

Authority Figures

To the Editor: In the September-October 2011 issue, Daniel Groll addresses the question of what health care providers can know about patients' interests ("What Health Care Providers Know"). He offers helpful refinements to my claim in *Patient, Heal Thyself* (Oxford, 2008) that generally health providers cannot know what serves patient interests. I am honored that a careful student of the patient-physician relationship has taken my arguments so seriously and has, for the most part, stated them accurately. Groll, for example, recognizes that the dispute about whether physicians can know patients' interests is not about the priority of autonomy.

Groll makes two key points: (1) when it comes to medically assessable means-ends disagreements, physicians really do know best, and (2) when it comes to patient ends, physicians are as good as anyone else in knowing what is best for the patient, not because of their medical expertise, but based on simple common sense. Both claims, however, are problematic.

First, regarding physician knowledge of means-ends relations, medical experts are clearly expert in matters of medical fact: diagnosis, prognosis, and likely intervention outcomes. These would include what Groll calls medically assessable means-ends disagreements. I suggest, however, that these disputes, properly understood, almost never occur. What Groll considers disagreements about a means to medical ends (such as staying alive), are, when properly analyzed, really more likely to be disputes over subtle differences in ends. Consider Groll's case involving physician and patient disagreement about whether amputation of a gangrenous toe will save a patient's life. He claims the shared goal is "a gangrene-free

[living] patient." He claims, more or less correctly, that the physician is the real expert here in determining whether amputation is the best means to achieving this end. The problem, however, is that, if the goal is stated more precisely, the parties probably do not agree on it. For some (unstated) reason, the competent patient rejects that amputation. If the physician probed, the patient likely is really holding out for a slightly different goal, such as living without gangrene, but without the pain and disfigurement of the amputation, or living at a price he can afford. He may not even be committed to living. Every medical end offers multiple ways of pursuit. Each treatment option, however, offers some-

know the facts of medicine. They still have no particular knowledge of what is best for patients, only what achieves predetermined ends.

This leads us to Groll's second and more important point: when it comes to patient ends, he claims, providers really know what is best for patients, not based on medical authority, but rather on the authority of "an ordinary, sensible person." Any reasonable person should see that it is better to amputate a toe than die. Here he suggests the physician is as good as the farmer, florist, or philosopher.

I think there is some truth in this, but raise two problems. First, as I have suggested, stating the goal as saving a

Specialized professionals are likely worse at knowing patient interests. Health providers overemphasize our medical well-being. My physician tells me to walk two miles per day rather than one when he can't possibly know how I value the marginal use of my time.

what different intended and side effects. Choosing among them requires clearer specification of ends.

Almost never do ethically interesting cases involving mentally competent patients feature real disputes over what Groll calls means-ends relations. I think Groll underestimates the extent to which patient-physician disagreements are over ends. Physicians' medical competence is not in dispute; their nonmedical value judgments are. If I am right, Groll's first point is trivially true, but generally not relevant. Moreover, even if disputes involves means-ends disagreements that are medically assessable, the fact that physicians are the presumed experts does not show that they know patient interests, merely that physicians

life even at the cost of toe amputation is much too vague. If we knew the real reasons for the patient's refusal, they might not be so obviously contrary to the patient's interest.

The second problem with claiming that physician common sense means that physicians know patient interests as well as ordinary citizens is that there are good reasons to believe that specialized professionals are likely to be worse at knowing them. Doctors are atypical in the weight they give to medical dimensions of well-being in comparison to nonmedical dimensions and atypical in which medical goals they value. Professionals are biased in assessing client interests. Lawyers overvalue our legal interests; accountants recommend

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The Hazards of Fast Science

BY FRANÇOISE BAYLIS

Increasingly, and as a direct result of the Canadian government's funding philosophy of trickle-down economics for science, science that doesn't support the "knowledge economy" is science that won't get funded. But if the research will contribute to the economy by creating new products, new services, and new jobs, then the research is pursued—the faster, the better. I worry that science funding in Canada might be killing science as an independent exercise in knowledge production.

Pink Ribbons, Wire Hangers, and the Politics of Women's Health

BY COLLEEN FARRELL

It seems that many are upset that politics in any form got involved with breast cancer advocacy, as if it were some idealized form of advocacy that could be free of politics. While I don't agree with the particular politics that influenced Komen's decision, I'm even more concerned with the idea that there's a way of truly advancing women's health while avoiding politics altogether.

Why Shame Won't Stop Obesity

BY DHRUV KHULLAR

Shaming children and parents into losing weight is unlikely to be an effective strategy. It increases stigma on those already struggling with the psychosocial consequences of being overweight and shifts the focus of obesity control efforts to personal responsibility at a time when, for many individuals, options for improving eating habits may be limited.

Also: **Halley S. Faust and Paul T. Menzel** revisit a landmark article by the late Benjamin Freedman; **Susan Gilbert** sums up TEDMED; **Gregory E. Kaebnick** evaluates "Principles for the Oversight of Synthetic Biology"; **Holly Fernandez Lynch** questions the "historical accident" of health insurance being coupled with employment; and **Tia Powell** examines justified restrictions on religious freedom.

that too much time be spent on record keeping; clergy would have us spend too much time praying and attending church. Health providers systematically overemphasize our medical well-being. (My physician tells me to walk two miles a day rather than one when he can't possibly know how I value the marginal use of my time.) Dedicated professionals are not merely as good or bad as anyone else in assessing what is best for clients; they are systematically worse. How many times a day should you brush your teeth? Dentists should give the wrong answer.

When Groll claims that physicians have "special responsibility to the patient as a clinician" and that clinicians are "specially tasked to look out for the patient's well-being," he is making suspect presumptions. If all professionals in relationships with clients have such special responsibility, lay people will be bombarded with well-meaning attempts to persuade them of the proper course to pursue their well-being by people (doctors, lawyers, teachers, priests, accountants, and philosophers) who will give contradictory advice about how to maximize their overall well-being. They will get advice that is biased toward the special interests of the various professionals and advice they may well not be seeking. Doctors don't know what is best for their patients; they don't even know as well as ordinary citizens. That does not necessarily mean they should remain silent when they believe their patients are making bad choices, but they need to realize, as Groll correctly argues, they are not offering advice based on their medical expertise. They may not—as Groll fails to acknowledge—even offer advice that is as good as the ordinary citizen's.

Robert M. Veatch

The Kennedy Institute of Ethics

To the Editor: Daniel Groll presents an interesting view on how to determine when physicians are stepping

over the line between respecting patient autonomy and acting paternalistically. Simply put, as long as the physician limits her recommendations and advice to factual matters that are "medically assessable"—and so well within the medical expertise of a physician—and avoids delving into matters that are "nonmedically assessable," her actions are ethically consistent with the current value placed on patient autonomy. But Groll also acknowledges that even though the physician may have no special expertise regarding, say, the relative values a patient may place on disparate treatment options and goals, the physician may still "weigh in" with her own views so long as she is aware that she has no professional credentials to make value judgments for others.

In their Another Voice column ("Patient Autonomy and the Twenty-First Century Physician"), Jeremy Garrett and John Lantos support Groll, stating that he defines a role for physicians that is "uniquely twenty-first century." They present the issue as a dichotomy—the "unbridled paternalism" of the old medical ethics set against the "rigid, simplistic deference to patient autonomy of the late twentieth century." Their conclusion is that the patient-physician relationship of the current twenty-first century may come to be defined by a combination of these extremes.

The model suggested by Groll, Garrett, and Lantos is already long established. Physicians currently treat their patients with large doses of both medical expertise and counseling that often requires exploration of the non-medical merits of different plans and choices. Moreover, I would argue that it is their duty to do so, and that there is an extensive literature that supports this. The dichotomy referenced is useful at the theoretical level, but is nonexistent at the practical. The core of the patient-physician relationship is the physician as advocate. True, there are many instances in today's relatively

impersonal age of specialization where it is reasonable to view some physicians as mere body mechanics—repositories of narrow medical expertise who have little or no contact with the patient as a person. But when faced with those most important issues at the margins of life (which are the issues I assume Groll is addressing), the physician cannot and indeed should not avoid discussions that involve values.

At the very least, the physician must explore the reasons underlying her patient's choices so she can clear up any misconceptions as to the relative likelihood of different options for achieving the patient's goals. Is the patient declining chemotherapy because several friends or family members with similar but different diseases suffered without benefit? If the physician doesn't ask why when her patient says no, then she will never have the opportunity to address such misconceptions. Or consider the patient who wants to stop all treatment. Should the physician not ask him if he has thought about the burdens he might be placing on his spouse? What about the effect of such a choice on his children? Society has all but assigned the task of securing advance directives for end-of-life choices to physicians, who are chastised for not doing enough to encourage their patients to put their values in quasi-legal format. Can any meaningful end-of-life discussions take place in the absence of a conversation about values?

I don't disagree with Groll, Garrett, and Lantos when they aver that "unbridled paternalism" is wrong, and physicians are wrong to impose their values on others. But caring physicians are not wrong in sharing their values as long as they respect that ultimately their patients' choices trump them.

When physicians discuss values in the context of medical care, they are not acting in an offensively paternalistic manner. The principle of autonomy does not preclude physicians from exploring and even influencing the values

of their patients. The ethical physician cares for the patient, not just the patient's disease. She seeks to cure if possible, to relieve always, and to support and honor her patient's goals and values. But to do so she must know and understand those values, so it is her professional duty to clarify them. And if in doing so she somehow, through her own biases, influences her patients' choices, she is still acting well within the best ethical traditions of her profession.

Richard W. Clark

Los Angeles, California

Daniel Groll replies:

Robert Veatch grants that the various distinctions I draw—between means and ends and between medically and nonmedically assessable treatments—

to evidence. Perhaps part of what leads parents to decline immunizations for their children is a disagreement with medical professionals over the end(s) of immunization. But I think there can be no doubt that much of the disagreement comes from the parents having a set of entirely false beliefs about the nature of immunizations. This is but one example. It is not hard to think of others where people choose "treatments" that all the available evidence tells us do nothing (or at least nothing more than a placebo). In these cases, it seems to me likely that a person's disagreement with someone who thinks he or she should pursue a different treatment option depends in large part on the first person's lack of knowledge about what actually works.

The dichotomy of "paternalism" vs. "autonomy" is useful at the theoretical level, but is nonexistent at the practical. The core of the patient-physician relationship is the physician as advocate.

are good ones. To that extent, we agree. The disagreement is about whether my taxonomy (as I term it) has any real application. Veatch's concern is twofold: first, there really are no disagreements merely about means, and second, when it comes to disagreements about ends, there is reason to think that clinicians are especially ill-suited to know what is best for their patients.

I think Veatch is probably right that many disagreements about ends masquerade as disagreements about means. But I do not share his confidence that genuine disagreements about means almost never occur. It's hard to know who is right without some serious empirical work on the nature of disagreements in a clinical setting. But my reason for thinking that there are genuine disagreements about means comes from my impression that our culture is largely ignorant about and insensitive

Is it true that clinicians are especially ill-suited to know what is best for their patients? Answering this question is not just an empirical matter. We do not learn that clinicians are bad at knowing their patients' best interests simply from learning that clinicians systematically differ from their patients (and the population at large) on judgments about what is best. At times, however, Veatch seems to suggest this: how can Veatch's physician know that walking two miles a day is best for him "when he can't possibly know how I value the marginal use of my time"? The implicit suggestion here is that what Veatch values settles the matter of what is good for him. But one may well resist that conclusion, as those that resist subjectivist conceptions of well-being do. I wonder, then, whether the disagreement between Veatch and me stems from a deeper disagreement about what determines

well-being. I do not deny that a patient's actual values play an important role in determining what is best for her. But I suspect I do not think they play as large a role as Veatch seems to think they do. However, having said all that, I grant that it is surely true that many physicians vastly overestimate their ability to know what is best for their patients and that the presumption should be that the patient knows her own interests better than anyone else does.

Richard Clark's criticisms of my paper are premised on a misunderstanding. I do not say that physicians should simply stick to the medically assessable facts and avoid discussion of nonmedically assessable ends. Nor do I maintain that in discussing nonmedically assessable ends, a physician violates a patient's autonomy. It is true that John Lantos and Jeremy Garrett frame the issue in terms of "autonomy versus paternalism." I, however, do not, since I don't see the issue I deal with as being connected to the principle of patient autonomy. That principle maintains, roughly, that patients ultimately have the right to make decisions about their own care. My question was about the role clinicians should play in arriving at judgments of what is in the patient's best interests, given that the final decision is the patient's. The principle of autonomy is silent on this (though it will bar coercion or nonrational persuasion). As Clark notes, it "does not preclude physicians from exploring or even influencing the values of their patients." I agree, and nowhere did I say—or, I think, even suggest—otherwise. In fact, the final part of my paper was dedicated to making the case that physicians should trust their judgments of patients' best interests more than Veatch would have them do. The point was not that physicians should remain silent, but that they should recognize that when they share their value judgments with patients, they are not doing so as people with any kind of special authority on the matters under discussion. The danger—which I

tried to highlight, and which is a central concern of Veatch's—is that the persuasion Clark mentions can often happen in a nonrational way when a vulnerable patient misconstrues a physician's authority as extending beyond the realm of medicine.

Research /s Care

To the Editor: The article by Emily Largent, Steven Joffe, and Franklin Miller on the integration of research and treatment ("Can Research and Care Be Ethically Integrated?" Jul-Aug 2011) is a valuable contribution in many ways. However, it perpetuates two significant problems. First, they frame the issue as the integration of research and care—rather than health care, medical care, clinical care, treatment, or practice. The problem with contrasting research with care is the implication that researchers are uncaring, when in truth they have a robust duty of care that is both substantively different from that of clinicians and substantially underappreciated. Simply choosing a term other than care would facilitate better understanding of clinical research, just as discussion of withdrawing treatment rather than withdrawing care helps facilitate better understanding of palliative care.

Second, the authors accept without question the standard contrast between informed consent in research and in treatment, referring to "informal" and "routine" clinical decision-making as acceptable in prescribed trials. Yet a central point of ethical integration, as attested to by their quote from Daniel Wikler, is that what is in the patient's best interest may in reality be far from clear to the physician. For this reason, informed consent in the clinical context should be more like consent to research. A more robust informed consent practice, requiring clinicians to articulate probabilities, uncertainties, and alternatives to their prescriptions and recommendations, would, to paraphrase Alexander Capron, encourage physicians to

scrutinize themselves. It would also help teach patients that most recommended treatments are neither 100 percent effective nor risk-free. Changes like these could help bring research and treatment closer in spirit, as Ruth Faden, Tom Beauchamp, and Nancy Kass suggest through their emphasis on learning in health care.

Nancy M.P. King

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An Unintended Misrepresentation

To the Editor: As a practicing Buddhist of Asian origin and a board-certified intensive care specialist, I read the case study "Too Much to Ask?" (Jul-Aug 2011) with great interest. The obvious ethical dilemma of acceding to the family's wishes based on its members' religious beliefs at the expense of wasting a valuable resource that another patient desperately needed is nicely highlighted and illustrates the ongoing struggle to balance beneficence and holistic care with social justice in a world of finite (and dwindling) resources. However, I am concerned that the brief explanation given for the root of this quandary—that the body should remain undisturbed because of a Buddhist belief that the soul needs time to exit—is inaccurate and erroneously portrays Buddhism as a superstition, rather than a system of practice that relies more on empiricism and less on faith than any other major religion today.

One of the fundamental principles of Buddhist doctrine is the lack of a permanent abiding self—in other words, a soul. Along with the understanding that all manifest phenomena are temporary and thus ultimately unsatisfactory, this belief is the absolute cornerstone of Buddhism. While the Buddha did not expect his followers to accept the "no soul" doctrine merely on faith, but instead to follow a path of practice that would allow them to realize this for themselves, it is still the underpinning

of all currently extant schools of Buddhism—Theravada, Mahayana (which includes the Chinese school of Cha’an or Japanese Zen), Pure Land, and Vajryana (which consists of the Tibetan sects). Therefore, to state that this request was due to the family’s Buddhist faith is misleading.

I do not dispute that the belief in a soul transmigrating the body exists among certain Chinese families, including the one mentioned in the case study; however, it is probably based on local cultural and traditional influences, which may be a mix of folk religion, Buddhism, Confucianism, and Daoism. The fact that this family tried herbal remedies in addition to Western medicine suggests that there were multiple traditional influences in this case. Since the authors were probably not familiar with the intricacies of the family’s life, culture, and belief systems, it is probably best not to ascribe these practices to specific religions unless there is objective evidence that this is accurate.

A 2010 Gallup poll showed that 35 percent of Americans had an unfavorable perception of Buddhism, and several studies have shown that the extent of knowledge about a religion correlates directly with how favorably one views that religion and its followers. Therefore, it is inappropriate to foster negative perceptions, especially in a journal dedicated to ethical concerns.

Sharmila Dissanaiké
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Patricia Lyndale and Lauren Smith
reply:

We appreciate the thoughtful comments provided by Sharmila Dissanaiké. In response, we would like to apologize if we misrepresented Buddhist beliefs in any way. It was not our intention to foster a negative view of this, or any, religion. The case description is based loosely on an actual case we have encountered. We are not certain of the exact origin of the family’s beliefs; we only

know that they said they were Buddhist and that this was their specific request at the time of death.

We would like to emphasize that our job as ethics consultants is to work with each individual or family’s faith and cultural beliefs, whatever they may be. It is not our role to question or verify the accuracy of specific beliefs or impose a strict interpretation of a particular religious tradition. Our primary intention was to highlight the importance of any belief or cultural tradition.

Toward Universal Standards

To the Editor: In “Questioning the Universality of Medical Ethics: Dilemmas Raised Performing Surgery around the Globe” (Sept-Oct 2011), Aron Rose

Rather than challenge the universality of ethical principles, Rose provides an example of how those principles may be used to provide ethically justifiable care despite the challenges of austere environments.

brings into focus the ethical tension that exists between the good intentions of physicians who travel to austere environments and their inability to provide care that meets the standard they are accustomed to in their native countries. Candid appraisals of his own experiences along with humble self-scrutiny make his arguments compelling and poignant. I would argue, however, that rather than challenge the universality of the ethical principles discussed, Rose provides us with an example of how those principles may be used to provide ethically justifiable care despite the challenges of working in austere environments.

No one ethical principle is absolute. Rose describes the concept of avoiding harm, however, as the “sine qua non of ethical practice.” In addition to this concept, respect for persons, justice, and beneficence represent the oft-cited

principles that form the basis of U.S. federal regulations governing medical care and research. What is not as commonly understood is that these principles are all equally important and should be used as a framework to assess moral problems, rather than as strict rules. We violate the edict to do no harm, for example, when we remove a kidney from a healthy consenting donor because we find it more compelling to honor the altruism of the donor’s decision and the benefit to the recipient.

In his vivid description of confronting the challenges of working in the developing world, Rose wrote that he “flew without a moral compass,” relying instead on professional instinct. Although the notion of what constitutes the standard of care in austere environments is influenced by the con-

text in which it is provided, fair treatment using the resources available may nevertheless be possible. This may be achieved through treating “similar cases similarly, and unequals unequally,” satisfying the formal definition of justice. That Rose’s approach was informed by surgical experience speaks to his expertise and is an important and appropriate part of his decision-making regardless of the setting in which he practices.

Providing appropriate medical interventions assumes a favorable balance between risks and benefits of the care delivered. As an emergency physician, for instance, I would not attempt to perform the same procedures Rose performs as a trained ophthalmologist because I do not have the training to reasonably expect a patient to sustain clinical benefit from the procedure. Given the high mortality rate of children

who become blind in subsistence-level societies, Rose's efforts to restore his patients' sight justify the risk of the procedures he performs. This is true even if his approach in the developing world differs from what would be expected in his native country, where medications and technology allow for more conservative, nonsurgical interventions. Because of the nature of short-term international medical initiatives and the frequent lack of follow-up care, however, elective procedures do not have the same sound ethical foundation as do procedures that either save lives or restore patients' ability to function within their environments.

Having been on short-term medical initiatives to Ghana, Guatemala, and Haiti, I have faced similar ethical challenges to providing medical care in austere environments. I have witnessed ethically questionable decisions camouflaged by the good intentions of traveling professionals and volunteers. Although I agree that ethical standards

of care are poorly applied in developing countries, I believe our efforts ought to focus on making those principles contextually relevant to medical initiatives in developing countries, rather than rejecting the principles that guide our interventions in the developed world.

John E. Jesus
Newark, Delaware

Uncomfortable Humor

To the Editor: Hooray for Katie Watson's defense of dark humor in medicine ("Gallows Humor in Medicine") in the September-October issue of the *Report*. This is a topic that has also interested me, and her article sounds many of the same themes as talks I've been giving on the subject.

All I would add is that dark humor works by causing the audience to experience both laughter and discomfort, simultaneously. This is a clue to why dark humor can be so funny. The laughter is

first a response to the surprising incongruity between the perspective created by the comment or joke and the actual situation. But the laughter also serves to release the psychological tension between the pleasure the joke gives us and our simultaneous feeling that we really shouldn't laugh in the circumstances. Dark humor hits the funny bone in two ways.

Perhaps more importantly, it's this dual perspective that helps preserve the moral integrity of those who use or enjoy dark humor. The joke doesn't obscure the seriousness of the situation. It relies on it, and for that reason, once the laughter subsides, attention can quickly return to the patient's needs. Like the Fatman in *The House of God*, the dark humor jokester can be—and often is—a model of compassionate, patient-centered care.

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