

Postprint

This is an Accepted Manuscript of an article published in [*American Journal of Bioethics*] on 13 May 2015, doi: 10.1080/15265161.2015.1021970.] ; available online at <http://www.tandfonline.com/doi/full/10.1080/15265161.2015.1021970> (paywalled).

Please cite as:

Isaacs D, Kilham H, Kerridge I, Newson A. Rethinking pediatric ethics consultations (Open Peer Commentary), *Am J Bioethics*. 2015 May;15(5):26-8. Published online: 13 May 2015, doi: 10.1080/15265161.2015.1021970.

Rethinking Pediatric Ethics Consultations

Kilham, H., Isaacs, D., Kerridge, I., Newson, A.J. (2015)

Johnson and colleagues (2015) report a retrospective review of the experience of an ethics consultation service at a single, highly specialized children's hospital over an 11-year period. Despite its methodologic limitations, the results of this study are worthy of note. The St. Jude Children's Research Hospital ethics consultation service consulted on a range of complex cases, including the management of conflict between parents and physicians, futility, parental demands, treatment nonadherence, and, less commonly, end-of-life issues. The number of case consultations was small, fewer than five per year, and did not increase over time. The retrospective nature of the study prevented eliciting how often consultations altered treatment or other decisions. No record was kept of clinical staff, parent, or patient perception of the value of the ethics consultation, nor of the frequency or value of informal (curb side) ethics consultations.

The St. Jude ethics consultation process is consistent with "standard" models in the field. An ethics team comprising two to five staff members, including an ethicist, performs the initial ward consultation, which is then discussed with the formal clinical ethics committee of 21 people. Other involved services participate via interdisciplinary meetings. The types of consultation are consistent with many other services, including both formal and informal consultations using a range of methods to assist resolution of cases, including mediation and arbitration.

Despite open access to requesting consultations, including anonymous enquiries, almost all requests came from physicians, often the same ones. Only a few came from nurses and none from parents or patients. Importantly, nurses appeared to be subject to repercussions from physicians if they requested consultations, an important issue that requires further attention but goes beyond the scope of our commentary.

We suggest that the experience of the St. Jude service illustrates both the limitations of ethics consultation and the need to evaluate the importance and impact of an ethics service using metrics other than simply the number of case consultations.

WHAT QUESTIONS ARE PROMPTED BY THE ARTICLE?

Why does the comprehensive St Jude ethics service receive so few consultations, particularly when there must have been hundreds of difficult, ethically charged situations over 11 years? Why do so many of those referrals come from the same physicians? And why do nurses rarely request consultations and parents or patients not at all? Are most physicians so ethically capable that they do not need extra ethics advice? Are physicians concerned they will lose control of decision making? Or do "curb side" ethics consultations provide all the ethical advice needed? As with any single-centre report, the key question is whether the experience at St Jude is generalizable. While St Jude ethics consultations dealt with fewer end-of-life matters than other health care centres (Feudtner and

Nathanson 2014; Orr and Perkin 1994; Streuli et al. 2014), other clinical ethics services also report small numbers of case consultations (Kesselheim, Johnson, and Joffe 2010).

It may be a mistake, however, to regard low rates of consultation as an indicator that a clinical ethics service has “failed.” While the number of consults is one possible measure of success, it is not the only one and perhaps should not even be the first one. Clinical ethics services serve many purposes: contributing to policy development and processes of equitable health care, educating staff, promoting formal debate, fomenting informal discussion, and contributing to the development and maintenance of an open and democratic “ethical culture” within an institution. Case consultation is perhaps the most visible and controversial aspect of an ethics service’s work, but only one marker of its “success.” Simply counting the number of consultations fails to account for the many ways in which ethics services may contribute in health care settings. Importantly, knowing the number of ethics consultations tells us little about what impact case consultation has had on clinical care and how it was perceived by all those involved—outcomes that would seem far more important than the bare number of referrals. To this end, we suggest it is vital that clinical ethics consultation services measure more comprehensively the range of outcomes that may follow consultation, including the response to consultation (we would avoid the term “decision” or “recommendation”) and the opinion of the child, if old enough to express it, and of the family.

INCREASING INVOLVEMENT OF THE CHILD AND FAMILY IN ETHICS CONSULTATION

One notable aspect of the St. Jude study is the lack of requests for consultation from patients or their family and their absence in the formal process. The article also mentions little of the extent to which older children are involved in decision making crucial to their lives. The nature and extent of the role patients and their family should play in ethics consultations are contested. However, it does not seem far-fetched to suggest that patients or their families should have some involvement in almost all pediatric ethics consultations. Like other pediatric services (Gold, Hall, and Gillam 2011), our own experience leaves no doubt of the value of meeting and talking with the child and family, wherever possible. We believe it is good for parents and professionals to talk more with children of all ages about their illness and to involve them in decision-making; there is no *prima facie* reason why this should not include relevant ethical considerations. This is not to say it will always be appropriate to involve a patient or family in every ethics consultation. The level of engagement will inevitably vary according to the nature of the issues involved and the attitudes of the patient and/or family toward participation. It is important, for example, to safeguard the child and family against malicious or otherwise damaging referrals. Additionally, ethics consultation may sometimes need to proceed without the family, such as where child abuse is suspected.

HOW SHOULD PEDIATRIC ETHICS SERVICES PROVIDE ETHICS SUPPORT?

Differences in expectations within families and between parents and physicians and unrealistic expectations are all mentioned by Johnson and colleagues as reasons for consultation. In this case, one must ask whether clinical ethics services are best suited to handling these oft-repeated and major concerns.

We suggest that questions raised by the St. Jude report and by other reviews should prompt a complete rethinking of ethics services, notably consultations. By not asking more frequently for ethics consultation, what are physicians telling us? That consultation is not needed? Not wanted? Not understood? And if not wanted, is this because it is felt to be too cumbersome, too time-consuming, too confronting, or simply unlikely to help? We wonder whether the consultation model employed at St. Jude, widely replicated elsewhere, has major intrinsic faults. While the model is

comprehensive, this may make it inflexible and excessively bureaucratic. It is also “interventionist,” providing not only advice, but mediation and arbitration. By making recommendations and giving a treatment plan, ethics consultation might challenge or be perceived as challenging the authority of the physician in charge. We see some parallels between a physician in charge of a seriously ill child, a captain flying a passenger jet, and a conductor of a symphony orchestra. Each depends on the skilful work of many others, but each must take overall responsibility and will be held accountable. Each scenario involves safeguards for catastrophic events. Although the degree of “hands-on” control in each activity will vary greatly from time to time, there are good reasons for having one person in overall charge. Ethics consultation can undoubtedly assist in the discussion leading up to decision making, and may provide ongoing support to staff and possibly to parents after the decisions are made. But the intimacies of clinical care lie outside the domain of ethics consultation, and best decisions are likely to be made between the physician in charge, the patient, and the family (Gill et al. 2004).

The experience of pediatric ethics consultation reported by Johnson and colleagues provides a reminder of why it should be offered essentially as an advisory service, whether it is a single question answered via a single telephone call or full deliberation by a group with full representation of those required. The primary aim should always be directed to assisting the clinical team work toward the best interests of the patient, by clarifying ethical issues, suggesting options and possibly new perspectives, and using the benefit of previous experiences. The aim is to provide support, but not to mediate, arbitrate, delay, obstruct, or direct clinical management. Ultimate decisions should be left to those most intimately involved: the patient, the family, and the doctor in charge. Outcomes must be recorded and evaluated. Clinical ethics services play multiple roles, including in policy development and education (Gold et al. 2011). While consultation will always be a feature of the activity of ethics committees, it will likely never be a major part of their work, and the impact that it has is likely to be manifest more through education, institutional change, and staff and public engagement than through its contribution to individual patient care.

REFERENCES

1. Feudtner, C., and P. G. Nathanson. 2014. Pediatric palliative care and pediatric medical ethics: Opportunities and challenges. *Pediatrics* 133(suppl. 1): S1–S9.
2. Gill, A. W., P. Saul, and I. Kerridge. 2004. Acute clinical ethics consultation: The practicalities. *Medical Journal of Australia* 181: 204–206.
3. Gold, H., G. Hall, and L. Gillam. 2011. Role and function of a paediatric clinical ethics service: Experience at the Royal Children's Hospital, Melbourne. *Journal of Paediatrics and Child Health* 47: 632–636.
4. Johnson, L. M., C. L. Church, M. Metzger, and J. N. Baker. 2015. Ethics consultation in pediatrics: Long-term experience from a pediatric oncology center. *American Journal of Bioethics* 15(5): 3–17.
5. Kesselheim, J. C., J. Johnson, and S. Joffe. 2010. Ethics consultation in children's hospitals: Results from a study of pediatric clinical ethicists. *Pediatrics* 125: 742–746.
6. Orr, R. D., and R. M. Perkin. 1994. Clinical ethics consultations with children. *Journal of Clinical Ethics* 5: 323–328
7. Streuli, J. C., G. Staubli, M. Pflander-Poletti, R. Baumann-Holzle, and J. Ersch. 2014. Five-year experience of clinical ethics consultation in a pediatric teaching hospital. *European Journal of Pediatrics* 173: 629–636.