

James Lindemann Nelson, "Families and Bioethics: Old Problems, New Themes," *The Journal of Clinical Ethics* 16, no. 4 (Winter 2005): 299-302.

Families and Bioethics: Old Problems, New Themes

James Lindemann Nelson

James Lindemann Nelson, PhD, is Professor and acting Chair, Department of Philosophy, and Faculty Associate, Center for Ethics and Humanities in the Life Sciences at Michigan State University, East Lansing, jlnelson@msu.edu. © 2005 by *The Journal of Clinical Ethics*. All rights reserved.

Families, as has been observed before now, serve healthcare practitioners as conduits who can lead practitioners toward the choices, desires, and values of patients; help physicians and nurses through barriers of incapacitating illness or cultural differences to reach a sense of who a patient is; and what that means for how they, as professionals, ought to act. Families also increasingly see service in the role of semi-skilled providers of increasingly sophisticated forms of care, as financial pressures tend to push patients out of professional healthcare settings and back into such homes as they may have.

Families are also served by healthcare: whenever the ill, injured, or impaired are helped to become healthy and to function, everyone bound to them benefits. Families rely on healthcare resources to see them through many of the landmark events that define them: births and deaths, serious accidents and illnesses, addictions, eating disorders, and unwanted pregnancies. Perhaps most distinctively, healthcare serves families by overcoming the biological barriers to their formation or extension with ever-more-ingenious ways of overcoming infertility.

When families encounter healthcare, whether as servants or as those served, particularly tough ethical problems show up. When we deliberate morally, we seem most comfortable dealing with disputes that concern the distinct interests of distinguishable individuals, puzzles that lend themselves to calculative forms of rationality, situations that can be clarified by simple rules. That's just the sort of menu that's not on offer when families are in the center of the picture: interests and identities merge and oppose, sentiment and deliberation interpenetrate, and the arbitrariness of simple rules becomes almost embarrassingly plain. The ethical terrain at the intersection of families and healthcare presents a challenge not only to our skills in wielding the tools we have, but to our imaginations as we work to make those tools better suited to the task.

The six articles that make up this special section of *The Journal of Clinical Ethics* take on both challenges. They offer distinctive ways of understanding what's at stake in specific kinds of interchanges between families, illness, and healthcare, and what responses are called for. But they also engage, more or less explicitly, with the enduring meta-problem of bioethics, and indeed, of ethics in general: how are we to think well about how we ought to live? In my own view, one of the great attractions of trying to "do ethics" within the rich texture of practices that constitute healthcare is that it becomes hard to rest content with arguments that have chiefly theoretical elegance to recommend them, and it is unsatisfying to draw, in a settled way, on images of lives and interactions that are pertinent only to some situations, or few, or none.

So when we consider families as avenues to patients' subjective preferences, we can ask not only, "How reliable?" or "How trustworthy?" families are (measured against the going alternatives), nor only, "How reliable or trustworthy do they need to be?" but also whether families have exhausted their value to health-care once they have reproduced the formed preferences of their loved ones, acting as solely as transmitters, or, at most, interpreters. Might some family members also help *construct* preferences and choices out of what may be no more than a patient's inchoate, indeterminate scattering of values, interests, and desires? Might they take into account considerations whose connection to the patient is indirect, considerations that bear primarily on the needs of other family members or to the family, as such? When we consider how some families are being progressively transformed into professional healthcare providers *manquè*, we need to think about justice, not between strangers, but about between people who help constitute each others' evaluative outlooks. We must understand what notions of obligation and supererogation mean, in contexts of intimacy. And when we think about how to direct or whether to limit reproductive assistance, we need not merely specify and balance the standing moral terms, but to reflect on the impact of new technologies on standing conceptual systems, on imaginative and affective associations, and on material practices that make families the many things that they are. Can good intentions ensure that the new understandings of families' roles and responsibilities that are emerging from these techniques and practices are progressive? Can we purposively give these systems of meaning a shape that corresponds, at least tolerably, to our ideals, or are the norms they embody too deeply entrenched for us to sculpt as we please? Attending to intimacy, and to its powerful, sometimes violent, emotions, prompts a more realistic representation of what ethical thinking faces, nudging us to develop a more expressive vocabulary to describe problems and a more adequate store of tools to resolve them.

In articles touched off by stories of daughters tending mothers suffering from dementia, Tia Powell and Hilde Lindemann flag the implications for our understanding of "intimacy" and "empathy" that come into view, if we take seriously the thought that human lives are often shared, and hence are *sharable things*. An appropriate appreciation of that idea, theoretically supported by a view of selfhood that stresses its analogies with narrative form, has consequences for how we make sense of the authority that people have to make decisions for their incapacitated intimates, as Powell argues. At the same time, it should alert us to intimacy's dangers, of how, in particular, the identities of persons need to be protected against the kind of iatrogenic injuries that can come from care provided by intimates, as Lindemann urges. Carelessness with how we think about those we are closest to can be damaging, as can the influence of theories of minds and selves that, in effect, deny some of our special vulnerabilities to each other.

The articles by Catherine Belling and Laura Purdy address expanding families in ways that involve eliminating any involvement of biological fathers and mothers, respectively. Belling focuses on fathers who are removed from nurturing roles through anonymous donor insemination. Purdy addresses a more radical means of canceling the connection between the social and the biological — the prospective use of female fetuses as a source of ova. Both authors deal with another fraught connection: that between cultural and bioethical constructions of sentiment and rationality. Policy and standard ethical analysis tend to dissociate these features of human lives; the lived experience of reproduction and family life tends in another direction. Belling argues against a bifurcation of sense from sensibility as we think through what children can demand from their progenitors; Purdy's article inspires a critical assessment of the very fountainhead of assisted reproduction, the "pronatalist" yearning that the children one cares for must be, if at all possible, of one's own body.

John Hardwig and the team of George Hardart and Robert Truog consider the role of families in making clinical decisions. Hardwig's examination of challenges to family decision making that are based on futility portrays these disputes as due, not to irrational families, but to medicine's culture — its propaganda, its rhetoric, its resident moral understandings — all of which inveigle some families into just the resilient hopefulness that providers sometimes abruptly abandon. Hardwig sees this impact of medical culture as another kind of iatrogenic injury, a cost that healthcare extracts from families. Hardart and Truog discuss the

results of their study of clinical conceptions of the role of families' interests in treatment decisions. They investigated whether and to what extent the standard view that the welfare of patients trumps the interests of others actually guides clinical self-understanding and action. Their findings suggest that practice in health-care is much less regimented by the primacy-of-the-patient view than might be thought, given the consensus of normative authority that stands behind it. Instead, on reflection, very few of the physicians in their sample are willing to endorse a purely instrumental view of the role of families in healthcare. They also found that different moral understandings and strategies emerged from different kinds of practice and from different amounts of experience.

As all of these authors are more than capable of stating their own cases clearly and economically, I will say no more here about the specific arguments and conclusions they advance. Despite the fact that their readers are also more than capable of making their own assessments, I will conclude by calling attention to the persistence of certain themes in these articles that strike me as especially important to ongoing thinking about patients, families, and the ethics of healthcare. One such theme concerns what I'll call — not without some misgivings — the relationship between sentiment and rationality. Something in the neighborhood of how this distinction is often understood can be detected easily in the contributions of Powell, Purdy, and Belling, and is not far below the surface in some of the other essays. The passion with which people seek out lives within families — an institution whose instrumental goods, while no doubt very important to individuals and societies both, could be more efficiently and perhaps more justly secured in other ways — can be seen as an instance of the "heart's reasons": clearly powerful, clearly motivating, hard to articulate. Bioethics, both in and outside of family contexts, encounters such reasons a good deal, sometimes in the guise of "yuck" factors, sometimes more gravely presented. Both "reason" and "sentiment" have their champions in the field; it seems to me that it is well past the time to move beyond partisanship here and to try to better understand the deep and interrelated importance of these core dimensions of human life.

Another important, and related, theme might be called the "moral psychology" of bioethics. What do our favored conceptions of moral deliberation and decision making say about our psychological propensities and powers, about what kind of selves we fundamentally are? A related question needs to be pressed as well: How might our best conceptions of what we are and what we can do influence our ideas about the character of moral problems and the best ways of solving them? The Lindemann, Powell, and Belling articles in particular all view images of human selves, their powers, and their relationships that have strong family resemblances, and that also stand as alternatives to assumptions that are prevalent in a good deal of the ethical theorizing available to, and sometimes prompted by, bioethicists; they ought to incite further, explicit work on how various conceptions of human selves operate in bioethics.

A third theme I find in several of these essays resonates with both considerations of sentiment and selfhood; it might be called the "situatedness" of practical rationality. Hardwig's article might be read — superficially, I think — as claiming that families who insist on treatments that professional tell them will not work are in fact being, in some objective sense, irrational, but they have an excellent excuse for it: they have been mightily encouraged to believe that healthcare is capable of near miracles by people they have good reason to regard as experts. If the experts start contradicting themselves, you can hardly blame the laity for getting confused and digging in.

But Hardwig also points out how forms of life that seem pointless to professional health providers may seem deeply significant to families whose own lives are caught up in caring for their relatives; there need be nothing irrational about that at all. It is in part through awareness of what people make of their situations that we can understand the sense in what they do. Hardart and Truog's study helps to alert us to differences in notions of what counts as a "good reason" for action within a "healthcare culture" that might strike those outside it — patients, families, even some bioethicists — as monolithic. Their work provides a basis for thinking that even those moral maxims that seem to form the most venerable and respected part of healthcare's evaluative outlook may penetrate practice incompletely, and serve as reasons for action to different extents in different situations and with different providers. Further studies, focusing on how differently situated

patients and families understand themselves, their relationships, their decision making, and their disputes with healthcare providers, need to be part of a continuing effort to encourage us to keep better track of all those whom healthcare serves, and all those who serve healthcare.

ACKNOWLEDGMENT

I'm grateful to Hilde Lindemann for her reading of an earlier draft of this introduction.