(s) attached to this summary ☐ No note placed in chart
Fellow: ________________________ FCME Faculty: ________________________
Other Ethics Consultant(s): ____
Report Submitted by: ____________________ Contact Phone #: ____________________

PLEASE SEE PAGE 2 FOR A LIST OF ETHICS ISSUES

Entered into RedCap: Date__________ Data Entry by: ______________ Survey Card Distributed: ☐

FIGURE 1. Consultation Summary Sheet, *continued*



Confidential Information by Indiana Peer Review Act

Please place a check on the line indicating which ethics issues were present in this case.

Most FREQUENT Issues

- ☐ Withholding/withdrawing treatment
- ☐ Code status (DNR)
- ☐ Non-beneficial treatment (“futility”)
- ☐ Provider moral distress
- ☐ Patient/family & provider conflict
- ☐ Decision making capacity
- ☐ Surrogate decision making
- ☐ Patient/family demand for treatment
- ☐ Communication
- ☐ Intra-team conflict

Other Ethics Issues

- ☐ Patient best interest
- ☐ Patient/family refusal of treatment
- ☐ Legal/risk management
- ☐ Informed consent
- ☐ Confidentiality (disclosure)
- ☐ Pediatric Issues (e.g. assent)
- ☐ Discharge disposition
- ☐ Advance directive(s)
- ☐ Patient’s rights
- ☐ Truth telling
- ☐ Pain
- ☐ Artificial nutrition
- ☐ Policy interpretation
- ☐ Gender Identity
- ☐ Reproductive Health
- ☐ Allocation of resources
- ☐ Prisoner
- ☐ Conscientious objection/refusal
- ☐ Guardianship/unrepresented patient
- ☐ Professional standards
- ☐ Patient conflict with his/her family
- ☐ Intra-family conflict
- ☐ Obstetrics (e.g. pregnancy termination)
- ☐ Organ/tissue donation
- ☐ Brain death
- ☐ Clinical research
- ☐ Behavior problems
- ☐ Psychiatric/mental illness
- ☐ Other: ____________________
- ☐ Other: ____________________

NOTES:

families' race, ethnicity, preferred language, or payer source. We secured data via detailed EMR review. We excluded cases when a patient was 18 years of age or older, the request for consultation was placed in the outpatient setting, or the CSS did not contain enough information to accurately identify the patient for the necessary review of their EMR. There were no other exclusion criteria. Once cases were identified, we reviewed medical records for key demographics including age, sex, race, ethnicity, preferred language, and payer source. The data were then compared to inpatient hospital population demographics for the same time period. We extracted inpatient hospital demographics through the hospital system's electronic data warehouse, filtered by hospital and inpatient encounters. We retrieved data from the last inpatient encounter of each year, to eliminate multiple data points for a single patient in a given calendar year. We analyzed the data using Fisher's exact test or chi-squared analysis, as appropriate. This study was deemed exempt from review by our affiliated institutional review board (IRB).

RESULTS

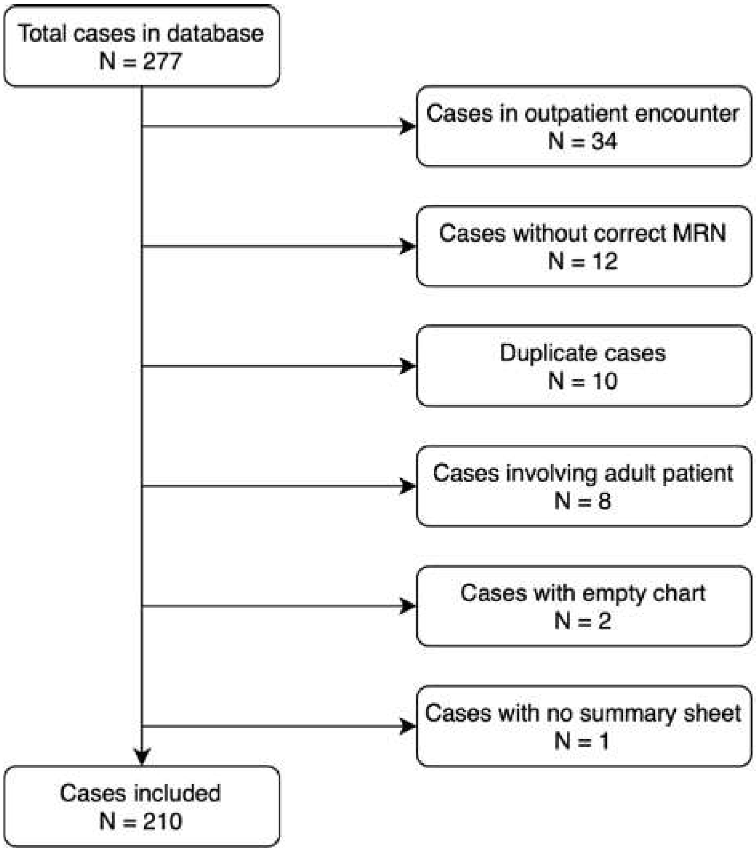
We reviewed 277 CSSs for pediatric ethics consultations during the study time frame. After applying exclusion criteria, 210 pediatric ethics consultations were eligible for review (see figure 2). The demographics of the study population are summarized in table 1.

We collected inpatient hospital demographics for 82,822 patients for the same period for comparison (see table 2).

Nearly half of the patients in the consultation study group were younger than 12 months old at the time of consultation request, and less than 25 percent of patients were 12 years or older. The median ages of our two populations were not significantly different. Males were a slight majority in the inpatient hospital population compared to the study population, but this difference was not statistically significant.

The two populations differed significantly with respect to race. Black patients were overrepresented in our study population ($p < 0.01$). Ethnicity between groups differed significantly, but this was confounded because 92 percent of patients in the consultation population had no specific ethnicity documented. We found no statistically significant difference between groups for preferred language. We found statistical significance in the comparison of insurance coverage types: patients who were insured through government programs (for example, Medicaid) were overrepresented in our study population.

FIGURE 2. Application and breakdown of exclusion criteria of cases within our database



MRN = medical record number

DISCUSSION

There is a paucity of literature that explicitly evaluates potential disparities in requests for ethics consultation. There is some evidence to suggest that the core problematic issues that lead to ethics consultation are associated with the contextual attributes of the situation, which include emotional, relational, and pragmatic attributes.[9] Contextual attributes may be influenced by biases that may, in turn, influence how problematic situations are perceived and addressed. Since ethics consultation is intended to provide a non-biased evaluation of an ethical dilemma and provide frameworks for decision making, demographic disparities between the general inpatient population and patients who receive ethics consultations must be taken seriously. When we compared patients who received ethics consultation with the inpatient hospital population in the study period, we found that Black patients and patients insured by a government payer were disproportionately represented. Each met statistical significance. Our results are consistent with those reported

TABLE 1. Consultation population demographics

Demographic	*n*	%
Patient age		
< 1 year	101	48.1
1-4 years	38	18.1
5-11 years	19	9.0
12-15 years	27	12.9
16-17 years	25	11.9
Patient sex		
Male	105	50.0
Female	105	50.0
Patient race		
White or Caucasian	135	64.3
Black or African-American	59	28.1
Other	7	3.3
Not specified	9	4.3
Patient ethnicity		
Hispanic or Latino	15	7.1
Not Hispanic or Latino	2	1.0
Not specified	193	91.9
Preferred language		
English	195	92.9
Spanish	13	6.2
Other	2	1.0
Insurance coverage*		
Government	149	71.0
Private	47	22.4
Self-pay	14	6.7

* This total is more than 100% due to rounding.

TABLE 2. Demographics of the study population compared with the inpatient hospital population

	Study population		Historical control	
	Median patient age in years	Inter-quartile range	Median patient age in years	Inter-quartile range
	1.17	0.25, 11	3.00	0, 10.00
	$p = 0.78$			
Cohort	*n*	%	***n***	%
Sex				
Male	105	50.0	45,444	54.9
Female	105	50.0	37,367	45.1
Not specified	0	0	11	0.0
	$p = 0.19$			
Race				
White	135	64.3	63,300	76.4
Black	59	28.1	15,139	18.3
Other	7	3.3	1,662	2.0
Not Specified	9	4.3	2,721	3.3
	$p < 0.01$			
Ethnicity				
Hispanic or Latino	15	7.1	7,563	9.1
Not Hispanic	2	1.0	71,345	86.1
Not specified	193	91.9	3,914	4.7
	$p < 0.01$			
Preferred language				
English	195	92.9	78,581	94.9
Spanish	13	6.2	2,806	3.4
Other	2	1.0	656	0.8
Not specified	0	0	779	0.9
	$p = 0.08$			
Insurance coverage				
Government	149	71.0	49,506	59.8
Private	47	22.4	30,310	36.6
Self-pay	14	6.7	3,003	3.6
Not specified	0	0	3	0.0
	$p < 0.01$			

by Olszewski and colleagues.[6] While eligibility rules differ among states, patients covered under government insurance programs typically qualify based on income and family size.[10] Income qualification is often tied to families who face housing instability, food insecurity, and fractured family structures, with limited social support.[11] The communities are often marginalized and feel significant distrust for the medical system.[12] We found a disparity between patients who were the subject of an ethics consultation and those who were not, but we could not determine if the disparity (difference) represented inequity (unjust difference). While disparity does not by default equate to inequity, these findings deserve scrutiny and an evaluation of practices moving forward.

While ethnicity was a key demographic variable identified *a priori* in this study, it is important to note that ethnicity information was often difficult or impossible to locate in the patient chart for our study population; 92 percent of ethnicity data were not recorded in the EMR for these patients at the time of review. Demographic information at our institution is collected by frontline nonclinical staff and recorded via report of the surrogate present on behalf of the child, usually within the first hours of hospitalization. Demographic categorization is not performed by the clinical team. It is unclear if ethnicity was not consistently requested or not well understood by patients and families who were asked for the information. It is also unclear why ethnicity information was more available in the inpatient hospital cohort for comparison. Our findings are not dissimilar to the existing body of literature, with ethnicity rarely, if ever, reported in reviews of ethics consultations. Race was more commonly but inconsistently reported.[13-17]

Our findings are not dissimilar to the existing body of literature, with ethnicity rarely, if ever, reported in reviews of ethics consultations.

Although our analysis found statistical significance between the study population and the hospital population with respect to ethnicity, we cannot draw comparative conclusions from the data, given the proportion of EMRs for our study population that did not include this demographic information.

It is important to explore potential bias in the context of our study results. On one hand, bias in requests for ethics consultation might exist because one party believes the other party's thought process is flawed. For example, in taking care of a child with profound neurocognitive impairment, one may find it morally distressing that a family would like to continue medical therapies despite the significant burden of ongoing treatment, because their expression of hope for recovery runs counter to the potential based on clinical data. Bias can also be based in values and preferences. While clinicians may question the balance of burdens and benefits (in large part informed by value-laden judgments) for the ongoing treatment of a child who is dependent on technology, families may believe that all life has value and feel an obligation to continue support for a child, regardless of the heroic nature of the care. Alternatively, bias may exist because the involved parties are demographically different from each other, which may lead to a subconscious dislike of the other person. This could also be referred to as prejudice.

This reality can complicate well-intentioned efforts to promote proactive ethics, because it may exacerbate the potential that bias informed a request for an ethics consultation. Rather than a request that is the result of the clinical situation, a request may be motivated by bias that contributed to a provider's assumption about how a specific family would navigate a given situation, or the outcome of a family's impending decision. While providers are encouraged to leverage situational awareness to identify impending communication challenges or ethically complex interactions, unchecked bias may cause inappropriate, overly paternalistic, or even punitive mobilization of ethics resources. Another important contextual feature described in the literature that seems to be a particularly high risk for disparity in ethics consultation by team members surrounds the power dynamic between patients and families and providers.[18,19] It is well described that greatly different levels of authority can exacerbate power dynamics.[19] Greatly different levels of authority may compound conscious or subconscious bias toward the mobilization of ethics consultation services by those on the healthcare team. Physicians may be most at risk.

An appreciation for the implications of bias is necessary to this discussion because bias can lead to inequitable approaches to conflict resolution.[20] Among our 210 inpatient ethics consultations, 204 were requested by a member of the healthcare team, three were requested by a patients' parents, and three were not specified. Often, requests for an ethics consultation can signify disagreement or conflict between the patient or their surrogate decision maker and the healthcare team. If the majority of ethics consultations are initiated at the request of the healthcare team, and the definition of ethics consultation is to address value-laden concerns, then the trigger for consultation is most commonly a value-laden concern from one or more members of the healthcare team. It is unclear if families do not share these concerns or, more likely, have no knowledge of their access to the resource of ethics consultation, a shortcoming that must be remedied.

Finally, this discussion must consider potential positive explanations for increased ethics consultation requests for Black and government-insured patients and families. As previously stated, an identified disparity does not necessarily equate to inequity. It is possible that increased ethics consultation requests in underprivileged and marginalized groups is a reflection of altruism in the healthcare team. Historically marginalized groups, victims of systemic racism, and populations that have been deceived and harmed by the healthcare community are at heightened risk of ethical conflict. Clinical ethicists have an opportunity to actively engage in antiracist activities when they name racism as a problem and promote activities to actively address it.[21] Acting as an ally requires and deserves additional attention, with a particular focus on high-quality communication and values clarification. These are skill sets inherent in expert ethics consultation. Whether this framing is described as antiracism, affirmative action, advocacy, or educated insight, all speak to the possibility that increased ethics consultation in certain minority or marginalized populations indicates positive change and proactive ethics consultation.

LIMITATIONS

Even though the primary objective of this study was comparative analysis of the demographics of patients whose care included ethics consultation and the general inpatient hospital population, one of the most significant limitations to our study was the challenge to obtain demographic information. While a patient's sex and age were readily available in the EMR, it was more difficult to ascertain the patients' race, ethnicity, and religious affiliation, as described above.

Additionally, using race or ethnicity to identify patients within cultural groups is imprecise and ignores other culture-defining factors.[22] In most pediatric ethics consultations, given the age or development of patients, much, if not all of the interaction from the ethics consultation team is with their surrogate decision makers, rather than the patients themselves. While most patients share many, if not most, demographics with their respective surrogate decision makers, this is not always the case. Surrogates' demographics are equally if not more important when disparities in providers' requests for ethics consultation are considered, particularly in pediatric ethics consultations. But patients' surrogate decision makers' demographic information was not available from chart review, which precluded useful analysis.

IMPLICATIONS FOR CLINICAL PRACTICE AND FUTURE RESEARCH

Statistically significant differences between patients who were the subject of an ethics consultation and the general inpatient hospital population are likely incomplete representations of potential disparities. A more precise, albeit resource-intense and exceedingly difficult to obtain comparison would be between patients who were the subject of an ethics consultation and either historical matched controls based on diagnosis or the patient population of the inpatient units where the patients received care, for example, the NICU or Pediatric Intensive Care Unit (PICU), since these populations may differ from the overall hospital demographic.

In response to the preliminary results of this investigation and a concurrent reinvigorated commitment to diversity, equity, and inclusion (DEI) at our institution, the ethics consultation service modified the CSS to include additional patient and family demographic information. Using the acronym PEARLS, we now specifically document **p**ayer, **e**thnicity, **a**ge, **r**ace, **l**anguage, and **s**ex.

The EMR was also updated to facilitate collection and awareness of these important data. Keeping good demographic records allows us to review our practice and note any disparities that may exist. Routine retrospective review is crucial to a high-quality ethics consultation service. The intentional collection of these data is also an opportunity to raise consciousness about possible inequity that is based on disparity. If we don't collect or evaluate this information, we don't have a way to identify potential paths forward.

At our institution, information about the availability of ethics consultation is buried in documentation that describes patients' rights and responsibilities. This makes it less likely that patients and parents will learn about their access to this resource. To mitigate the potential bias caused by team members' disproportionate number of requests for ethics consultation, patients and their surrogate decision makers must be informed about the availability of ethics consultation. This project unveiled opportunities for better communication about the availability of the ethics consultation service to all families, particularly in areas of the hospital where ethics consultations are frequently requested. Changes are underway to refresh and relocate information about ethics resources for patients and families, to promote awareness and streamline access.

CONCLUSION

When compared to the pediatric inpatient hospital population at our academic health center, patients whose care included a request for ethics consultation were statistically significantly more likely to be Black and insured by a government payer. The data show disparities between racial groups and groups of varying socioeconomic status, but we cannot conclude definitively that they reflect inequity. To help consultation service teams identify any disparities in practice and enhance efforts to make ethics consultation services as equitable as possible, we can make these data more accessible in the EMR and be intentional about the collection of data.

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