Clinical Ethics and Ethics Consultation

Summary: This project explores ethical issues faced by various health care providers and clinical investigators and the ways in which ethics consultants can enhance the ethics of clinical practice and clinical research through education and consultation. Research methods used in this project include both conceptual analysis and survey research.

Section: Ethics and Health Policy

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Background:

The thrust of our scholarship regarding clinical ethics and ethics consultation has aimed at achieving new insights in three areas that we believe have not been well studied previously. First, while, moral philosophers such as Norman Daniels, Dan Brock, and others have provided a strong theoretical foundation for analyzing questions of distributive justice, clinical ethicists have offered little assistance in promoting fair allocation of resources at the bedside. Our scholarship has thus explored how clinical ethicists might apply their efforts to improve resource allocation and bedside rationing.

Second, ethics consultation is increasingly sought in the context of clinical research. A recent requirement for a mechanism to address ethical concerns raised by research for recipients of the NIH Clinical and Translational Science awards has brought substantial attention to research ethics consultation and how it differs from clinical ethics consultation and the work of the institutional review board. The Clinical Center Bioethics Service has been serving NIH researchers and IRBs, in addition to clinicians and patients and families, and thus has a unique perspective to offer to the development of literature on research ethics consultation.

Third, the clinical ethics literature has largely focused on the ethical quandaries faced by physicians. Yet a substantial part of medical care is delivered by other clinical practitioners whose perspectives, patient encounters, and work environments often differ from those of physicians. Toward this end, a large part of the research in this project has involved surveys to explore the attitudes and experiences of clinicians including nurses, social workers, physician assistants, and nurse practitioners.

In addition to these three main areas of scholarship, a number of stand-alone papers address ethics education during medical training and a number of dilemmas in clinical practice.

Theoretical analyses

- **Ethics consultation to promote ethically sound rationing**

Decisions about the allocation and rationing of medical interventions likely occur in all health care systems worldwide. Yet little attention has been paid to the question of what role ethics consultation and ethics committees could or should play in questions of allocation at the hospital level. In light of this, Danis and a post-doctoral fellow, Samia Hurst and a visiting scholar, Daniel Strech argued for the need for ethics consultation in rationing decisions using empirical data about the status quo and the inherent nature of bedside rationing. A review of qualitative and quantitative findings in the published literature reflects a significant need for ethics consultation as expressed directly by doctors. There is additional indirect evidence of such a need as indicated by the occurrence of inconsistent and inequitable rationing decisions. We therefore proposed a four-stage process for establishing and conducting ethics consultation in rationing questions by systematically referring to core elements of procedural justice. We recommended that clinical ethicists be involved in: 1) training, 2) identifying actual scarcity-related problems at clinics, 3) supporting decision-making and 4) evaluation. This process of ethics consultation regarding rationing decisions would facilitate the

achievement of several practical goals: (i) encouragement of an awareness and understanding of ethical problems in bedside rationing, (ii) encouragement of achieving efficiency along with rationing, (iii) reinforcement of consistency in inter- and intra-individual decision-making, (iv) encouragement of explicit reflection and justification of the prioritization criteria taken into consideration, (v) improvement in internal (in-house) and external transparency and (vi) prevention of the misuse of the corresponding consulting structures (Strech 2010).

- **Educating medical students to engage with patients and moral agents**

Doctors and patients ideally work collaboratively to promote patient health. Doctors' efforts to advise patients to adopt a healthful lifestyle can dovetail effectively with patients' health behaviors to improve patients' health status. Often, however, patients do not follow their doctors' recommendations. Medical students and physicians can become frustrated by patient "non-adherence." While doctor-patient communication strategies such as motivational interviewing can be very helpful in addressing the obstacles to patient participation in their medical care, much of medical education falls short of adequately training physicians in these strategies.

When medical students learn to perform a history and physical, they are taught to formulate an assessment and plan for patient care. But students and young clinicians must also learn to elicit, understand, and achieve realistic and meaningful medical goals with their patients. How does a clinician learn what might aptly might be called clinical management? Danis and Caldecott argued that more nuanced education of medical students about the ethics of the doctor-patient relationship that encourages students to appreciate patients as active moral agents could improve how medical students engage with patients and manage their health issues. We suggested that through this insight, ethics education can make an important contribution as medical students learn patient care management (Caldicott 2009).

- **Ethics of complicity for physicians practicing in conflict laden settings**

The clinical ethics literature tends to focus on standard practice settings but some of the most difficult ethical choices encountered by physicians occur outside of this standard setting. One of our post-doctoral fellows, Chiara Lepora, who previously worked with Doctors without Borders, built upon her experience in providing humanitarian aid to analyze one of the most difficult dilemmas encountered in war torn settings: how to deliver medical care in conflict laden situations where torture is occurring. Torture is unethical and usually counter-productive, and prohibited by international and national laws and a number of professional codes. Yet it persists. According to Amnesty International torture is widespread in more than a third of countries. Physicians and other medical professionals are frequently asked to assist with torture.

Medical complicity in torture, like other forms of involvement, is prohibited by international law and codes of professional ethics. However, when the victims of torture are also patients in need of treatment, doctors can find themselves torn. To accede to the requests of the torturers may entail assisting or condoning terrible acts. But to refuse care to someone in medical need may seem like abandoning a patient and thereby fail to exhibit the beneficence expected of physicians.

Lepora and Millum argued that sometimes the right thing for a doctor to do requires what some might view as complicity in torture. Though complicity in a wrongful act is itself prima facie wrong, this judgment may be outweighed by other factors. They proposed several criteria for analyzing how those factors apply to particular cases:1) doctors should assess the consequences of the different options open to them, including for themselves, for the patient, and the possible wider social effects, such as encouraging or discouraging policies that permit torture; 2) doctors should attempt to discern and follow the requests of the patient regarding his or her care, and 3) doctors should weigh the degree to which the act would be complicit in torture (Lepora 2010) .

- **Research Ethics Consultation**

In collaboration with other members of the Clinical Research Ethics Key Function Committee of the CTSAs, Grady explored possible models for research ethics consultation services. First, the group examined how a research ethics consultation service may differ from and complement the role of an Institutional Review Board by offering a definition of 'research ethics consultation' and exploring the potential scope of research ethics consultation services in terms of types of clients served, questions addressed, and assistance provided at various stages of the research process. Then, 3 possible models of the relationship between a research ethics consultation service and an IRB were considered, including issue that may arise and possible conflicts of interest: model 1) the research ethics consultation service and IRB are the same; 2) the research ethics consultation service and the IRB are separate and distinct, and 3) the research ethics consultation service is separate but there is overlap in function and the need for careful delineation of spheres of responsibility (Beskow 2009).

Empirical studies

Under the umbrella of this project, three large surveys have been administered to clinicians to ascertain information about their experience with and response to ethical problems in their work settings. One cross-sectional self-administered mailed survey which was developed while Dr. Connie Ulrich was a fellow in our department was sent to 3,900 NPs and PAs randomly selected from primary care and primary care subspecialties in the United States (adjusted response rate, 50.6%). A second study, also developed during Connie Ulrich's tenure in the department, was a self-administered survey sent in 2004 to 1000 nurses and 2000 social workers in four states in four different census regions of the U.S. (adjusted response rate was 52%). A third study was a cross-sectional mailed survey on random samples of general physicians in Norway, Switzerland, Italy, and the UK, conducted with European colleagues while Dr Samia Hurst was a fellow in the department.

The following analyses, derived from these surveys, have been carried out and published during the last four years.

- **Examining factors associated with ethical stress, moral action, and job satisfaction among nurses, physician assistants, nurse practitioners, nurses and social workers**

Nurses encounter ethical issues in daily practice and are often unprepared and uncomfortable in addressing them. Responses to our survey from nurse respondents in four different census regions of the U.S. were analyzed to determine the prevalence and type of ethical issues they encountered. A total of 422 questionnaires were used in the analysis. The five most frequently occurring and most stressful ethical and patient care issues were protecting patients' rights; autonomy and informed consent to treatment; staffing patterns; advanced care planning; and surrogate decision-making. Other common occurrences were unethical practices of healthcare professionals; breaches of patient confidentiality or right to privacy; and end-of-life decision-making. Younger nurses and those with fewer years of experience encountered ethical issues more frequently and reported higher levels of stress. The frequency of ethical problems also varied by region. The findings suggest that to retain nurses, targeted ethics-related interventions that address caring for an increasingly complex patient population are needed (Ulrich 2010).

As the health care environment becomes increasingly complex, nurses and medical social workers are likely to encounter more difficult ethical issues in patient care while their working environment may be increasingly hard pressed to be supportive. Common complaints among them relate to the perception of limited respect in their work and increasing dissatisfaction with their jobs. However, the link between ethics-related work factors and job satisfaction and intent-to-leave one's job has rarely been studied. In a separate analysis of our national survey of nurses and social workers, we examined how nurses and social workers in the US view the ethical climate in which they work, including the degree of ethics stress they feel, and the adequacy of organizational resources to address their ethical concerns. Controlling for socio-demographics, we examined the extent to which these factors affect nurses and social workers' job satisfaction and their interest in leaving their current position. Respondents reported feeling powerless (32.5%) and overwhelmed (34.7%) with ethical issues in the workplace and frustration (52.8%) and fatigue (40%) when they cannot resolve ethical issues. In multivariate models, a positive ethical climate and job satisfaction protected against respondents' intentions to leave as did perceptions of adequate or extensive institutional support for dealing with ethical issues. Although the number of black nurses surveyed was small, they were 3.21 times more likely than white nurses to want to leave their position, suggesting the need for more research on differences among nurses. We suggest several strategies to reduce ethics stress and improve the ethical climate of the workplace for nurses and social workers. (Ulrich 2007).

In a separate analysis of the social work respondents of our survey, we examined the hypothesis that value conflicts can be a source of ethical stress for social workers in

health care settings. That stress, unless mediated by the availability of ethical resource services, can lead to social workers' dissatisfaction with their positions and careers, and possibly result in needed professionals leaving the field. Findings showed the inter-relationship between selected individual and organizational factors and overall ethical stress, the ability to take moral actions, the impact of ethical stress on job satisfaction, and the intent to leave position (O'Donnell 2008)

As the need for primary care providers expands, patients will receive an increasing amount of their healthcare services from nurse practitioners (NPs) and physician assistants (PAs). These providers are likely to be confronted with a variety of ethical issues as they balance quality care with their patients' rising cost concerns. However, little is known about the ethical conflicts and causes of these conflicts experienced by NPs and PAs in their daily practice. In our study, respondents were surveyed on ethical issues and concerns, ethics preparedness, and ethical conflict. Using the data derived from this study we identified ethical concerns and conflicts NPs and PAs encounter related to managed care in the delivery of primary care to patients and the factors that influence ethical conflict. The majority of respondents (72%) reported that insurance constraints interfered with their ability to provide quality patient care, with 55.3% reporting daily to weekly interferences. Nearly half of respondents (47%) had been asked by a patient to mislead insurers to assist them in receiving care. A perceived obligation to advocate for patients, even if it means exaggerating the severity of a patient's condition, was the single most significant predictor of ethical conflict, explaining 25% of the variance. These findings suggest that NPs and PAs are experiencing ethical conflicts that are often associated with their perceived professional obligations to advocate for patients. Being well-prepared in ethics and having sufficient professional independence help clinicians balance the ethical complexities and demands of meeting patients' needs within a constrained healthcare system (Ulrich 2006).

- **Examining the influence of ethics education on the moral action of clinicians**

This analysis investigated the relationship between ethics education and training, and the use and usefulness of ethics resources, confidence in moral decisions, and moral action/activism through our survey of practicing nurses and social workers from four United States (US) census regions. Among our sample (n = 1215), no ethics education at all was reported by 14% of study participants (8% of social workers had no ethics education, versus 23% of nurses), and only 57% of participants had ethics education in their professional educational program. Those with both professional ethics education and in-service or continuing education were more confident in their moral judgments and more likely to use ethics resources and to take moral action. Social workers had more overall education, more ethics education, and higher confidence and moral action scores, and were more likely to use ethics resources than nurses. Ethics education has

a significant positive influence on moral confidence, moral action, and use of ethics resources by nurses and social workers (Grady 2008).

- **Study of physicians' access to ethics support services**

Clinical ethics support services have been gradually developing in Europe, albeit at a slower pace than in the U.S. We anticipate that such support services will be most useful if they are designed to match the needs and ethical concerns of clinicians. In our survey of four European countries, we conducted an analysis to assess primary care physicians' access to the different types of ethics support services, and to describe what makes them more likely to have used available ethics support. Respondents reported access to formal ethics support services such as clinical ethics committees (23%), consultation in individual cases (17.6%), and individual ethicists (8.8%), but also to other kinds of less formal ethics support (23.6%). Access to formal ethics support services was associated with work in urban hospitals, while informal ethics resources were more evenly distributed. Although most respondents (81%) reported that they would find help useful in facing ethical difficulties, they reported having used the available services infrequently (14%). Physicians with greater confidence in their knowledge of ethics (P=0.001), or who had had ethics courses in medical school (P=0.006), were more likely to have used available services. Access to help in facing ethical difficulties among general physicians in the surveyed countries is provided by a mix of official ethics support services and other, less formal, resources. We conclude that developing ethics support services may benefit from integration of informal services. Development of ethics education in medical school curricula could lead to improved physicians sensitivity to ethical difficulties and greater use of ethics support services. Such support services may also need to be more proactive in making their help available. (Hurst 2007)

- **Views of clinicians regarding advice from ethicists about scarce resources**

In our international survey of European physicians we examined the extent to which respondents encountered scarcity-related ethical difficulties, and the extent of any dissatisfaction they might have with the resolution of many of these difficulties. We further examined survey results to explore whether ethics support services would be potentially useful in addressing scarcity related ethical dilemmas. Results indicate that while the type of help offered by ethics support services was considered helpful by physicians, they rarely referred difficulties regarding scarcity to ethics consultation. We propose that ethics consultants could assist physicians by making the process less difficult, and by contributing to decisions being more ethically justifiable. Expertise in bringing considerations of justice to bear on real cases could also be useful in recognizing an unjust limit, as opposed to a merely frustrating limit. Though these situations are unlikely to be among the most frequently referred to ethics support services, ethics consultants should be prepared to address them. (Hurst 2008)

- **Examining deterrents to ethics consultation**

Reports suggest that some health care personnel fear retaliation from seeking ethics consultation. We therefore examined the prevalence and determinants of fear of retaliation and determined whether this fear is associated with diminished likelihood of consulting an ethics committee. Based on data from our survey of registered nurses and social workers in four US states, we developed a retaliation index (1-7 point range) with higher scores indicating a higher perceived likelihood of retaliation. Linear regression analysis was performed to identify socio-demographic and job characteristics associated with fear of retaliation. Logistic regression analysis was performed to determine whether fear of retaliation was associated with less likelihood of seeking consultation.

Among the study sample, 293 (48.7%) RNs and 309 (51.3%) SWs reported access to an ethics consultation service. Amongst those with access, 2.8% (n=17) personally experienced retaliation, 9.1% (n = 55) observed colleagues experience retaliation, 30.2% (n = 182) reported no experience with retaliation but considered it a realistic fear, and 50.8% (n = 305) did not perceive retaliation to be a problem. In logistic regression modeling, fear of retaliation was not associated with the likelihood (OR=.81; 95% CI= 0.27-2.38) or frequency of requesting ethics consultation (OR=0.86; 95% CI 0.29-2.57) We concluded that fear of retaliation from seeking ethics consultation is common among nurses and social workers, nonetheless this fear does not appear to be associated with reduced requests for ethics consultation (Danis 2008).

- **Evaluating the current state of medical school education in bioethics, health law, and health economics**

Current challenges in medical practice, research, and administration demand physicians who are familiar with bioethics, health law, and health economics. Curriculum directors at American Association of Medical Colleges-affiliated medical schools were sent confidential surveys requesting the number of required hours of the above subjects and the years in which they were taught, as well as instructor names. Relevant publications of instructors were assessed by a PubMed search. Findings revealed that teaching in all three subjects combined comprises less than two percent of the total hours in the American medical curriculum, and most instructors had not recently published articles in the fields they teach. Persad and colleagues thus suggested that medical schools should reevaluate their curricula and instructors in bioethics, health law, and health economics (Persad 2008).

Impact

Results of our surveys have been presented nationally at the American Society for Bioethics and Humanities meetings and internationally at the International Association for Bioethics meetings. We have had a number of requests to use our survey instruments by researchers who wish to survey other samples of clinicians to explore the ethical dilemmas they encounter.

Samia Hurst has become president of Swiss Society of Biomedical Ethics and one of the founding members of the European Clinical Ethics Network. She and our European

colleagues have been informed by the findings of our European survey in their work with the Network.

Dr. Ulrich has become a Senior Fellow in the Center for Bioethics, Department of Medical Ethics and Senior Fellow, The Leonard Davis Institute of Health Economics at the University of Pennsylvania.

The procedures and experience of the CC Ethics Consultation Service has served as a model for developing the research ethics consultation service at the University of Washington Seattle Children's Hospital where a former faculty member of our department, Benjamin Wilfond, directs the Bioethics Program. In addition, the unique experience that we have in research ethics consultation has yielded a taxonomy of ethical queries pertaining to clinical research that will be utilized by the CTSA Clinical Research Ethics Key Function Committee in its future efforts to develop research ethics consultation.

Future plans

Plans include the conduct of additional survey research as well as additional analyses, and publication of a book:

- **Survey of surgeons about ethical dilemmas**

Clinical ethicists at many institutions are often aware that some physicians are more likely to request ethics consultations than others. By and large, surgeons are among the least likely to request consultations. We plan to conduct a survey of surgeons to learn more about the ethical issues they encounter, their perceptions and responses to these issues, and their views regarding how clinical ethicists could be of more value to them.

- **Publication of a casebook of on research ethics consultation**

Ethics consultation, which has long been offered in clinical care settings, is increasingly sought in the clinical research context. As a result, there is a growing call for literature on the substance and process of research ethics consultation. This trend has been bolstered by the launch of the National Institutes of Health (NIH) Clinical and Translational Science Awards (CTSA) program in 2006. The CTSA program, which is a national consortium of medical research institutions that work together to facilitate the timely translation of laboratory findings into treatments for patients is ultimately expected to include as many as 60 research institutions. All CTSA applicants must address how they will handle any ethical concerns raised by their research, leading many to develop a process for research ethics consultation.

The Clinical Center Bioethics Consultation Service has been serving the NIH community of researchers, administrators, healthcare providers, and research participants for more than a decade, conducting nearly 1,000 consultations in that time. This long track-record of ethics consultation for clinical research is unique in the extent of experience and the breadth of issues it has addressed. Faculty of the Department of Bioethics who

serve on the Clinical Center Ethics Consultation Service will therefore be building on this experienced to publish an extraction of exemplary consultations in a volume to be entitled *Clinical Research Ethics Consultation: A Casebook* which will be published by Oxford University Press. Among the more important features of this book will be the presentation of a taxonomy of consultation issues that arise in research ethics consultation.

- **Collaborative empirical studies of research ethics consultation**

Marion Danis will be collaborating with the CTSA Key Function Committee on Research Ethics Consultation to develop standards for conduct and documentation of research ethics consultation.

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