

Virtual Mentor

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Goals of Medicine: Decision Making at the Margins

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Virtual Mentor

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From the editor

What we talk about when we talk about goals

by Emily E. Anderson, PhD, MPH

What are the goals of medicine? Are they fixed and immutable? Is there consensus concerning them? Current thinking about the goals of medicine should guide health care delivery, research and medical education. The literature on the goals of medicine is sparse, however, and “issues of purposes and values tend to be crowded out by...technical questions” [1] related to science or the organization and financing of health care. Therefore, I wanted this issue of *Virtual Mentor* to focus on some of the basic questions about medicine and its aims. I also wanted these discussions to be sufficiently concrete to have relevance for practicing physicians; for example, to what extent are physicians obligated to respond to patient demands? This collection of writings aims to link reflections on the goals of medicine with day-to-day decisions regarding patient care and with laws, policies and education methods that directly affect medical practice.

The Hastings Center Goals of Medicine project articulated four goals: (1) the prevention of disease and injury and the promotion and maintenance of health; (2) the relief of pain and suffering caused by maladies; (3) the care and cure of those with a malady and the care of those who cannot be cured; and (4) the avoidance of premature death and the pursuit of a peaceful death [2]. Although we might squabble over wording, the substance of these intentions is difficult to dispute, and these goals provide a starting point for discussion.

Writing for the Hastings goals project, Hanson and Callahan present three very compelling reasons why we—physicians, bioethicists and patients—should care about the goals of medicine. The first is that “it makes no sense to talk about the financing and organization of health care systems unless we understand the purpose of the enterprise” [3]. The second is that “the rapid advances of twentieth-century medicine have generated enormous ethical, cultural, and legal problems—and a remarkable number of them turn on what it is thought right or wrong, good or bad, for medicine to do for people in the name of preserving or improving their health” [4]. The third is that “modern scientific medicine seems to have elevated some goals of medicine—its intent to save and extend life, for instance—over other important goals, such as the relief of suffering and the pursuit of a peaceful death. It is exceedingly helpful to realize or sense the ensemble of medical goals, and then ask how they should fit together” [2]. In addition to addressing specific medical goals, each article in this issue of *Virtual Mentor* demonstrates how discussion of ethical issues in medicine can always benefit from some thinking about basic goals.

Taking the goals of medicine into consideration can help physicians solve clinical ethical dilemmas. Modern medical technology offers considerable potential to alter and control human life and not simply cure disease. The three clinical cases in this issue illustrate dilemmas faced by physicians when patients request treatments that may not be medically necessary. In each of these cases, a physician struggles to identify the legitimate medical goal. First, physician and attorney Julie D. Cantor discusses a physician's misgivings when a patient mentions cosmetic surgery—a common and socially acceptable practice performed under the aegis of medicine that carries real risk without direct medical benefit. In the second case, a pediatrician faces parents' demand for an immediate medical solution to a yet-undefined problem. Psychiatrist Elizabeth Kieff emphasizes the importance of not letting patients' (or, in this case, parents') requests distract physicians from providing appropriate care. To supplement this case, Sarah Maitre summarizes the complicated diagnosis of attention deficit hyperactivity disorder in the clinical pearl. In case three, a young couple seeks assistance from a reproductive endocrinologist in selecting the sex of their child. Physician and attorney Louise P. King asks whether a physician should provide services that are not medically necessary simply to satisfy patient demands.

In the medical education section, Elliot M. Hirsch explains how empathy can enhance patients' experiences and treatment, stressing that medical care involves more than technical skills. In the journal discussion, Erica Rangel critiques an argument on the definition of cosmetic psychopharmacology (the use of psychoactive substances to effect changes in function for individuals who do not have diagnoses of mental illness). Absent a diagnosis, prescribing medication can sometimes fulfill legitimate medical goals; in other cases, it may simply be bad medicine.

In the health law forum, Lee Black traces the development of defensive medicine—a practice that arises from physicians' fear of malpractice lawsuits and distorts the goals of medicine. In the policy forum, Mary Simmerling argues (in the vein of Norman Daniels) that one of the key goals of medicine is to protect fair equality of opportunity and uncovers problems with the current (purportedly equitable) organ transplantation system. In medicine and society, Bruce Jennings reflects on how consideration of goals of medicine should inform end-of-life care decision-making. And Kenneth A. Richman highlights the importance of communication between doctors and their patients about treatment goals in a second contribution to the medicine and society section. Barbara A. Hinze closes out the June 2007 issue with a medical humanities piece that looks at medicine's goal of relieving suffering and how that can be aided by giving patients a voice of their own and understanding their narratives.

As editor of this theme issue, it is *my* goal that readers be stimulated to consider the core aims of the enterprise of medicine and how those aims should guide decisions at the level of both patient care and public policy.

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Clinical case

Cosmetic surgery: when fifty doesn't feel fabulous

Commentary by Julie D. Cantor, MD, JD

Ms. Wagner has been a patient of Dr. Holmes, a general practitioner, for over 15 years. Ms. Wagner is 51 years old and recently became a partner at a prominent law firm. She is in generally good health but takes prescription medication for mild hypertension and seasonal allergies, so she comes in every few months. Approximately five years ago, after the death of Ms. Wagner's mother, Dr. Holmes prescribed antidepressants and recommended counseling because she was having some difficulties at work.

During a recent visit to renew a prescription for her blood pressure medication and request a prescription for a sleeping aid, Ms. Wagner told Dr. Holmes that she had been considering cosmetic surgery. She wanted to "make some improvements" on her eyes, chin and forehead—hoping to appear younger. Due to her recent promotion, Ms. Wagner had more face-to-face contact with clients. She seemed very happy about this promotion and talked about how much she loved her job. She admitted that her new responsibilities had increased the pressure she felt to look good at work. She mentioned that her appearance was discussed during her promotion review but did not elaborate. Ms. Wagner also mentioned that she was becoming increasingly self-conscious about her age. She had taught high school for 15 years and had not entered law school until she was in her late 30s. Due to this somewhat late start on her legal career, she was a bit older than the other lawyers who had recently made partner at her firm. Ms. Wagner, who had always maintained a stable, normal healthy weight, had lost almost 15 pounds since her last visit six months before. When Dr. Holmes asked about dieting methods, Ms. Wagner laughed and said, "I guess I've been so swamped at work, I've been forgetting to eat."

Dr. Holmes asked Ms. Wagner how much research she had done on cosmetic surgery. Ms. Wagner said she had not done any research but had made up her mind about undergoing the procedures. She asked Dr. Holmes to recommend a reputable local cosmetic surgeon. Money was not a problem for her, and she said, "The potential impact a new face will have on my career is worth some temporary pain and swelling." Dr. Holmes personally believed that unnecessary surgery for aesthetic reasons was not worth the medical risks but wanted to give appropriate medical advice.

Commentary

Headlines about beauty are as ubiquitous as reports on the weather. They're everywhere, screaming at us to be thinner, prettier, younger. And nowadays, plastic surgeons with well-honed skills and fancy academic appointments have merged medicine with marketing and taken their show to suburban malls, opening Botox boutiques where nurse practitioners play doctor with people's faces [1]. Everyone wants a piece of the cosmedicine world, a "happy" place where a full-time anesthesiologist can become a part-time aesthetician and "make a few bucks" by wielding a laser at a beauty salon [2]. No wonder Nora Ephron feels bad about her neck [3].

Meanwhile, the American workforce doesn't exactly welcome age. Regardless of their experience or skill, commercial airline pilots must retire at 60. A group of television writers over the age of 40 has brought a class action suit alleging age discrimination against certain Hollywood studios, broadcast networks and talent agencies. Greeting cards joke about aging, but, for many people, there is nothing funny about it. It has become, fairly or not, synonymous with uselessness, ugliness, and, from an employment perspective, a rather short goodbye.

In the case presented here, Ms. Wagner's concerns are understandable. Couple the social pressures about beauty and aging with the recent changes in her own life—a promotion, pressure at work to look good, increasing concerns about competing with younger colleagues—and it is easy to see why she wants to "make some improvements" through cosmetic surgery.

Yet Ms. Wagner's case raises red flags that should give Dr. Holmes pause and guide his actions. For one, he should screen this patient for depression. Ms. Wagner may have a history of depression, given her course of antidepressants and counseling five years ago, and her recent promotion is a stressful, albeit positive, event. She has also lost 15 pounds, experienced a drop in self-esteem, and complained of difficulty sleeping—all possibly associated with depression. Although cosmetic surgery may have psychological benefits, it may not be a panacea for patients who need psychiatric care. In fact, studies suggest that such patients may be unhappy with their surgical result and face "postoperative psychological complications" [4, 5]. Even if Dr. Holmes offers recommendations about cosmetic surgeons, he should also suggest that Ms. Wagner meet with a mental health professional and explain why he thinks such a consultation is in order.

Dr. Holmes should also discuss the perils that are apparently inherent in partnership at Ms. Wagner's current law firm or recommend someone who can. That Ms. Wagner's appearance came up in a promotion review is troubling, if not potentially illegal, and stressful. To be sure, appearance is important in the workplace. But it is one thing to present a neat and professional look; it is quite another to work in a law-firm-cum-beauty-pageant, where looks are part of the calculus for success. Although she says that she loves her job, both her psyche and her career may benefit from moving to a firm that is more interested in cultivating good lawyers than it is in

rewarding good-*looking* ones. Because she is now a partner, Ms. Wagner may have gained the requisite clout she will need to make such a move.

While Dr. Holmes may not agree with cosmetic surgery, his personal beliefs should not dictate the advice he offers to patients. In recent years, a sort of “practice what I preach” medicine has emerged. Physicians and other health care professionals have refused to offer information about some procedures or fill prescriptions for certain medications which ostensibly violate their personal beliefs. Arguably, that behavior chips away at what it means to be a professional—to put patients’ needs ahead of one’s own, to offer a panoply of options as part of an informed consent process, to fulfill the basic requirements of the job. In a case where a police officer was fired after he refused to patrol a casino (gambling violated his religious beliefs), the 7th Circuit Court of Appeals held that civil servants may not pick and choose their job assignments [6]. Writing for the court, Judge Easterbrook noted, “Firefighters must extinguish all fires, even those in places of worship that the firefighter regards as heretical. Just so with police” [7].

Perhaps a variant of that principle—that those who serve the public must put the public first—should apply to doctors. With their specialized knowledge and extensive training (much of it on the public dollar), they should have a duty of candor to patients—to present all options, even those they might not choose for themselves. Informed consent demands nothing less. Thus, Dr. Holmes should discuss the risks and benefits of cosmetic surgery, and he may even offer his opinion, but he should provide the names of reputable and board-certified plastic surgeons. After all, just about anyone with an MD can call himself or herself a “cosmetic” surgeon, and most members of the general public have no idea that there is a vast difference between a board-certified plastic surgeon and a cosmetic surgeon. Without professional advice, Ms. Wagner may be left to find a surgeon on her own. As great as Internet search engines are, they are no substitute for a professional recommendation about a physician.

If Ms. Wagner wants cosmetic surgery and has realistic expectations about such surgery—it may not be a perfect salve for insecurity and it cannot excise time—then she should certainly continue to research her options. Her body is her own, and, subject to the above caveats, if she wants to change it, she should be offered the information she needs to do so. But she may not need a new face. She may need a new law firm. And she may need to come to terms with a difficult reality: that time moves in one direction, and for many people, 50 isn’t fabulous. It’s downright depressing. Cosmetic surgery may be a coping mechanism, but it is only one strategy among many.

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Related articles

[Teenagers and cosmetic surgery](#), March 2005

[Adding burden to burden: cosmetic surgery for children with Down syndrome](#), August 2006

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Clinical case

Negotiating parental requests for medication

Commentary by Elizabeth Kieff, MD

Mr. and Mrs. Green took their 11-year-old son, JJ, to see Dr. Frank, a pediatrician. This was the first time Dr. Frank had seen JJ, who was in the sixth grade and had played piano since he was five. JJ loved music and showed exceptional promise. Within the preceding month, however, JJ had been struggling with piano lessons and practice. JJ told Dr. Frank that piano was very important to him and that he really wanted to be accepted into a special school for the performing arts. His audition for the school was to take place in six months. But he had been having trouble concentrating and therefore had been practicing less. His parents said that “until now,” JJ had never exhibited any behavioral or emotional problems at home or at school. Mr. and Mrs. Green wondered whether he had attention deficit hyperactivity disorder (ADHD) and whether medication could help their son with his concentration, at least until after his audition.

Dr. Frank asked the Greens if JJ had been evaluated by a school psychologist. They replied that JJ attended a small private school with no psychologist on staff. To determine whether JJ met the criteria for a diagnosis of ADHD, Dr. Frank asked the Greens about symptoms of inattention, hyperactivity and impulsivity. The Greens said that, in addition to trouble with piano practice, JJ’s math teacher had contacted them regarding his forgetfulness, distractibility and daydreaming in class. JJ had always done well in math, but now he was struggling to keep a C. They stressed several times that JJ’s piano teacher was especially concerned about his recent distractibility.

Dr. Frank asked the Greens about JJ’s mood, and they admitted that he had become somewhat withdrawn. Every day he sat down at the piano after finishing his after-school snack. Mrs. Green had noticed that he played for a few minutes and then stopped, and she would find him staring off into space, still sitting at the piano, 15 or 20 minutes later. He exhibited no signs of hyperactivity. The Greens said that there had been no major changes at home and no incidents at school that they were aware of, such as fights with friends or teachers.

During most of the appointment, JJ sat quietly in a chair with his head down. When questioned by Dr. Frank about his mood and concentration, he responded mostly with “yes” and “no” answers, and a few times he said, “I’ve just been having trouble concentrating.” Dr. Frank did not believe that JJ met the criteria for a diagnosis of ADHD and, because the changes had only occurred in the last month, Dr. Frank was

not yet concerned. He recommended some dietary changes, told Mr. and Mrs. Green to monitor JJ's sleeping and activity habits, and said that he would like to schedule another appointment in six weeks to see whether the dietary changes had had any effect. Mr. Green got very angry and said, "This is ridiculous! There's clearly something wrong with the kid. Why can't we just get a prescription to try for a few months?"

Commentary

This is a complicated but common situation for primary care physicians. JJ is a new patient. Dr. Frank is challenged with the task of physically examining JJ, getting a full medical history and performing a meaningful psychiatric evaluation. These challenges are further complicated by the variable of time: most first visits to a pediatrician last from 20 to 30 minutes. In contrast, first visits to a child psychiatrist range from 45 to 60 minutes. Dr. Frank cannot possibly achieve all of the above objectives in one visit. His task is to initiate care in the most effective and appropriate manner.

One ethical principle at play in any clinical encounter is that of beneficence—the duty to help or to do good. In clinical terms, this implies figuring out what is wrong (in some instances actually making a diagnosis) and offering some possible solutions. In this case, JJ and his parents complain of his lack of concentration. The differential diagnosis for this particular symptom is broad. For example: JJ could be depressed, have generalized anxiety disorder or attention deficit disorder, or there could be an underlying organic cause for his lack of concentration, such as poor nutrition or low iron. In addition to these codable diagnoses, a social stressor might well have prompted this change, for example, new-onset drug use or, perhaps more likely, the upcoming piano audition.

The Greens seem to insist on framing the issue in a somewhat narrow fashion: "if you want to help us you will give us medicine." It is often the case that patients come to their physicians not only with a sense of what they think is wrong but also with certainty about what they need to get better. The demand for antibiotics to treat viral illnesses is a good example of such a scenario. The duty of a doctor (which comes from the Latin word for "teacher") in any circumstance is partly to educate. To that end, Dr. Frank should broaden the Greens' understanding of what is wrong, or could be wrong, and what help might be available.

The meaning behind a parent's request

As a psychiatrist, I am struck by the many possible meanings that JJ's parents' request may have. They may be asking for medicine to treat ADHD because that is the language most readily accessible to them: they might really be saying, "We need help because we recognize something is wrong." Certainly, it is also possible they have been too demanding of JJ all along, and this desire for perfection is playing out now as his piano audition approaches. Dr. Frank not only fails to elucidate the meaning behind their request; he also fails to recognize the most essential content: JJ and his parents are in distress and asking for help.

It should also be pointed out that Dr. Frank is not appropriately concerned by the change in JJ. He is relieved to find out that the problem is a new one and misses the relevance of sudden behavioral change as a marker for something more significant. Moreover, he does not initiate a medical workup or the gathering of collateral data from teachers; nor does he take the important step of talking to JJ alone.

Finally, in failing to educate the family or to reframe the visit, Dr. Frank misses an opportunity to alleviate the very real suffering in JJ's presentation regardless of the cause. The family is left with the advice to vary JJ's diet and to keep track of his sleep, and they are told to follow up in six weeks. It is here that Dr. Frank both neglects to do "good" and begins to do "harm."

With an act of unintentional harm, Dr. Frank may violate a second ethical principle, that of nonmaleficence, often stated as "first do no harm." Dr. Frank may already be engaged in balancing potential harms: the possibility of doing harm by prescribing stimulants is weighed against the possibility of doing harm through inaction. The problem is that his solution does several potentially harmful things. He does not educate the family; he does not properly initiate a work-up of the patient; and, most significantly, he does not provide any relief to JJ or to the Greens. In this context, we can understand better Mr. Green's anger and his demands.

Prescribing can stifle other interventions

But what if we take Mr. Green's request at face value? Would there be a problem with Dr. Frank prescribing stimulants under these circumstances? Yes. Certainly, JJ could be harmed by taking a medication to treat a disorder he might not have. In prescribing medication as "the answer" to the problem, Dr. Frank would collude in the inappropriate framing of the encounter. This may stifle the possibility of another intervention (for example, decreasing the intensity of JJ's piano practices). Finally, just as with the overprescription of antibiotics, there are larger social implications in the overprescription of stimulants for children without clear disease. Inevitably, as people in the community share information, more children receive stimulants, and more parents interpret their children's behavior as indicative of ADHD, causing them to go to the pediatrician's office with requests like that of the Greens. It is not difficult to imagine an overall increase in stimulant use—in fact, we are living in that world now. But overuse of stimulants is not the only problem. Rather, prescribing medications might prevent an adequate consideration of patient issues. Caught in this dilemma about whether or not to prescribe, practitioners may miss the chance to fully help their patients. Dr. Frank certainly did.

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Related articles

[Unnecessary antibiotics](#), June 2006

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Virtual Mentor

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Clinical case

Sex selection for nonmedical reasons

Commentary by Louise P. King, MD, JD

Dr. Harris has been helping couples have children with the use of assisted reproductive technology (ART) for over 20 years. A reproductive endocrinologist, he got involved in the practice when it was new and extremely controversial and has had a rewarding career helping infertile couples. ART includes in vitro fertilization-embryo transfer, gamete intrafallopian transfer, zygote intrafallopian transfer, tubal embryo transfer, and frozen embryo transfer. These procedures help couples when less complex and less expensive methods of treatment have failed. Recently, Dr. Harris has been disturbed by trends at fertility clinics, including the one at which he works, to provide reproductive services based on patient demands and ability to pay rather than on medical need.

Recently, for example, Mr. and Mrs. Taylor, a couple in their late 20s, came to see Dr. Harris. Neither husband nor wife had any suspected fertility problems but they had decided they wanted only one child, and both really wanted a girl. Initially interested in preimplantation genetic diagnosis (PGD) followed by selective implantation (of female embryos), the Taylors had read a newspaper article about sperm sorting and sought more information about this technique. Although sperm sorting was not available at the clinic, Dr. Harris was conflicted—not only regarding how to counsel this couple, but about whether or not he could in good conscience continue to provide ART to couples for reasons he viewed as nonmedical.

Commentary

Beginning with the birth of Louise Brown in 1978, each novel technical advance proposed by the diverse field of reproductive endocrinology and infertility (REI) has met with vigorous debate. The debate surrounding both sperm sorting techniques and sex selection for nonmedical reasons via PGD touches on many of the same arguments raised in 1978.

In response to long-standing arguments that physicians attempt to “play God” when they interfere with reproduction and are slowly advancing towards a program of eugenics, proponents of ART have consistently pointed to society’s strong presumption in favor of reproductive choice. This presumption is exhibited in the United States in part by the decisions in *Griswold v. Connecticut* and *Roe v. Wade* [1, 2] as well as the prohibition against sterilization programs, even those seeking to avoid perpetuation of inheritable disease or fetal drug exposure [3]. Thus, prenatal screening with the possible option of early termination is offered to couples who

wish to know if their child has a disorder, sickle cell disease for example. But a policy preventing two carriers of sickle cell trait from reproducing is unimaginable. Nor are pregnant mothers required by law to stop drinking alcohol; instead they are subjected to ubiquitous and possibly ineffective educational messages on public bathroom stalls. The real message here is that reproductive decisions and choices are by and large in the hands of the parents-to-be.

Proponents of prenatal or pregestational sex selection resort to this presumption in favor of reproductive freedom and argue that it extends to all available technology if a couple would not otherwise reproduce without the benefit of that technology. Thus, a couple has the right to be assisted in conception of a child of a particular gender if they would not reproduce unless they could realize their preference [4]. Proponents of this view note that, absent proof of objective harm to others, this fundamental freedom should not be abridged.

Opponents of sex selection argue that there *is* risk of harm. The American College of Obstetricians and Gynecologists (ACOG) [5], the American Society of Reproductive Medicine (ASRM) [6], the International Federation of Gynecology and Obstetrics (FIGO) [7], and the United Kingdom's Human Fertilisation and Embryology Authority *Code of Practice* (HFEA) [8] all oppose meeting requests for sex selection for nonmedical reasons, in large part because they believe such requests may ultimately support sexist practice and reinforce devaluation of women. They point to India where between 1982 and 1987 the number of clinics for sex determination in Bombay alone increased from 10 to 248; in 1998, 7,997 of 8,000 elective abortions were female abortuses [9]. ACOG, ASRM and FIGO support offering patients sex selection techniques only to avoid transmission of sex-linked disorders, for example, Duchenne muscular dystrophy.

Those who favor sex selection for nonmedical purposes correctly point to differences between Western and Eastern culture. In India, a daughter's dowry can bankrupt a family. No such burden exists in Western culture. In fact, the vast majority of couples surveyed who would seek ART for sex selection would do so to ensure a "balanced family" with a child of each sex. Notably, Israel permits sex selection for couples who have had four children of one sex and wish the next child to be of the other sex [10]. Implicit in this policy is the argument that such a desire is not inherently sexist but merely recognizes that raising a girl is different from raising a boy. Opponents counter that this position reinforces sexual stereotypes and that parents will have unreasonable expectations of sex-selected children who may not conform to sexual "norms," thus negatively impacting the welfare of their children [11].

Other objections to sex selection deserve consideration too, such as the potential inequality of access to sex-selection technology, the likely disruption in the ratio of male to female births, and the ethical danger of condoning so-called designer babies. The first is a weak argument in the United States, where we have long accepted that access to nonessential medical care is far from available to everyone. The second

consequence is highly unlikely because fewer than 20 percent of couples surveyed wished to take part in sex selection [10], and, as noted by the first argument, many of them would lack the funds to take advantage of the technology. Finally, advocates of ART in general and sex selection in particular have long rejected the slippery slope argument, noting that freedoms should not be abridged when no harm exists simply for fear of future unproven harm. They argue that, if genetic selection for designer traits becomes a reality in the future, legislation against harmful practices can be considered at that time.

Dr. Harris is right to pause when confronted with the Taylors' request. As illustrated above, the issues are complex and spark great debate. HFEA's recent decision to ban all forms of preconception sex selection for nonmedical purposes in Britain met with vigorous objection and complex discussion in the literature [12, 13]. Dr. Harris, however, raises a new objection rarely discussed in the current literature, namely, whether a physician should participate in medical services on demand, thereby converting his or her practice into a purely commercial enterprise.

No standard definition of the goals of medicine exists. A report of the Hastings Center advances the following list of goals: (1) the prevention of disease and injury and the promotion and maintenance of health; (2) the relief of pain and suffering caused by maladies; (3) the care and cure of those with a malady, and the care of those who cannot be cured; (4) avoidance of premature death and the pursuit of a peaceful death [14]. Franklin Miller and Howard Brody would add to this definition four core "internal duties" essential to the professional integrity of physicians, the second of which requires that one "avoid disproportionate risks of harm that are not balanced by the prospect of compensating medical benefits" [15]. They argue that enhancement technologies, of which sex selection could be considered an example, challenge this second internal duty in that medical risks can be identified yet no medical benefit is present. Similarly, although psychosocial benefit to families that desire sex selection is evident, it is not immediately clear that these benefits can be construed as "medical," even when that term is defined broadly.

Risks from sperm sorting are theoretical at this point because no controlled outcome trials have been conducted; however, potential risks should not be trivialized. Of note, the Microsort technique uses fluorescent dyes bound to sperm DNA. Because X-bearing sperm contain 2.8 percent more DNA than Y-bearing sperm, they take up more dye thus distinguishing XX chromosomes from XY chromosomes. Moreover, most sperm sorting techniques require that the sperm be frozen for transfer from fertility clinic to laboratory and back again. It is not yet clear what effect these techniques might have on embryonic development and, specifically, whether the addition of fluorescent dye to DNA increases the risk of chromosomal abnormalities.

The risks from PGD include the well-defined risks to the mother associated with invasive procedures needed to harvest and implant eggs. Thus, according to Miller and Brody's framework, it might be difficult to justify sex selection whether by

sperm sorting or PGD since no “legitimate medical goal” is served and the risks are potentially great.

Miller and Brody note that some argue for applying a consumer and service provider framework when it comes to medical enhancements. This argument, however, is precisely what has given Dr. Harris pause:

The whole point of looking at medical practice in terms of professional integrity is based on an argument that medical ethics can never be reduced to the ethics of marketplace encounters. To claim that physicians are professionals is to claim that they can never become mere “consumer service providers” while still maintaining their integrity [16].

These statements are most likely anathema to cosmetic plastic surgeons, but they provide strong support for Dr. Harris’s gut reaction to the Taylors’ request.

In sum, if Dr. Harris believes he should refuse the Taylors’ request, there is much to support his decision. Although the Taylors wish to have a female child, their decision could still be considered sexist in that they presumably value having a male child less than having a female. Consequently, Dr. Harris could subscribe to the position espoused by ACOG and ASRM. As a reproductive endocrinology and infertility specialist, however, Dr. Harris has probably predicated much of his practice on a presumption that women and their partners should be assisted in exercising their fundamental reproductive liberty. Thus, it might be difficult for Dr. Harris to accept the ACOG and ASRM positions as justification for limiting this freedom. If Dr. Harris is not comfortable providing gender selection services on demand for nonmedical reasons, however, it is his professional right to reasonably refuse—as a violation of his integrity as a physician. Moreover, Dr. Harris, and indeed any physician who encounters a patient interested in sex selection, should counsel that patient about the absence of controlled trials to evaluate the safety of these techniques or of long-term studies to determine the psychosocial effect of sex selection on children and their families.

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Related article

[Assisted reproductive technologies, sex selection, and the commodification of children](#), May 2003

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Medical Education

The role of empathy in medicine: a medical student's perspective

by Elliot M. Hirsch, MD

Introduction

Throughout medical school, my instructors stressed the importance of empathy, generally defined as the understanding of and identification with another person's emotional state. Sympathy and empathy, commonly confused with each other, are not the same. Sympathy is a statement of emotional concern while empathy is a reflection of emotional understanding. The applications of empathy are widespread [1, 2], and are especially relevant in fields such as medicine, where the successful treatment of patients depends on effective patient-physician interactions. This article explores the concept of empathy and examines its utility in medicine from the perspective of a medical student.

What is empathy?

Empathy is an emotional experience between an observer and a subject in which the observer, based on visual and auditory cues, identifies and transiently experiences the subject's emotional state [3]. In order to be perceived as empathic, the observer must convey this understanding to the subject. During the initial phase of the process, the observer must not only identify but also understand the basis of the subject's feelings. For example, a physician may encounter a patient who appears depressed, expresses feelings of sadness and informs the physician that a close relative has recently passed away. This may cause the physician to recall subconsciously his emotional state during a similar situation in which a close relative died. Alternatively, he may not have experienced death in his family but may understand the emotional response to death in the patient's culture. In both of these situations, he may be able to respond empathically because he understands and can relate to the patient's current grief. In a different situation, the physician may have a dissimilar cultural background in which death is not associated with sadness but with joy and celebration of the deceased's life. Due to the conflicting associations with death, the physician may feel confused because he does not understand the basis of the patient's sorrow. Without understanding the nature and circumstances of the patient's emotional state, it may be difficult for the physician to generate an empathic response.

There is more to empathic understanding than simply knowing and evaluating objective information about a patient, however. Researchers have found that male friends have higher empathic accuracy than male strangers [4]. While this is not surprising, it is interesting to note that the greater accuracy was correlated with a

higher *quality* of shared information rather than a greater *quantity* of information. This result is especially relevant for practicing physicians, for it indicates that it is not enough to know a large amount of factual information about a patient. The physician who understands each patient on a personal level stands a far better chance of experiencing and conveying empathy and treating the patient and illness effectively than the physician who does not have that level of understanding.

It is also important that the physician possess sufficient communication skills to convey the feeling she is experiencing to the patient. In everyday life, people who are poor communicators and cannot adequately express their feelings are misunderstood by people around them. Thus, it is possible for a physician to be perceived as nonempathic when in actuality, she feels empathy but is unable to express it. Conversely, a physician who may not actually feel empathy may still be able to generate an appropriate response because she understands how she should respond in the situation and possesses excellent communication skills [5]. As these examples illustrate, many factors influence the generation, expression and perception of an empathic response.

Clinical empathy

Researchers have long examined and discussed the utility of empathy in medicine and have found differing results. Some argue that it is not possible for a physician to genuinely empathize with every patient—to do so would be emotionally draining and difficult under modern time constraints [6]. These researchers paint a picture of a physician who is best able to care for his or her patients by remaining “clinically detached” [7]. By not becoming emotionally involved with patients, the argument goes, the detached physician is able to make objective decisions concerning their care.

Yet there is increasing evidence that, when choosing a physician, patients value affective concern as much as, if not more than, technical competence [6]. As a medical student, I often heard descriptions of the characteristics of a “good doctor” from patients, instructors and even my family members. The one attribute that was always mentioned as necessary to being a good physician was being a good listener. Each patient wants to be treated as a person, not as an illness, and wants to be reassured that the doctor understands the nonmedical aspects of his or her condition. A doctor may be listening carefully to a patient, but the only way for the patient to know that is for the doctor to reflect that he understands the patient’s concerns; i.e., to respond empathically. If it is a goal of medicine to treat the patient—to alleviate suffering and not simply cure disease—then empathy is a necessary clinical skill. It seems, then, that the physician must perform a difficult internal balancing act: by becoming too emotionally involved with the patient, she may lose objectivity; by not becoming involved enough, she may be unable to relate as a human being.

Research has shown that empathy is also useful on other levels; it has been found to be directly therapeutic by reducing anxiety in patients [7]. When a patient feels that a physician understands his condition and apprehensions, he may feel more

comfortable confiding in the physician. This process of telling one's story can be therapeutic [8] and may also help facilitate the healing process. Moreover, patients often do not explicitly state their psychosocial concerns [9], which may manifest as physical illnesses (somatization). The prevalence of somatoform disorders has been estimated to be as high as 30 percent [10], and can only be diagnosed by a physician who is carefully attuned to the patient [11]. And, finally, empathy is beneficial to physicians; it has been demonstrated that doctors who are more attuned to the psychosocial needs of their patients are less likely to experience burnout [12].

Teaching and learning empathy

Although there is not a consensus on the best method of doing so, many researchers currently think that it is possible to teach and learn empathy [13-15]. When considering ways to develop the ability to be empathic, it is important to consider that empathic responses result from the interaction between behavioral and emotional factors. Thus, it is possible that increasing one's sensitivity to either of these factors will improve one's capacity for empathic response. For example, enhancing observation skills should make it easier to detect a patient's emotional state, while improving communication skills should help a physician convey his feelings to the patient.

The actual emotional process of empathy may be aided by exercises such as self-reflective writing, which helps an observer become more aware of her own emotions and subsequently improve her ability to be empathetic towards another [14]. Cultural education and a wide range of interests should give physicians a greater frame of reference with which to understand and relate to a patient, thus making an empathic response more likely. Finally, it has recently been suggested that physicians who act empathically may be perceived by patients as being genuinely empathic [5]. Physicians who practice this "deep acting" technique may, over time, learn to be genuinely empathic; thus, teaching acting may be a method of teaching empathy [5].

Conclusion

During the first two years of our medical education, my classmates and I were instructed in empathy and medical professionalism in a course that also entailed cultural awareness and the patient-physician relationship. Course methods included lessons in cultural awareness, ethics discussions and role-playing, in which we acted the parts of physician, patient and other members of the care team. During a typical session we attended a lecture and then met in groups of 24 to explore the current topic with our faculty mentors. Several sessions were devoted to each topic, after which we were required to complete a written self-reflection form.

Initially, it was somewhat difficult for me to understand the importance of these sessions. I appreciated our instructor's intentions but often felt that the material could have been more effectively presented. In retrospect, I was probably one of the milder critics of the course; a large number of students did not take the curriculum seriously, seeing it as a waste of time that could have been better spent studying. Possibly this reflects the views of many people in the medical community who see cultural

education and professionalism training as being “soft.” Another possibility is that medical students, who have been trained throughout their academic careers to value objective performance, simply do not want to spend their time with a subject that cannot be measured objectively.

The turning point for me came while I was working on this essay. After several months of research and discussion with my mentors, I began to understand that our professionalism course was building a base of knowledge and experience for us to use when relating to patients. A computer can read a list of signs and symptoms and give a diagnosis, but it does not have a range of experiences and cultural knowledge to draw on that would enable it to treat the person, as well as the illness. The empathic component of medicine is what makes a physician special; without it we are, in essence, highly trained computers.

The challenge for medical educators is to present the information in a format that makes it relevant and actively engages the students. Although students may not immediately see the value of this type of education, it is to our benefit that my generation of physicians is specifically instructed in empathy and professionalism. Programs such as these build a strong foundation for empathic interaction and give us the tools to be both effective communicators and skilled physicians.

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Journal discussion

Cosmetic psychopharmacology and the goals of medicine

by Erica K. Rangel

Bjorklund P. Can there be a “cosmetic” psychopharmacology? Prozac unplugged: the search for an ontologically distinct cosmetic psychopharmacology. *Nurs Phil.* 2005;6(2):131-143.

Happiness has long been recognized as one of the central aims of life. It is not surprising that for centuries humans have been using mood-altering agents, such as alcohol and opiates, to aid in their pursuit of happiness. Since the 1950s, psychiatrists have treated mental illness with tricyclics and monoamine-oxidase inhibitors (MAOIs), and in 1987 fluoxetine was developed as the first selective serotonin reuptake inhibitor (SSRI) to combat depression. With rapid advances in neuroscience and biotechnology contributing new and powerful mood-controlling agents, questions regarding the acceptable prescription and use of such agents are prompting heated debate. The term “cosmetic psychopharmacology”—first coined by Peter Kramer in his 1993 bestseller *Listening to Prozac* [1]—refers to the use of psychoactive substances to effect changes in function for individuals *without* clinical diagnoses. Such use raises questions about what qualifies as a cosmetic use of a psychoactive drug and whether physicians prescribing psychopharmaceuticals for cosmetic purposes are acting within the boundaries of their proper role as physicians.

In a sophisticated discussion of cosmetic psychopharmacology, Pamela Bjorklund addresses these questions and comes to some surprising conclusions. After examining the definitional boundaries of several crucial distinctions, such as health versus illness and clinical versus cosmetic, Bjorklund argues that many practices typically classified as cosmetic psychopharmacology are in fact either variations of legitimate clinical practices or clear examples of substandard care. Finally, she examines nuanced cases where the classification is less clear. After discussing the nature of suffering as it relates to clinical illness rather than to existential crisis, she concludes that, even in the absence of a clear classification and underlying etiology for clinical depression, treating subclinical cases of mental illness should be considered clinical, not cosmetic, psychopharmacology.

Introducing cosmetic psychopharmacology

Consider the following three cases adapted from examples presented by Sperry and Prosen [2]:

Luis is generally considered by his family and friends to be an outgoing and likeable man. In recent months, Luis’ disposition has changed for the worse.

He is angry and irritable with his wife and children. He is often anxious and restless, unable to get a full night's sleep. Luis demonstrates several of the symptoms for clinical depression, but according to Sperry and Prosen, he does not cross the clinical threshold as set forth by the *Diagnostic and Statistical Manual for Mental Disorders (DSM-IV)* [3]. Luis sees a psychiatrist and requests fluoxetine.

Since childhood, Linda has been shy and despondent. Regardless of changes in her life circumstances, her mood always reflects some degree of melancholia. Friends and family characterize her temperament as negative and gloomy. After developing an interest in meditation, Linda realizes that her constant dysthymia interferes with her ability to meditate. She requests an SSRI to help alleviate the problem.

Larry considers himself to be healthy and fairly normal mentally and emotionally. Every now and then he has episodes of pessimism and melancholy, but he eventually returns to his normal temperament of quiet happiness. He is neither gregarious nor diffident. Larry is a car salesman and he believes that fluoxetine will improve his personality and help him become more effective in his job.

Which, if any, of these examples constitutes the cosmetic use of an antidepressant? Bjorklund argues that this question hinges largely on how we differentiate the “clinical” from the “cosmetic,” an especially blurry distinction in mental health. The etiology and biochemical markers of mental disorders are tenuously defined, and it is sometimes difficult to distinguish illness or disorder from normal mental states. A normal depressed mood must be distinguished from clinical depression, and both must be differentiated from a melancholic temperament. Further, depression is never simply biological; it results not only from physiological dysfunction but also from the interaction of psychological, social and environmental conditions with an individual's biological dispositions. This vague taxonomy is reflected in the diagnostic method used by most mental health professionals, which depends almost exclusively on observable psychological, physiological and behavioral signs, symptoms and clusters to identify and diagnose illnesses [3]. Thus, according to the original definition, all three of the examples above constitute the cosmetic use of an antidepressant; none of the individuals has a clinical diagnosis (i.e., they are all either normal or subclinically variant).

Working at the margins

Bjorklund challenges simplistic applications of the term cosmetic psychopharmacology. She argues that the concepts of health and illness—and thus the concepts of cosmetic and clinical—are neither binary nor mutually exclusive; instead they lie on a complicated continuum where “health slides into illness and illness slips back into health almost imperceptibly” [4]. Additionally, Bjorklund sees disorder (and mental disorder in particular) as encompassing a broader range of cases than the *DSM-IV* might allow. She adopts Wakefield's [5] conception of disorder as

a “harmful dysfunction.” Thus, whether or not Luis’ symptoms are broad or severe enough to reach the *DSM-IV* threshold for clinical diagnosis, he certainly has described some sort of dysfunction. According to Bjorklund’s analysis, Luis’ use of antidepressants should not be considered cosmetic.

Regarding Larry (who considers himself mentally and emotionally healthy but thinks fluoxetine will help him sell cars), Bjorklund asserts that, without any symptoms of disorder, most psychiatric providers would refuse his request for an SSRI and consider Larry’s problems to be cosmetic. Bjorklund is hesitant to agree, because classifying this use as cosmetic “confer[s] some legitimacy to the practice...that it does not deserve” [6], referring to the social and medical acceptability that cosmetic surgery seems to have garnered in recent years. Instead, Bjorklund would classify a psychiatrist’s prescription of an antidepressant for Larry as inept or substandard care.

Bjorklund’s judgment seems slightly hasty. Her visceral reaction to this use of an antidepressant is understandable. Of course no physician should prescribe an antidepressant for Larry; there’s nothing wrong with him. Readers should remember, however, that doctors treat other conditions that are not technically illnesses fairly regularly: “minoxidil for baldness, estrogen for postmenopausal women, cosmetic surgery for people unhappy with their looks, acne treatment for self-conscious teenagers” [7]. Why is social and medical acceptability conferred upon these practices and a similar use of an antidepressant quickly labeled inept care? Perhaps it is because Larry only wants the prescription to improve his sales. But what about the woman who wants a breast reduction because it will improve her career as a ballet dancer? Would her request be refused as well? Not likely, because most physicians would see the physical (and likely, the psychological) benefits of such a procedure for a professional dancer.

Although she does not explicitly say, it is possible that Bjorklund believes this sort of care to be inept because it is ineffective and, thus, would fail to offer any benefit to Larry. This claim is supported by recent research showing that, although antidepressants are effective in improving mood from a subnormal state to a normal state, they do not effectively raise mood from a normal state to an enhanced state. If this were true, prescribing an antidepressant for someone like Larry would be clearly inept or substandard medical care. (For a discussion of the possibility of truly cosmetic psychopharmacology, see Cerullo [8].) Perhaps Bjorklund draws this line because cosmetic psychopharmacology has the potential to affect manifestations of the self directly, whereas cosmetic surgery affects the self only indirectly. Regardless of her reasons, Bjorklund’s judgment of prescribing an antidepressant for Larry as inept care requires substantial justificatory work beyond what she offers in the text.

The nature of suffering and the goals of medicine

After dismissing both Luis’ and Larry’s cases from the category of cosmetic psychopharmacology, Bjorklund considers Linda, whom she deems to be a trickier case. Bjorklund notes that Linda’s inability to meditate effectively, while not representing a clinical diagnosis, constitutes an existential crisis experienced as

illness. It is at this juncture that Bjorklund contributes a particularly convincing account of the problem of suffering and its relationship to the goals of medicine. How is one person's subjective experience of existential suffering to be understood by others? Should another's suffering be dismissed simply as a legitimate part of the human life, not meant to be medically "treated"? Or should existential suffering be acknowledged as, at least partly, akin to physical suffering and appropriately treated with pharmaceuticals?

Bjorklund concludes that the relief of suffering even purely metaphysical suffering, by "appropriate, clinically sound means is a legitimate medical...purpose" [9]. And it would seem that most medical practitioners would agree with her. According to Jonsen, Siegler and Winslade, the "maintenance or improvement of quality of life through relief of symptoms, pain and suffering" is a goal of medicine [10]. Callahan and Hanson [11] articulate a similar objective, "the relief of suffering," among their widely accepted list of medicine's goals. Moreover, Bjorklund rightly discusses the possibility that so-called metaphysical illnesses or melancholic temperaments are, in fact, rooted in actual physiological abnormalities. In such cases, the use of antidepressants would be clearly noncosmetic and appropriately clinical. While neuroscientific research on the biological foundation of seemingly incorporeal mental states remains inconclusive, it is important to recognize this possibility when dealing with the diagnoses and treatments of conditions considered to be subclinical.

Finally, it should be noted that Bjorklund acknowledges that not all negative, low moods are worthy of antidepressants. Certainly, there are plenty of situations where a physician is right to put the prescription pad away and recommend psychotherapy, spiritual counsel or a vacation to treat a subclinical depression. However, Bjorklund ultimately advances the view that, as the patient, "I am the arbiter of my own suffering. I get to participate in the decision that my melancholy is a disorder or a normal response to disordered times" [12]. Her sentiment reflects the current widespread bioethical conviction that patient autonomy should be both protected and promoted. While patient autonomy is by no means the only consideration in this discussion, it should, nevertheless, be taken seriously.

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Clinical pearl

Attention deficit hyperactivity disorder in childhood; overview, diagnosis and treatment

by Sarah Maitre

Attention deficit hyperactivity disorder (ADHD) is the most common neurobehavioral disorder of childhood and among the most prevalent chronic health conditions affecting school-age children. ADHD is characterized by some combination of hyperactivity, impulsivity and inattention. Children with ADHD may experience functional difficulties in every aspect of their lives, including behavior, academic achievement, and interpersonal relationships with family and peers [1]. In the long term, the combination of frustration, rejection and failure can have a serious detrimental effect on developing self-esteem [2].

With the establishment of more comprehensive diagnostic criteria that identify the various subtypes, estimates now place the childhood prevalence of ADHD at 4 to 8 percent [3]. Once thought to affect boys more than girls, the disorder now appears not to discriminate along gender lines. While, indeed, more boys than girls are diagnosed with ADHD, girls are being identified more often now than in the past, particularly in the inattention subtype. Possibly girls are less likely to be recognized and diagnosed with ADHD because their behavior is generally less overactive and disruptive. ADHD was originally thought to be a condition that resolved in adolescence, but new evidence suggests that this is not the case for the majority of children. For up to 65 percent of patients diagnosed in childhood, the symptoms persist into the teenage years and, for some, into adulthood [4].

Diagnosis

The American Academy of Pediatrics (AAP) has developed diagnostic guidelines based on the *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition (*DSM-IV*) criteria [5]. They urge that all children between the ages of 6 and 12 who present with symptoms of inattention, hyperactivity, impulsivity, academic underachievement or behavior problems be evaluated for ADHD. The criteria for establishing an ADHD diagnosis are as follows:

Either A or B

A. Six or more of the following symptoms of inattention have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level:

Attention deficit

1. Often fails to give close attention to details or makes careless mistakes in schoolwork, work or other activities.
2. Often has difficulty sustaining attention in tasks or play activities.
3. Often does not seem to listen when spoken to directly.
4. Often does not follow through on instructions and fails to finish schoolwork, chores or duties in the workplace (not due to oppositional behavior or failure to understand instructions).
5. Often has difficulty organizing tasks and activities.
6. Often avoids, dislikes or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework).
7. Often loses things necessary for tasks or activities (e.g., toys, school assignments, pencils, books or tools).
8. Is often easily distracted by extraneous stimuli.
9. Is often forgetful in daily activities.

B. Six or more of the following symptoms of hyperactivity-impulsivity have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level:

Hyperactivity

1. Often fidgets with hands or feet or squirms in seat.
2. Often leaves seat in classroom or in other situations in which remaining seated is expected.
3. Often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness).
4. Often has difficulty playing or engaging in leisure activities quietly.
5. Is often “on the go” or often acts as if “driven by a motor.”
6. Often talks excessively.

Impulsivity

1. Often blurts out answers before questions have been completed.
2. Often has difficulty awaiting turn.
3. Often interrupts or intrudes on others (e.g., interrupts conversations or games).

Along with the *DSM-IV* criteria, the symptoms must have been present before the age of seven, be found in two or more settings, and result in significant impairment in social, academic or occupational functioning. The symptoms must not occur exclusively during the course of a developmental disorder or be better accounted for by another mental disorder.

The AAP also requires that parents, caregivers and teachers provide direct evidence regarding the core symptoms of ADHD in various settings, the age of onset, duration of symptoms and degree of impairment. Evaluation of the child with ADHD should

always include assessment for co-existing conditions [1]. Two-thirds of children with ADHD have at least one other psychiatric disorder, the most common of which are depression, anxiety disorders, conduct disorders, oppositional-defiant disorders and learning disabilities [6].

Treatment

ADHD is currently considered to be a persistent and chronic syndrome for which no cure exists. Treatment should begin early to avert as much of the academic struggle, family conflict and social ostracism as possible and to avoid the long-term development of anxiety, depression and diminished self-esteem [7]. A multimodality approach to treatment that emphasizes both behavioral interventions and pharmacotherapy is considered optimal. Combined therapy is found to be especially useful for children with comorbid anxiety, depression or stressed family situations. It may also reduce the medication doses needed for symptomatic control [8].

Behavioral therapy—most of which relies on a system of positive and negative reinforcements—consists of interventions designed to alter a child’s behavior at home and school. With time and consistent, repeated application, these interventions are thought to gradually reshape a child’s behavior.

Pharmacotherapy consists of short-term and long-term stimulants. The active ingredients in the majority of both these formulations are methylphenidate (Concerta, Ritalin) and dextroamphetamine (Dexedrine). It is believed that stimulants work to minimize ADHD symptoms by altering the levels of neurotransmitters in the brain. Eight out of 10 children show improvement on stimulants. For children with inattention alone, low doses are generally sufficient. Higher doses may be required for a diagnosis of combined attention deficit and hyperactivity [6].

Conclusion

ADHD is a chronic disorder that affects a substantial number of American children. Untreated, the symptoms of ADHD can make the developmental tasks of childhood nearly impossible and place children at increased risk for depression, school failure and substance abuse as they grow older. The guidelines for establishing a diagnosis of ADHD encourage the use of *DSM-IV* criteria, rely on information obtained about symptoms from a variety of settings and sources, and highlight the need to evaluate for co-existing conditions. Safe and effective treatment that utilizes both behavioral modifications and stimulant medications is available and can dramatically alter the negative course of ADHD.

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Related article

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Health law

Effects of malpractice law on the practice of medicine

by Lee Black, LL.M.

The medical and legal professions have similar goals. For each, the interests of the patient and client are of paramount importance—the professions' respective ethical codes require this. When the patient of a physician becomes the client of an attorney, however, medicine's goal of providing appropriate and safe care may get distorted.

The premise of a medical malpractice action is “a doctor's failure to exercise the degree of care and skill that a physician and surgeon of the same medical specialty would use under similar circumstances” [1]. This area of law, where an individual is compensated for a harm caused by another, has long provided the means to ensure a just outcome, where otherwise there would be none. Yet the modern medical malpractice system appears fraught with injustice, and that perception negatively affects how physicians view and care for patients.

It is frequently argued that, because injured patients are able to obtain large jury awards, medical malpractice causes insurance rates to rise and access to care to decline [2]. Others dispute this claim and instead point to different factors as causing the crisis in medicine [3]. Regardless, the mere perception of injustice and the danger of liability have fueled physician paranoia and distracted physicians from the goal of providing the best and safest care to patients.

Defensive medicine

Paranoia is a strong word but accurate in the sense that physicians often take actions that may not be necessary yet, because of the fear of liability, appear justified to avoid lawsuits. This practice is known as defensive medicine. The defensive practice of medicine is the “deviation from sound medical practice that is induced primarily by a threat of liability” [4] and it includes supplemental care, such as additional testing or treatment; replaced care, such as referral to other physicians; and reduced care, including refusal to treat particular patients [4].

The goal of defensive medicine is to ensure that, if the patient later sues, the physician has gone above and beyond what is required. Defensive medicine is directly traced to medical malpractice law—without the threat of litigation, there would be no reason to practice defensively.

To many, supplemental care is not a bad thing. Why not do everything possible for patients? One reason is the fiscal consequences. Some believe that it is a primary

factor in the high rate of increase of health care spending; others acknowledge the impact but discount its overall effects [5]. Cost aside, the physical and psychological consequences should be of real concern. Diagnostic tests and invasive procedures increase the risk of psychological harm, with the possibility of false positives and ensuing anxiety. Unnecessary invasive procedures increase the risk of physical injury to patients (and therefore can ultimately increase the risk of liability).

No physician wants to be sued on the premise that he or she did not do enough. Yet, the medical profession sets its own standards of care, as the definition of medical malpractice noted above specifies. If other physicians using appropriate judgment and skill would not run a test or use a procedure in a given situation, it need not be done. In many instances, patients themselves request something that is not medically indicated. Physicians should not comply with the request just because a patient asked and the physician fears future liability.

Unfortunately, because physicians set the standard of care, defensive medicine can create new standards. If enough physicians react a certain way to a particular diagnosis, that reaction could very well become the standard [4]. In effect, bad medical practice could become the standard, and what used to be the standard (i.e., a practice formerly considered good medicine on the basis of scientific evidence, not paranoia) could then become a basis for liability.

State recognition of defensive medicine

A study by Studdert et al. [4] notes the difficulty in measuring the true extent of defensive medicine but also provides good evidence that the practice is, to some extent, really happening. Limited knowledge has not stopped legislatures from using concerns about defensive medicine as a basis for tort reform legislation. Utah's legislature states that "the effect of increased insurance premiums and insurance claims is increased health care cost...through the provider's practicing defensive medicine because he views a patient as a potential adversary in a lawsuit" [6]. The legislature of Wisconsin similarly found that "the rising number of suits and claims is forcing both individual and institutional health care providers to practice defensively, to the detriment of the health care provider and the patient" [7].

Questions have been raised as to the accuracy of defensive medicine claims by legislatures. The Wisconsin Supreme Court argued that it is "virtually impossible" to measure defensive medicine accurately, the same conclusion reached by Studdert et al. While there is much anecdotal support in favor of the widespread practice of defensive medicine, governmental agencies have found that this does not contribute significantly to the cost of health care [8]. For this reason, the Wisconsin Supreme Court determined that defensive medicine should not be a factor for damage caps.

A distorted goal of medicine

The debate over the extent and cost of its occurrence notwithstanding, there is enough anecdotal evidence that defensive medicine is being practiced [9]. Some physicians say that they will not treat a patient who is perceived to be litigious, or is

a medical malpractice attorney (or is related to an attorney). There have even been incidents of blacklisting patients who have filed claims in the past [10]. Other physicians say that they provide additional tests or recommend procedures that, while not necessary, could protect them in event of a lawsuit. This is not the way medicine should be practiced, and doing so risks further damaging the patient-physician relationship, as well as access to quality care.

The specific effects of defensive medicine are claimed to include additional and unnecessary care, referral to other physicians and refusing to serve certain patients or patient populations. Certainly, physicians who reduce their practices or leave litigious regions of the country have been major drivers of the American Medical Association's tort reform efforts, primarily because of the recognition that these actions can have severely detrimental consequences for patient populations.

Yet all of these effects stem from a system of law meant to ensure that the injured are properly compensated—an important societal goal. The medical malpractice system can also promote quality care by properly punishing those who fail to provide it. Indeed, quality and access have long been concerns of the legal system. The Emergency Medical Treatment and Active Labor Act (EMTALA) and current efforts to encourage quality care through payment incentives are legislative means for encouraging physicians to meet the goals of medicine.

Defensive medicine, though, is an aberration of both the law and the practice of medicine. Exaggerated or not, publicity surrounding large, but rare, jury verdicts and other horror stories of medical malpractice have led to the perception that the legal system is hostile to physicians and the practice of medicine. In response, some physicians have begun to act in their own best financial interests, rather than the interests of the health and well-being of their patients. This is not to say that patients are no longer the primary concern of physicians, but another factor has entered the equation and, in many ways, corrupted physicians' dedication to patient-centered goals.

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Policy forum

Beyond scarcity: poverty as a contraindication for organ transplantation

by Mary Simmerling, PhD

In almost every aspect of society, the resource-rich have an advantage over the resource-poor. The richer people are, the longer and healthier are their lives [1, 2]. The philosopher Norman Daniels has argued that social policies are responsible for the inequalities that produce health disparities and suggests that we must look upstream from the point of medical delivery when examining the fairness of the distribution of these goods. Daniels uses Rawls' theory of justice as fairness [3] as the basis for his argument that health care is morally unique because it protects an individual's equality of opportunity:

The central moral importance, for purposes of justice, of preventing and treating disease and disability with effective health care services...derives from the way in which protecting normal functioning contributes to protecting opportunity...by keeping people close to normal functioning, health care preserves for people the ability to participate in the political, social and economic life of their society [1].

That is, by keeping people close to normal functioning, medicine also aims at the goal of protecting their equality of opportunity. In this policy forum, I will consider the extent to which medicine has met this goal in the area of organ transplantation.

Daniels claims that a principle that assures fair equality of opportunity will—among other things—prohibit discriminatory barriers to accessing the goods of health care. In the area of organ transplantation, the Uniform Anatomical Gift Act (UAGA) and the National Organ Transplant Act (NOTA) are intended in part to ensure this kind of equity of access to organs [4]. An important purpose of NOTA was to prohibit the assignment of a monetary value to an organ in order to prevent the commercialization of organs, thereby ensuring some level of equity of access to organs—and by extension to organ transplantation. Discrimination in access to deceased donor organs based on the socioeconomic status of the transplant candidate is prohibited. Title III of NOTA on the “Prohibition of Organ Purchases” states that it is “...unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce” [5].

It is in part because of this ban on socioeconomic discrimination that organ transplantation enjoys a privileged position with regard to the presumed fairness of its access system. It is often viewed as one of the only arenas in health care in which everyone has an equal opportunity of access, regardless of race, gender, socioeconomic status, celebrity, etc.—despite an absolute scarcity of resources.

There are currently more than 96,000 people listed on the United Network for Organ Sharing (UNOS) deceased organ donor waiting list, all of whom are waiting for an organ from the approximately 6,000 deceased individuals who donate organs in the U.S. each year [6]. A recent description of the UNOS waiting list and organ distribution system exemplifies the perception of the system's impartiality and fairness:

The rich ones don't get a leg up by mounting publicity campaigns or bribing doctors on the side. The poor ones don't have to worry because they know the list guarantees them an equal opportunity to live. There is no public outcry that the chief executive officer or celebrity has a secret edge over the others on the list [7].

The focus on equity and equality of access to organs is understandable given the persistent and critical scarcity of organs; however, it has overshadowed other critically important justice-related problems facing the transplant community. For instance, attention is often skewed to the particular ways in which the wealthy can leverage their socioeconomic status to gain access to organs, for example, by purchasing them. While it is true that attention should be paid to issues of unequal access to organs based on the greater advantages that wealthier transplant candidates have, the current national focus on access to organs only—and to deceased donor organs in particular—as a measure of equality of access to organ transplantation misses a larger and more pressing issue of inequality at stake in the area of transplantation: that of inequality in access to *successful organ transplantation*.

Only the appearance of equity

Indeed it may at first appear that any problems related to equity and equality of access to organ transplantation are related almost solely to this organ shortage. That is, one might think that if the supply of organs were adequate to meet the demand for them, everyone who needed organs could have them, and questions of equity and equality of access would become largely irrelevant, as they have in the case of dialysis. This, however, is mistaken; equal access to organs does not mean equal access to organ transplantation. Even if there were a sufficient supply of suitable organs for transplantation, the reality is that the uninsured, underinsured and the poor do not currently have an equal opportunity to fully realize the benefits of organ transplantation because they do not have equal access to very expensive and necessary post-transplant immunosuppressant medications. Looking upstream as Daniels suggests, it appears that the wealthy and well-insured do have a socioeconomic advantage over others on the national waiting list precisely because

they can afford the necessary immunosuppressants. Without this medication, an equal opportunity to live cannot be guaranteed, even with a new organ.

The financial burdens associated with access to post-transplant medications can be significant. For example, kidney transplant recipients who qualify for Medicare coverage based solely on end-stage renal disease (ESRD) currently receive 80-percent coverage for immunosuppressant medications for a maximum period of 36 months. Given that the average half-life of a deceased donor kidney transplant (i.e., the point at which 50 percent of the organs will have survived and 50 percent will have failed) is 10 years and the average cost of the immunosuppressant medications is approximately \$1,500 to \$2,000 per month, even with ESRD Medicare coverage, poor kidney transplant recipients can expect to face medication costs of \$300 to \$400 per month for the first three years of their transplant and \$1,500 to \$2,000 per month thereafter, or as much as \$182,400 over 10 years in costs not reimbursed by Medicare [8].

A potential transplant candidate with ESRD on Medicare and employed fulltime earning the 2007 minimum wage rate in Illinois of \$6.50 per hour can expect to spend 26 to 35 percent of her pretax income on these medications alone for her first three years post-transplant. (And that's assuming she is able to continue employment with minimal interruption from her organ transplant procedure and has no supplemental insurance). After paying for her medications, she will have a pretax monthly income of between \$737.50 and \$837.50. Once Medicare coverage ends after three years, even assuming no increase in the costs of immunosuppressant medications, the monthly costs for the immunosuppressant medications necessary to maintain organ function will exceed her monthly income [9].

The costs of post-transplant medications pose a real and significant barrier to successful organ transplantation based on the socioeconomic circumstances of the recipient. This barrier is not neutral; the wealthy do have an edge and the poor are not guaranteed an equal opportunity to live. In some cases, these costs prevent patients who are otherwise medically good candidates for transplantation from making it onto the national deceased organ donor waiting list, either by their own choice or based on the recommendations of their health care team. Those who do get on the waiting list and receive a deceased donor organ transplant but cannot in the end afford the necessary medication will inevitably experience organ failure. Among the survivors, some will go back on dialysis and possibly back on the national deceased donor organ waiting list. Many will die while waiting on the list; others will simply wait to die. Poverty is not only a significant barrier to organ transplantation, it is in effect a de facto contraindication for it.

Even if we could immediately and successfully implement measures to ensure that the poor have an equal opportunity to access suitable organs for transplantation, the reality is that the poor do not currently have an equal opportunity to access the necessary postoperative immunosuppressant medications to maintain and fully realize the benefits of organ transplantation. In addressing solutions to the problem

of access to organ transplantation, it is important to focus on the full scope of the problem in both its pre- and post-operative aspects. In the context of organ transplantation, justice requires both equal access to organs *and* equal access to the medications needed to maintain those transplanted organs. The current inequities in access to successful organ transplantation based on the socioeconomic status of potential transplant recipients do not assure fair equality of opportunity and thus are fundamentally unjust. The structural inequalities inherent in the larger health care and social systems in which organ transplantation takes place are not impartial but pose very real barriers to access based on the socioeconomic status of potential organ transplant candidates.

Equal access to successful transplantation, regardless of the socioeconomic status of the potential organ transplant recipient, would at minimum require guaranteed long-term access to post-transplant immunosuppressant medications—like the guaranteed access to dialysis currently provided by the federal government. Optimally, it would require significant changes to the fundamental structural inequalities inherent in the larger health care and social systems. Right now the only thing that the poor are guaranteed is that there will still be a spot open for them at the dialysis center if and when their transplanted kidneys fail because they cannot afford the necessary immunosuppressant medications to maintain organ function. When one looks upstream from the point of access to organs, one sees that the current system is not impartial. Moreover, its partiality is not just.

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Medicine and society

End-of-life care and the goals of medicine

by Bruce Jennings, MA

From the Quinlan case in 1975 to the Schiavo case in 2004, American law and medicine have struggled with quality, choice and ethics in end-of-life care. A tremendous amount of attention has been paid to these problems in the medical and bioethical literature. There has also been a great deal of public policy change through the actions of the legislatures and the courts [1]. Yet there remains a large gap between theory and practice in end-of-life care; a gap between what the law and ethics say ought to be done and what actually happens in hospitals and nursing homes [2]. Aggressive life-prolonging interventions remain the default treatment in American medicine, and palliative care is too often given short shrift [3].

End-of-life care reform has aimed at answering two questions. First, what constitutes sound decision making in the invasive medical treatment and management of critically and terminally ill patients? Second, what values should govern the balance we strike in our health care institutions and practice patterns between errors of excessive overtreatment, on the one hand, and errors of neglectful undertreatment, on the other? The power of medical interventions and technologies to prolong biological functioning is substantial, albeit still imperfect, and it is not always beneficial or benign in its effects on patients or on families or even on health care staff [4].

The answer that society has given to these two questions has placed great emphasis on the subjective values and preferences of the individual patient. In a word, dying is a personal matter and it should be directed as much as possible by the individual and not determined by the state. Autonomy, not communal values—such as sanctity of life or utilitarian quality of life—should govern [5-9].

Rights and rules can't replace relationships

There is a paradox at the heart of our society's approach to end-of-life decision making. We want to particularize these decisions, keeping them as close to the bedside and as close to the intimacy of the family circle and the patient-physician relationship as possible. Yet we have made general rules and laws about how this process should work, what standards it should follow and so on. The result has been that the intimacy and particularity we strive for is too often lost in a rather legalistic and bureaucratic mentality. Many hospitals confer greater importance on paper trails and formal compliance than on good listening, understanding, empathy and patience.

Good end-of-life care is not some stranger at the bedside. It is the same thing as good medical care; its goals and the goals of medicine are intertwined. Sad to say, this connection has been largely forgotten or overlooked in much of the commentary. A large part of the reason, I believe, is that the early efforts to change and improve end-of-life care grew out of the patients' rights movement and a cultural backlash against medical paternalism, which, in turn, were part of a more general questioning of all forms of authority in society [10]. This movement, from the 1970s on, rejected physicians' paternalistic practice of withholding information and even deceiving patients about their diagnosis and prognosis [11, 12]. Physicians, in fact, even decided on their own to withhold life-prolonging interventions, without patient or family consent, and thought about this as exercising a central moral tenet of the practice of medicine: namely, to take upon oneself the moral and emotional burden of making such life and death choices in order to spare laypersons from bearing it.

It is not my intent to idealize this older conception of doctoring or to defend the practice of medical paternalism. But I would point out that the first generation of end-of-life reformers made the pendulum swing to the opposite extreme. They enshrined, perhaps without fully intending to do so, a very individualistic conception of autonomy and patients' rights. If this new framework avoids some of the abuses, self-deceptions and problems of professional paternalism, it nonetheless has unresolved problems and unnoticed blind spots of its own.

One of the blind spots of the autonomy framework, I believe, is the redefined role of the physician that reduces the physician to a technical expert and advisor primarily, rather than a reflective practitioner and a moral decision maker in his or her own right. Amid the rights of the competent patient and the authority of health care agents and advance directives, the physician is relegated to the ethical sidelines. The ends of medical care are value-laden and therefore the province of the patient and family and intimates only. The doctor is there only to facilitate the "value-neutral" medical means to attain those ends.

Don't run for the moral sidelines

Physicians themselves, it must be said, have colluded with this pendulum shift. As educators, they have made medical education more and more a form of technical training. They have promised the public miracle cures and constant progress and have fueled expectations that often come back to haunt them in the end-of-life setting. They have indeed fallen under the spell of their own awesome technology and erred on the side of overtreatment far more often than they have erred on the side of undertreatment [3]. They have been inattentive for too long to nontechnologically oriented forms of hospice and palliative care, still seeing palliation as a hand-off to others and not as a skill set that they, even as interventionists and intensivists, should add to their own armamentarium [13]. There is something seemingly safe and comfortable about playing the role of technical expert and advisor and stepping out of the value-laden loop of decisions near the end of life. The older, heroically paternalistic physician's calling was a heavy yoke to bear. The moral sidelines are an attractive place to be.

What is wrong with this picture? It is empirically false, and it is conceptually misguided. In actual end-of-life care, physicians are far from powerless. What they say and how they say it inevitably wields tremendous, in most cases decisive, influence on the choices made by patients—and especially by the emotional families of incapacitated patients [10, 14-16]. And it is conceptually misguided because physicians do not respond to patient and family values in a merely passive way; to some extent they shape and define those very values, not explicitly or overtly perhaps, but through a biopsychosocial idiom (about quality of life, about suffering, about dying “naturally” and about what is seemly and appropriate) that is hardly value-neutral. So the clear separation between ends and means—value-based goals and technical options—is a false and misleading dichotomy in all medical practice, and particularly in end-of-life care [15].

Becoming an ethical practitioner

There is a middle ground between being a moralistic paternalist and an amoral technician. It is a ground on which a physician can still be a reflective, ethically oriented practitioner without being an overweening protector or tyrant [17]. To locate that ground, we need to revisit serious reflection on the goals of medicine.

Discussions of the goals of medicine are replete with stand-alone principles. Sustain and protect life. Restore and promote health. Respect autonomy and human dignity. None of these alone, crucial as it is, can render the meaning and telos of medicine adequately. In the debate over the legalization of physician-assisted suicide during the 1990s, one often heard the goal of preserving life pitted against the goal of relieving suffering. This was shaping the tradition of medicine’s self-understanding to fit the needs of the argument, not allowing reflection on the goals of medicine to inform and enlighten the argument.

My own position on the goals and philosophy of medicine is a pluralistic one. There is no single Archimedean point for doctoring. The practice of medicine must: (a) comprehend scientifically, but nonreductively, the ecosystemic, metabolic living processes of the human body, and (b) understand interpretatively the meaningful agency and the socially embedded relational character of the human mind and self.

Medicine sometimes prevents disease, sometimes cures, sometimes restores function or rehabilitates, and sometimes relieves or palliates [18]. Medicine is rooted in a science of the body, but its practice involves establishing and nurturing a relationship with persons in an interpretation of meaning [19, 20]. Medical practice is always relational and interpretative; it is not primarily manipulative and explanatory. It relates to persons with minds as well as bodies, and it helps the mind make sense of what the body (including the brain) is doing. Not with bodies in general, but with particular bodies. Not with persons or minds in general, but with particular persons in particular circumstances. Medicine, at its best, makes sense; it makes meaning, moral meaning. Such meaning rarely, if ever, grows out of a doctor’s repository of knowledge and technical skill alone. It grows out of practical, concrete experience.

Understanding and promoting lived meaning of unique individuals here and now—that is the multifaceted goal—perhaps I should say the complex of goals—of medicine [21]. We won't make much headway at improving the care of the dying (or anyone else) until we put this understanding, judgment and moral agency at the center of our social dialogue about the profession of medicine.

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Medicine and society

Achieving a shared view of treatment goals

by Kenneth A. Richman, PhD

To address this issue's theme, I want to consider the goals of particular encounters with particular patients. How these are set and pursued is central to the ethics of the clinical encounter. It is an ethical matter because being thoughtful about the goals of care helps physicians satisfy their obligation to provide medical benefit to the patient. It is an ethical matter also because of the physician's duty of respect for patients. Pursuing goals without patient buy-in is not just likely to fail, but is, generally speaking, contrary to the physician's duty to respect patients as persons. Respecting patients as persons requires, at a minimum, allowing them to veto the pursuit of certain goals, even those that seem to the physician to be clearly in the patients' interest. Like beneficence, respect for patients can help physicians identify appropriate goals, and it can also be a goal in itself. But it would be a mistake to overlook the fact that patients are not the only persons involved in the medical encounter who deserve respect. The physician can also have relevant goals for the encounter that may not fall under the categories described so far. Ignoring any one of these categories of goals can lead to miscommunication and unethical decisions.

The thoughtful reader will have noted that these goals can conflict with one another. That's one factor that makes the clinical encounter interesting. These potential conflicts will remain in the background for most everyday encounters. When communication seems to break down, however, or when physicians begin to feel frustrated with patient questions or noncompliance, making these goals explicit and setting them out for examination can help to clarify and address or resolve the issue.

Goals relating to medical benefit are often the simplest to manage. The patient might articulate her treatment goals as feeling better and returning to work; for the physician the goal of treatment might be to eliminate an infection. "Fill this prescription, take the pills as directed and come back if your fever persists." Patient complies. Mission accomplished for all parties. Does it matter that the patient and physician think differently about the goals? Not as long as the physician successfully communicates her medical goals for treatment to the patient.

Physician's duty to explain goals

Assuming that nothing is interfering with communication, the physician has the responsibility to explain the goals of treatment as she conceives them. She is, after all, the active party, acting on the patient, on the patient's behalf and as the patient's agent. Given that the nature of an action is determined by the intention of the agent

(whether a student is stretching his arm or signaling that he wants to ask a question depends on what's going on in his head—on his intention [1]), a patient cannot fully consent to a clinician's action or adopt her recommendation without understanding her goal for that action—what's in her head.

It is important to note here that our actions and goals are defined by how we think of them, even if our thinking fails to account for relevant facts about the world. (Students of philosophy may recognize the *de re/de dicto* distinction here.) For instance, the goal of visiting the gravesite of Mark Twain is not necessarily the same as the goal of visiting the gravesite of Samuel Clemens. Someone who held the first goal could truthfully say that she did not hold the second one, even though the gravesite of Mark Twain is precisely the same gravesite as that of Samuel Clemens. Similarly, a reasonable patient who knows that he has a fractured shoulder blade might be surprised to hear that he has a fractured scapula. Like actions, what goals a person has depends on what is in that person's head.

The features of actions and goals just discussed—that we cannot know what action is being performed without knowing what is in the agent's head and that actions and goals are what a given individual thinks they are—support the transparency model of informed consent, according to which "...disclosure is adequate when the physician's basic thinking has been rendered transparent to the patient" [2]. These features of goals also show how difficult transparency can be and how easy it can be for a patient to miss or misunderstand what a physician is doing or trying to do.

Patients generally have no reciprocal duty to make their goals transparent to the clinician, although one could imagine such a duty arising from specific patient-physician relationships. Such a duty might arise, for example, in a psychotherapeutic relationship or when the patient requests a treatment (such as a medication she read about on the Internet) and is initiating an encounter in which the physician is asked to act on the patient's intentions rather than vice versa.

The goals that patients have for the medical encounter often can be described in more simple terms than can those of their physicians, even though the patient's role in therapeutic relationships and decision making can be much more complicated. To give a personal example, I recently dislocated my right shoulder. As a patient, my short-term goals for treatment are to restore my ability to pick up my twin infant sons, to write on chalkboards with my right hand (as my students will attest, my left-handed writing is nearly illegible) and to avoid pain. My orthopedist's goals for my treatment probably have more to do with tendons, nerves, cartilage, etc. Obviously, this is not a case of conflicting goals. In principle (and, I dearly hope, in fact) both sets of goals can be satisfied. In this case I am likely to appreciate many of the implications of the physician's goals as he attempts to make the reasons behind his recommendations clear. But if I can't see how they relate to *my* recovery goals under the descriptions *I* give them, I will be confused, dissatisfied with the physician and much less likely to comply with treatment.

Getting patients to do what's good for them is an important goal of doctor-patient communication and a good reason to listen carefully to how patients describe their goals. Aside from diagnosis, compliance seems to be the primary reason given to medical students for listening to patients [3]. But listening to patients in this way for this reason is insufficient for respecting patients or for patient-centered care.

Defining health by disclosing goals

This is where things get even more interesting. I have argued elsewhere that an important aspect of what we mean when we talk of health refers to the ability to do the things we reasonably want to do [4]. What makes my shoulder injury unhealthy for me is that I became suddenly unable to do certain things that I want to do—for example, to reach into my sons' cribs when they wake up crying. This is not to deny the underlying physiological causes of this inability. But if the changes in ability occurred without the physiological changes, I would still be unhealthy simply because doing these things is a reasonable goal I have for my life. This perspective on the nature of health suggests that we cannot assess what would count as contributing to medical benefit (health of the patient) without understanding the patient's goals.

Of course, patient goals can be unrealistic, based on fears or false beliefs. They can be immoral, as when a patient wants treatment for his trigger finger in order to commit murder. They can be just odd, as when a patient wants to treat his arthritis in order to carve pencils into miniature totem poles. Patients can also have goals that are not directly related to a present illness, as when a patient mostly needs reassurance or a few minutes of conversation. When patient goals for an encounter seem a bit off, a lot can be gained simply by asking about the patient's hopes and expectations. Where the expectations are very different from yours, ask the patient why she has those goals or why she thinks they can be achieved. In some cases, the most effective part of the encounter can be some goal therapy, achieved by gently addressing false assumptions or faulty reasoning.

Even if we think of goals as inscrutable preferences (there's no accounting for taste, as they say), simple belief-desire psychology reminds us that a change in belief can effect a change in desires. For instance, if I come to believe that chocolate causes warts, my desire for chocolate will wane. Goal therapy can be thought of as a species of cognitive behavioral therapy (CBT). Some professional philosophers have developed related techniques based explicitly on the traditions and tools of their field and practice what is called philosophical counseling. Both of these traditions involve working with patients to identify false beliefs or bad reasoning. For instance, patients can have false beliefs about the efficacy or side effects of a treatment; they can also make mistakes of logic such as overgeneralization or failing to recognize patterns in symptoms. Of course, this type of therapy is done best by the pros, but they don't have a monopoly on truth and logic. As one experienced philosophical counselor puts it, "Reason is drug-free, internal medicine" [5].

Clinicians might have goals for interactions with their patients that are outside the categories discussed so far. For instance, it is legitimate for physicians to aim for efficiency in order to leave time for other responsibilities. They might also want to limit the number of times a patient comes to the clinic in order to keep costs down for everyone involved. My main point is that the goals of medicine are not a simple matter. When a clinical encounter isn't going well, making these goals explicit may be just what is needed. Where necessary, a little goal therapy can go a long way.

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1. This example is used to excellent effect by Stanley Fish in *Is There a Text in This Class? The Authority of Interpretive Communities*. Cambridge, MA: Harvard University Press; 1982.
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4. See, for example, Richman KA, Budson AE. Health of organisms and health of persons: an embedded instrumentalist approach. *Theor Med Bioeth*. 2000;21(4):339-352. Several other writers have adopted this general line with respect to understanding health, e.g.: Nordenfelt L. *On the Nature of Health: An Action-Theoretic Approach*. Boston, MA: D. Reidel; 1987; Porn I. An equilibrium model of health. In: Nordenfelt L, Lindahl BIB, eds. *Health, Disease, and Causal Explanations in Medicine*. Boston, MA: D. Reidel; 1984:3-9.
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Medical humanities

Saint Anthony's Fire and AIDS: two altarpieces and the oft-forgotten goals of medicine

by Barbara A. Hinze, MA

Sixteenth-century Isenheim, in what is now France, witnessed the anguish of those suffering from a mysterious disease called Saint Anthony's Fire (now commonly believed to be ergotism, caused by a fungus in rye flour). Often reaching epidemic proportions throughout the Middle Ages, this illness brought horrific suffering: nausea, vomiting, seizures, hallucinations, sores, gangrene and inflammation of nerve endings, making those afflicted by it feel as if their bodies were on fire. Sufferers would come to the Antonite monastery hospital seeking relief. To celebrate deliverance from this plague, the monks commissioned Matthias Grunewald to create an altarpiece for the monastery chapel. The [Isenheim Altarpiece](#) became one of the most important pieces of art of the Renaissance, a testament to the meaning and the mystery of suffering and the hope of redemption and restoration. Much scholarship has been directed toward the altarpiece in all of its complexity—both in its communication of doctrine and in its evocation of pain and isolation among those who suffered from Saint Anthony's Fire [1].

During the 1980s, AIDS spread throughout much of sub-Saharan Africa including the small fishing village of Hamburg, South Africa. It afflicted an estimated one-third of all adults in the Keiskamma River Valley. Those stricken with the disease were often isolated, dying in their parents' homes and then buried in cemeteries outside of town. Shame was strong, and the community remained silent—until 2002 when Dr. Carol Hofmeyr began to treat patients with HIV/AIDS. Hofmeyr and her husband, also a physician, worked to get AIDS medications to the area and established a hospice and treatment center in Hamburg. Hofmeyr, who studied art history, initiated a program to teach embroidery to local women, both for economic reasons and as a means of sharing their experiences of loss. After initial projects including a large tapestry depicting their region's history, the women began to plan their next project. Hofmeyr told the women about the Isenheim Altarpiece in France, which she had recently seen. The group considered how they might reinterpret it, and thus began the work of turning experience into embroidery (see figure 1) [2-4].



Figure 1. Keiskamma Altarpiece
 By permission of the UCLA AIDS Institute.
 Photo credit: Boza Ivanovic.

It took 130 women and several men approximately six months to finish the Keiskamma Altarpiece. Like the Isenheim, the Keiskamma Altarpiece is monumental, 13 feet tall and 22 feet wide, with three levels of panels. Also echoing the Isenheim Altarpiece, the three levels of the Keiskamma panels dramatically portray the sense of purpose and shared stories that drew the artists together. Hofmeyr describes the creation of the Keiskamma Altarpiece as a “turning point in our community’s relationship with HIV and AIDS...embod[ying] not just our fears and our losses but the slow restoration of hope in our community” [5].

“Be with me:” the sometimes forgotten goals of medicine

What turn-of-the 21st century Hamburg, South Africa, and turn-of-the 16th century Isenheim in Alsace Lorraine share—the experience of plague and their responses to it—informs, or should inform the goals and practice of medicine in a time where we increasingly look to technology for cure. In the broadest sense, the goals of medicine are to prevent or cure when possible and to care for patients when cure is not possible. When Grunewald created his altarpiece, the cause of Saint Anthony’s Fire was still unknown, and emphasis was placed on the alleviation of pain and transformation of suffering [6].

As knowledge in disease processes and technology has developed, however, the emphasis in medicine has shifted to cure [7]. This is obviously not a bad thing in and

of itself. Yet, one consequence of this shift has been the introduction of a clinical narrative of the patient that acknowledges neither the illness experience nor the relational aspect of human experience—a narrative that silences the voice of the patient [8]. The patient is objectified, becoming a body with an illness. Yet suffering is more than the physical presentation of an illness or disease. Thus, the clinical narrative eclipses the patient’s experience of suffering and its impact on her relationships. Isolated once by an illness, the patient is isolated again within the context of the patient-physician encounter.

Rita Charon puts this point so clearly: “Sick people need physicians who can understand their diseases, treat their medical problems, and accompany them through their illnesses” [9]. What does it mean for a physician to accompany a patient through illness? Patient abandonment is discussed in its legal sense, but is it possible to abandon the patient without ever outwardly severing the patient-physician relationship? To the extent that medicine remains myopic in its focus on cure, I would answer yes.

“Let me speak:” narrative as integral to the healing process

How does a physician accompany his patients through illness? Not only do the Isenheim and Keiskamma altarpieces remind us of the often forgotten goals of alleviating and transforming patient suffering and accompanying the patient, they also suggest *how* the patient might be accompanied by illustrating the therapeutic value of telling one’s story. The altarpieces are narratives of illness, suffering, transformation and hope. Patients at the monastery hospital were brought into the chapel to see the altarpiece and pray or perhaps meditate. Although Grunewald may not have had St. Anthony’s Fire, his depiction was a keen acknowledgement of the patients’ suffering. With this sensitive portrayal and hope of transformation, the altarpiece was in essence the story of each patient that came before it.

Arthur Frank refers to the patient as a “wounded storyteller,” “trying to survive in a world that does not immediately make sense [10]. Narratives, an integral part of the healing process, are a response to this upheaval. Frank describes three types of illness narratives: restitution, chaos and quest. Restitution narratives often feature technology and the expectation of getting well. In contrast, chaos narratives seem to have no end or resolution. Quest narratives are concerned with gaining insight as illness becomes a means of personal transformation.

The restitution narrative fits well into a clinical paradigm that focuses narrowly on cure. As Frank notes, patients become ill, visit the doctor, follow recommended treatment and return to their everyday routines as if illness were a temporary detour from normal life. But what happens when suffering is extended or the prognosis uncertain or without hope? These situations are likely to invoke chaos narratives. And perhaps nowhere has this sense of isolation and loss of control been greater than in the experience of Africans with AIDS. The patient is disempowered in her own healing process. Denied time to reflect and form a narrative and unable to give voice to her experience, she surrenders control. Frank argues that “To deny a chaos story is

to deny the person telling this story, and people who are being denied cannot be cared for. People whose reality is denied can remain recipients of treatments and services, but they cannot be participants in empathetic relations of care” [11]. Likewise, Charon argues that physicians must develop “narrative competence” to absorb, interpret and respond to stories [12].

Failing to listen may cause a patient to withhold important information or may result in unfocused and more costly workups or even in incorrect diagnoses [13]. Honoring patient narratives can empower the patient and transform the meaning of suffering. It can improve quality of care and foster genuinely empathetic patient-physician relationships. But what happens when the patient, in physical or emotional illness, cannot speak?

“When I cannot speak, speak for me:” suffering and the relational aspect of healing and transformation

Serious or chronic illnesses can isolate the patient. A clinical paradigm that focuses too narrowly on cure only deepens this isolation. The Isenheim and Keiskamma altarpieces exemplify another way in which the often forgotten goals of medicine may be pursued: the transformation of suffering via the patient’s rejoining of community. The patients at the monastery hospital were welcomed into a community whose narrative not only identified affliction with the sufferings of Christ but also conveyed the possibility of the transformation of suffering into meaning.

This is not to say that meaning must be religious but that there is a spiritual aspect to human transcendence of suffering [14]. Frank’s description of the third kind of illness narrative, the quest, is helpful here. In quest narratives the patient is the hero, searching for a new understanding of the illness experience. In telling how she meets this challenge, the patient creates an ethical practice toward others through recollection, solidarity, commitment and inspiration. When the patient tells her story to correct a past wrong, she practices recollection. In practicing solidarity and commitment, she uses her story to speak along with fellow-sufferers. And in supplying an example of how one might meet this particular challenge, the patient provides inspiration [15].

Because the story-telling involves the other, the quest narrative serves as a means for the patient to rejoin the community of others. As illustrated by the Keiskamma Altarpiece, the story is told not only to create meaning for one’s self but also to speak alongside other community members who have suffered the devastation of AIDS in shared understanding. Those who had once lost their voices have found them. Those who cannot speak are spoken for. Once isolated in illness, those suffering have found their way to a home within their community.

Though the contexts of medicine may change, physicians will always need to attend to goals of alleviating and transforming suffering. Narrative medicine is the work of patient, physician and community. Developing capacities for listening to the stories that shape understanding of illness and suffering is both clinically and morally

required. Not only do the Isenheim and Keiskamma altarpieces exemplify how narratives might inform patient care, they are examples of the kinds of narratives to which we should attend. Whether found in museums, literature or at the patient's bedside, listening to such narratives has the potential to transform the practice of medicine.

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Virtual Mentor

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