NEWSLETTER ON PHILOSOPHY AND MEDICINE

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ANNOUNCEMENTS
common moral consciousness, bioethics as a subdiscipline ethical theory provides a systematic and accurate account of death and end of life decision-making. On the other hand, if the way for medicine to navigate new territory such as brain helping to displace doctrinaire positions. Bioethics can light human choices, is a subdiscipline of moral philosophy that is about actions that are rational or reasonable, then bioethics, what we take right action to be. If, on the one hand, ethics is but illuminating strokes, Deigh frames his answer in terms of theory and right action. Tracing the history of ethics in broad genetic intervention to raise questions about the application raises issues about reproductive choice to show how bioethics how specific policy issues can challenge prioritarianism. He discussed health care allocation to show how ethical theory and the skills of a philosopher can be used to critique and illuminate medical practice.

Papers from the other three panelists are included in this issue. Dan Brock moves in the opposite direction, away from popular practice to an examination of some of the most controversial issues in contemporary bioethics. In his insightful paper, “What Can Bioethics Contribute to Ethical Theory?” Brock shows how bioethics can forward and enrich moral theory. He discusses health care allocation to show how specific policy issues can challenge prioritarianism. He raises issues about reproductive choice to show how bioethics can lead to theoretical revision and refinement. He explores genetic intervention to raise questions about the application of moral theory.

John Deigh focuses his attention on the nature of ethical theory and right action. Tracing the history of ethics in broad but illuminating strokes, Deigh frames his answer in terms of what we take right action to be. If, on the one hand, ethics is about actions that are rational or reasonable, then bioethics, as critical self-reflective application of medical science to human choices, is a subdiscipline of moral philosophy that is consonant with the broader field. Bioethics offers its expertise to the practice of medicine by bringing reason to the floor and helping to displace doctrinaire positions. Bioethics can light the way for medicine to navigate new territory such as brain death and end of life decision-making. On the other hand, if ethical theory provides a systematic and accurate account of common moral consciousness, bioethics as a subdiscipline is challenged and of little use when it comes to the strange and puzzling cases that arise on the cutting edge of medical practice, such as the ethical acceptability of genetic enhancement. On this second view, bioethics waits in the wings while others thrash out the issues, and then provides a systematic survey of the results.

Bernard Gert’s paper, “Is Bioethics a Challenge for Ethical Theory?,” argues that most ethical theories are too abstract to be used in resolving any ethical issues and are harmful to the extent that they encourage people to think that there is always a single correct answer to moral controversies. On the contrary, Gert maintains that his own theory of moral rules, moral ideals, morally relevant considerations for exceptions, and its publicity constraint is relevant and especially useful in bioethics. In his discussion he demonstrates how his theory can be used in resolving the controversy over physician-assisted suicide and in answering a question about withholding information in a particular case.

At the March 2002 meetings of the Central Division, the Committee on Philosophy and Medicine invited four individuals to address issues raised by the tension that exists at the point where the prerogatives of parents and the interests (or rights) of children converge in relation to health care. The four were philosophers Jeffrey Blustein and Kenneth Kipnis, philosopher and pediatrician Lainie Freidman Ross, and pediatrician Joel Fraser. Specifically, the session examined the extent to which, and under what circumstances, and at what age, children should be able to make decisions for themselves. Panelists also addressed deeper issues concerning, for instance, the significance of the family, the role and responsibilities of parents, and the responsibilities of health care professionals in relation to children and adolescents.

Jeffrey Blustein’s discussion, “Parental Authority, Children’s Rights, and Health Care,” is included in this issue of the Newsletter. Blustein briefly reviews the history regarding a variety of philosophical perspectives on the issue of parental authority, and then examines contemporary perspectives regarding the moral status of children and the ability of children to exercise decisional capacity. He concludes by setting out a general framework that challenges and sets the stage for the three other commentaries that will appear in the next issue of the Newsletter.

“Ethical Issues in Home Health Care” by Rosalind Ladd, Lynn Pasquercella, and Sheri Smith is not linked with any Committee panel. In this piece the authors point out that, a good deal of today’s medical care is delivered in the home and provided by non-physicians. This new context for health care raises a new and important consideration for bioethics. The authors discuss how this shift in treatment venue also changes the kinds of issues that arise and the kinds of answers that bioethics can give.

As always, please continue to send along your announcements, letters, papers, poetry, stories so that they can be shared, used, and enjoyed by all. Feel free to volunteer a book or movie review. Contributions and queries should be sent to Rosamond at the address below. For ease in communication please include your phone and fax numbers and your email address.

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FROM THE CHAIR

Kenneth Kipnis

Although the path has been decidedly bumpy, the Committee on Philosophy and Medicine has had a productive year.

We put together three panels, one for each of the 2001-2002 divisional meetings. The Eastern Division’s panel in Atlanta considered whether bioethics constitutes a threat to ethical theory. Rosamond Rhodes put the program together and chaired it. The speakers were Heidi Malm, Bernard Gert, Dan Brock and John Deigh.

The Central Division’s program in Chicago focused on the sources and scope of parental authority in the clinical setting. Mark Sheldon chaired the panel and the speakers included Lainie Friedman Ross, Jeff Blustein and Ken Kipnis. Joel Frader served as commentator. Some of these materials will be appearing in the Newsletter.

The academic year began, as all will recall, with the September 11 attack on New York and Washington. It seemed fitting to address ethical issues that can emerge in the medical response to terrorism. Kelly Freyer-Edwards chaired the session at the Pacific Division session in Seattle. The speakers were Rosamond Rhodes, Tom May and Ken Kipnis.

Having received an APA award for an op-ed he had published, Arthur Caplan has donated his prize money to the Committee on Philosophy and Medicine. We are grateful for the gift and are currently looking into ways to use it.

We now have a small list of email addresses for philosophers with interests in medicine. We have been working to broaden communication beyond the boundaries of the Committee, circulating information about some of the issues under discussion and inviting contributions. If you are interested in being included on this list, send an email to kkipnis@hawaii.edu, placing “P&M List” at the beginning of the subject line and asking to be subscribed. Eventually this may evolve into a roster of interested philosophers.

Something needs to be said about the P&M Newsletter, the work that has been done on it by Editors Rosamond Rhodes and Mark Sheldon, and the many others who have contributed to its quality. Readers will have noticed serious errors in the last issue, introduced after the manuscripts were sent to the national office. We regret the harms and inconveniences that these problems have caused, and are deeply appreciative of the steps taken by the APA to repair the damage to the work of the Newsletter’s contributors and editors.

The Committee continues to work on future sessions for the divisional meetings. We now anticipate panels on the right to health care, empathy in clinical ethics, international health, cybermedicine, and research ethics.
David Thomasma, In Memorial

Thomasine Kushner
University of California, Berkeley

Steve Heilig
San Francisco Medical Society

DAVID THOMASMA, Ph.D.
1939-2002

David Thomasma was always sharing his latest favorite books with his friends. His most recent “find” was Saul Bellow’s Ravelstein. He particularly relished the lines: “The philosopher Sidney Hook had told Ravelstein that philosophy was finished. We have to find jobs for our graduates as medical ethicist in hospitals,” Hook had admitted.” David had long agreed with Stephen Toulmin’s comment, that “medicine saved the life of ethics,” and he took pleasure in the large percentage of philosophy graduates now working in healthcare fields. However, he was fond of saying he was still waiting for the time when health care graduates are hired by philosophy departments.

David’s own career was spent cultivating the common ground between medicine and philosophy. He was one of the first to do so. Looking back he observed, “In our time, ethics itself was not where the action was in philosophy. Instead it lay in philosophy of science, linguistics, logic, epistemology, and critiques of existentialism and phenomenology. Ethics was far softer than these fields, and serious philosophers were justifiably concerned that their departments might suffer a serious blow by becoming involved in medical ethics.”

In the early days of bioethics, David described the image of pioneers carving out a legitimacy in a new land as being apt for the philosophers who took up residence in medical schools. In a memoir he wrote, “As can be readily imagined, philosophy of medicine and the bioethics that emerged from this direct engagement with both the other humanities and with medicine itself was destined to be a philosophy with a difference.”

David played an important role in initiating and developing that difference. The Program on Human Values and Health Sciences he inaugurated in 1973 at the University of Tennessee was one of the first to be established in the country. While at Tennessee, he introduced the practice of ethics rounds and formal ethics consult services in the university hospitals. In 1981 he took his innovative ideas with him when he moved to Loyola University Chicago Medical Center, as well as a new insight that a four year required curriculum was needed that focused less on class time and more on clinical reinforcement.

In addition to being widely recognized as an innovator of programs, a prodigious writer, and renowned speaker, his contributions extend far beyond scholarly publications and theories. David unstintingly lived the credo of helping others to realize their potential. There are legions of professional bioethicists, practicing clinicians, and others who owe much of their knowledge and dedication — and perhaps even their initial interest in the field — to David’s influence. His goal was to create an international community of bioethicists working together, as he often said, “toward good human ends.” He was unsurpassed in his efforts and successes in that regard.

As a proud Frisian, David’s earliest efforts in establishing an international bioethics community were generated by associations with friends and colleagues in the Netherlands during his Fulbright in 1984, the same year he served as president of the Society for Health and Human Values. It remained a source of pleasure that the origins of the European Society of Philosophy of Medicine and Healthcare, and its subsequent journal, are partially attributed to those long and close friendships. His work in international community-building expanded when he was asked by Kluwer Academic Press in the Netherlands to become an editor of Theoretical Medicine & Bioethics in 1985, and later its editor-in-chief in 1989.

In 1992, David’s, by now firmly established, global community formed a pivotal base for a new journal, Co-Edited by the three of us, the Cambridge Quarterly of Healthcare Ethics, published by Cambridge University Press. It is safe to say that the journal survived and thrived during the hazardous years of its infancy in no small part due to his prestige and efforts. In 1997, CQ gave birth to the annual Bioethics Retreat held each year in a different country.

David’s belief that “The communities we create in our personal and professional lives are the ones that matter most,” aptly describes the far-reaching effects he had on countless others. For the many of us who were fortunate enough to know him personally, he was a source of not only inspiration but unrelenting warmth. David was the personification of his ideals, always encouraging, helpful, supportively challenging. An immense number of patients benefited from his counsel and expertise, both directly when he was at the bedside and indirectly through his consultations, teachings, and writings. These very human connections testify to the real strength of David’s legacy.

PAPERS

What Can Bioethics Contribute to Ethical Theory?

Dan W. Brock
Department of Clinical Bioethics
National Institutes of Health

Introduction

The symposium for which this paper was prepared was entitled, “Does Bioethics Represent a Challenge to Ethical Theory?” Some defenders of the methods of particularism or casuistry in bioethics would argue that bioethics illustrates the dispensability of ethical theory. But I believe that neither of these are the proper method for bioethics or applied ethics more generally. Instead, the method that has come to be called reflective equilibrium is what is in fact typically employed, and I believe it is the correct method. In a reflective equilibrium approach, particular concrete moral judgments are brought into equilibrium with more general principles that are part of an overall ethical theory. And so neither bioethics nor applied ethics more generally can dispense with ethical theory.
Rather than bioethics constituting a challenge to ethical theory, I believe it can extend and enrich ethical theory and in this paper I shall illustrate from my own work three ways in which I believe it does that. Let me first summarize the three general points before pursuing each in more detail. First, moral and political theory is often at too high a level of abstraction and generality to address some important bioethics and health policy issues. For example, most theories of justice give special priority to improving the condition of the worse off. Rawls’ theory does so with his Difference Principle and prioritarianism does so in holding that benefiting people matters more morally the worse off those people are. How does this idea apply in the prioritization of health care resources? Answering this question should extend the content of moral theory and provide a bridge to an important concrete policy issue.

Second, bioethics sometimes raises problems that show the need to revise or supplement standard moral principles. For example, reproductive issues in bioethics often concern what kind of, or which, children to create. Perhaps the most important practical case is genetic testing to avoid the transmission of serious genetic disease. Intuitively, this is done to prevent harm to the child who would be born, but standard harm prevention principles do not fit these cases. Different non-person affecting principles are needed for many reproductive choices.

Third, biomedical advances sometimes raise new choices that require determining how familiar moral principles and theories should be applied to them. For example, standard accounts of equality of opportunity accept that natural differences between persons will result in unequal outcomes. Genetic interventions may become possible at some point that could enable us to reduce some of these natural inequalities. Does equality of opportunity support or require our doing so?

**Priority to the Worse off**

I shall now pursue each of these three points in a bit more detail, though of course a full exploration is not possible here. The issue of priority to the worse off arises in the context of many health care resource prioritization decisions. In a national health system it arises when explicit prioritization criteria are adopted and Swedish, Norway, and New Zealand have each adopted a commitment to giving some priority to the worse off. A state Department of Mental Health may have to prioritize between programs serving the severely and chronically mentally ill versus patients with mild to moderate Obsessive Compulsive Disorder. A hospital may have to choose between expanding an intensive care unit versus a clinic for teenage mothers. A Health Department may have to choose between establishing an outreach program for homeless persons versus a hypertension screening program for the general population. And finally, organ transplantation systems must choose criteria for prioritizing between different candidates for scarce organs. Each of these examples raises, in different ways, the question of what priority, if any, should be given to the worse off.

The question of priority to the worse off arises three main issues that I shall address briefly in turn: What is the moral reason for giving priority to the worse off? Who are the worse off for purposes of health care resource prioritization? How much priority should the worse off receive? (Brock 2002) The moral reason for giving priority to the worse off (prioritarianism) might be thought to be a concern for equality in outcomes between persons (outcome egalitarianism). But prioritarianism is a different view than outcome egalitarian and so the latter cannot provide support for the former. For example, consider the following two alternative distributions of welfare between three individuals or groups A, B, and C:

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Distribution 1 is the more equal, but distribution 2 is best for the worst off.

Moreover, outcome egalitarianism is subject to the powerful leveling down objection. As Derek Parfit has put it, according to outcome egalitarianism:

It would in one way be better if we removed the eyes of the sighted, not to give them to the blind, but simply to make the sighted blind. This would in one way be better even if it was in no way better for the blind. This we may find impossible to believe. It is not enough to claim that it would be wrong to produce equality by leveling down. Our objection must be that, if we achieve equality be leveling down, there is nothing good about what we have done. (Parfit 1991)

The view Parfit calls deontic egalitarianism opposes only inequalities that are brought about by unjust actions or institutions. But this too cannot support any general priority to the worse off in health care prioritization because many health inequalities, including those suffered by the worse off, are not the result of injustice; for example inequalities from genetically transmitted disease or from accidents that are no one’s fault.

It might be thought that a commitment to equality of opportunity will provide the needed support. But if we reconsider the example of the two distributions to A, B, and C above and assume it is a distribution of opportunity rather than welfare, then there is again a difference between the distribution with the most equal opportunity and that with the greatest opportunity for the worse off.

The priority view holds that benefiting people, or improving their condition, matters more morally the worse off the people are. One possible reason in support of the priority view might be that the worse off one is, the greater relative improvement a given size health benefit will produce, making it subjectively more important to its recipient. A second reason is that we might believe that the strength of claims for health improvements are greater, the greater the undeserved health deprivation. Of course, this leaves open whether all health deprivations are undeserved. A third possible line of argument might employ contractualist moral reasoning similar to Scanlon’s in which we seek to minimize individual’s moral complaints by treating the most urgent health needs first. (Scanlon 1998) None of these arguments for the priority view, but only the barest suggestions of the direction such arguments might take. Suppose one of these or some other line of reasoning can be successfully developed in support of giving priority to the worse off in health care resource prioritization. We then face the question of who are the worse off for health care resource prioritization.

The answer to this question may seem obvious—the sickest—but it is not. One issue is whether the worse off are the sickest, or those with the worst overall well being. On what might be called the global view the prioritarian position applies to those with worse overall well being. As Thomas Nagel has said, units for distribution in a theory of justice are whole human lives. (Nagel 1979) Moreover, we often think that a person’s being badly off in one aspect of well being can be compensated for by advantages in another aspect. Yet the global view has counterintuitive implications. In the clinical context it could imply that we should treat first a poor person who is much less seriously ill or injured than a rich person. In fact, we seem to apply what has been called a “separate
spheres’ view according to which health and health care are treated as a separate distributive sphere with only health relevant to the distribution of health care. (Kamm 1993; Brock forthcoming) This might be for moral reasons, perhaps of a Kantian nature, or for pragmatic policy reasons; physicians and health policymakers are trained to evaluate health, not overall well being, which would be deeply controversial in any event.

Even if we adopt a separate spheres view other questions remain. For example, are the worse off those with worse overall health or those who are sickest now. These will diverge in the case of those with other background health deficits different from the conditions for which they are now in need of treatment; for example, patients with chronic illness or disability distinct from the conditions for which they now need treatment may be in worse overall health, but less sick now, than other patients. A second question is whether past health is relevant or only current health. Arguments for treating health and health care as a separate distributive sphere will not answer this question. Persons are temporally extended beings who are treated by social practices as living a unified life over time. If the priority view is to express a special concern for those with worse health in prioritizing scarce health care resources, then it would seem that past, and perhaps also predicted future, health should count. How much ill health people have suffered seems a function both of the degree and duration of their disability, and if so this would imply special priority to those with long-term chronic disabilities and illnesses. If these and other issues can be settled in deciding who are the worse off for purposes of health care resource prioritization, we then face the issue of how much priority to give the worse off.

Giving absolute priority to the worse off is implausible because it leads to what has been called the “bottomless pit” problem. It could require us to pour very great resources into improving the condition of the extremely seriously disabled even if doing so produced only minimal benefits to them. Giving priority to the worse off is only one of our moral concerns, even in the context of distributive justice, and it must be balanced with other moral concerns such as the degree of benefits produced. Ideally, we would like a principled basis for balancing these disparate moral concerns, but it is not clear what that basis would be.

I have presented a number of issues in thinking through how a special concern for the worse off that is common to many conceptions of justice might apply in the context of prioritization of health care resources. I have not tried to resolve these issues here, but I believe work on these issues can extend and give detail to theories of justice and thereby bring them into closer contact with important policy choices.

Genetic Testing and the Non-Identity Problem

My second example concerns how particular bioethics issues can show the need for new or revised moral principles to deal with those issues. The point is made most clearly in the critique from the disability rights community of the practice of prenatal genetic testing for various diseases or disabilities in order to avoid bringing into existence persons with those conditions, most commonly by aborting an affected fetus. (Buchanan, Brock, Daniels and Wikler 2000) One central objection to this practice rests on distinguishing preventing people from becoming disabled and preventing the existence of disabled people. The former is uncontroversial whereas the latter is said to conflict people with their disabilities, to see them only in terms of their disabilities. Moreover, using genetic testing and either pre conception measures or abortion to prevent the existence of disabled persons seems straightforwardly to imply the judgment that it would have been better if persons with the disability in question had never been born. Yet the vast majority of genetic tests are for conditions or diseases that leave individuals who have them with a life that is from the person’s perspective well worth living; they are glad to be alive and value their lives despite their disabilities. So the question arises for whose sake is genetic testing and the prevention of the creation of persons who would have disabilities done?

The problem, which Derek Parfit has labeled the Non-Identity problem, can be illustrated with a case adapted from Parfit, call it the Pregnancy Case. (Parfit 1984) Suppose that a woman is told by her physician that she has a condition such that if she gets pregnant now her child will almost certainly be moderately mentally retarded, whereas if she takes a simple and safe medication for two months there is every reason to believe that she will have a normal child. If the woman fails to take the medication and wait to get pregnant because doing so would interfere with her vacation travel plans, but instead gets pregnant and gives birth to a mentally retarded child, most persons would judge that she has acted wrongly, and in particular wrongs her child. But why is her action wrong? It would seem that she has not harmed her child since taking the medication and waiting to get pregnant would have resulted in a different child being born and would have denied her child a worthwhile and valuable, though disabled, life. That would not have been better for her child. But if she does not harm her child then she apparently does not wrong her child, and so how can what she does be wrong? Indeed, since no one appears to be harmed or wronged by what she does, how can her child’s disability even constitute any moral reason at all for her to have taken the medication and waited to get pregnant?

The difficulty arises from a feature of typical harm prevention moral principles that has been called their person affecting feature. Here is an example of such a principle, call it Person-Affecting Harm Prevention (PAHP):

Those individuals responsible for another’s welfare are morally required to cause or let him or her suffer serious and inadequately compensated harm or loss of benefit that they could have prevented without imposing substantial burdens or costs on themselves or others.

What makes this principle person-affecting is that one and the same person is either harmed if it is violated or not harmed if it is followed; it applies in same-person cases where the same persons exist in the different alternative courses of action. That is why it does not apply to the Pregnancy Case where a different child is created depending on what the woman does. Nor does it apply to typical cases of genetic testing to prevent the birth of a child with a serious genetic disease because there a fetus is aborted and the parents generally try again for a normal pregnancy.

What is needed to apply to these same number but not same persons cases are non person affecting principles that allow for the prevention of harm not to a single individual, but by substituting the creation of an unharmed individual for the creation of a harmed individual. This is what should have been done in the Pregnancy Case and in some cases of genetic testing where a couple can prevent the birth of a seriously disabled child with a high likelihood of substituting a non disabled child in its place. In real cases, unlike the Pregnancy Case, there will be many factors that affect whether the parents are morally required all things considered to take the steps...
necessary to prevent the creation of a child with the genetic disease. My point here is only that these reproductive choices illustrate the need to supplement traditional person affecting harm principles in moral theories with non person affecting principles that can apply to these genesis cases of the choice of which individuals to create. How to combine person affecting and non person affecting principles in a single coherent theory is an unresolved problem in moral theory, but bioethics illustrates both the need for person affecting principles and the need to develop an overall moral theory that incorporates them in a coherent and acceptable manner.

**Genetic Modification and Equality of Opportunity**

My last example of how bioethics can force the extension and enrichment of moral theory concerns equality of opportunity. (Buchanan, Brock, Daniels and Wikler 2000) Here, advances in biotechnology are likely over time to force the application of a principle of equality of opportunity into a new domain requiring us to rethink the meaning of and the nature of our commitment to equality of opportunity. Equality of opportunity is an aspect of fairness in the distribution of scarce roles or benefits. Equality of opportunity is not a simple concept, but rather has several interpretations or components. Formal equality of opportunity attacks legal or quasi-legal constraints on people's freedom to compete for scarce benefits or roles; rules that no Blacks or Jews need apply, or strict quota systems, violate formal equality of opportunity. However, formal equality of opportunity is a very limited conception. Fair equality of opportunity adds two additional components. First, qualifying conditions for scarce roles should be reasonably related to performance in those roles; for example, promotion exams for various jobs have been attacked on this basis. Second, social and environmental barriers to success in competition for scarce benefits and roles should be removed; for example, large financial barriers to higher education can violate this aspect of equality of opportunity.

Even if formal and fair equality of opportunity are fully satisfied, there will still be substantial inequalities in outcomes between persons, and one important source of those inequalities will be genetically based differences in their natural talents and abilities. Are these genetically based inequalities unfair and a violation of equality of opportunity? Now, we in effect say, "Sorry, but there's nothing we can do about them—genetic differences between persons are beyond our control." We may try to put limits on the extent to which these natural differences result in differences in power, wealth, and other social advantages, but even a relatively egalitarian principle like John Rawls' Difference Principle does not seek to eliminate all effects of good or bad luck in the genetic lottery. In the future, however, although no one knows when and to what extent, genetic interventions may become possible that would reduce some of these natural inequalities between persons. Would a commitment to equality of opportunity provide a moral reason to do so? It appears that it would. If we learn that children's IQ's have been reduced as a result of exposure to lead paint, equality of opportunity requires that we remove that environmental barrier to their competing on a level playing field with others in the many contexts in which intelligence is important to success. Likewise, if a genetic intervention became possible that would enable us to raise the IQ's of children who would otherwise have below average IQ's it would seem that securing them equality of opportunity with others with higher IQ's would support providing the interventions. In the extreme, if we had full control over people's genetic inheritance, which of course we will not, equality of opportunity would seem to support the removal of any genetically based disadvantage individuals suffered in competitions for scarce benefits and roles, and this would seem to collapse equality of opportunity into equality as identity, as Bernard Williams pointed out many years ago. (Williams 1962) And this would put equality of opportunity into deeper and more pervasive conflict with other social values and institutions such as the family.

In our book, we distinguished two variants of the level playing field account of equality of opportunity. (Buchanan, Brock, Daniels, and Wikler 2000) What we called the structural account of equality of opportunity. (Buchanan, Brock, Daniels, and Wikler 2000) What we called the structural account draws on the idea of equality of opportunity as requiring that careers be open to talents. It focuses on removing the opportunity limiting effects of social injustices and ensuring that individuals will be normal competitors in the social system. Health care's role for equality of opportunity is to counter the effects of diseases that cause adverse deviations in normal function, and that in turn limit people's ability to be normal competitors. What we called the brute luck account holds that persons should not suffer lesser opportunities than others through no fault of their own and from factors beyond their control. Both accounts have similar implications for social inequalities arising from past injustice, but they diverge in other cases.

An example will illustrate the difference. Normal intelligence, even in the absence of disease, varies among individuals across a wide range. Consider a case of Adam and Bert, both of whom have IQ's of 90, well within the normal range and both of whom were raised in similar social environments. Adam's IQ is his "native intelligence" whereas Bert's IQ had been 100 but was reduced by a childhood neurological disease. Suppose a medical intervention is developed, whether genetic or pharmacological, which will counter the effects of Bert's disease and raise his IQ back to 100, but the intervention appears to have the potential to raise Adam's IQ to that level as well. (Readers will recognize the parallels with the widely discussed case of growth hormone.) Is there any moral difference in the claim of each on grounds of equality of opportunity to obtain this medical intervention?

On the structural account the role of health care is to counter the effects of disease on normal opportunity and on people's ability to function as normal competitors in the social system. According to it, Bert should get the intervention to counter the effects of disease on his level of intellectual function, but Adam should not get it because his intelligence is his natural level and leaves him a normal competitor, though at the lower end of the normal range of intellectual function. On the brute luck account, on the other hand, both Adam and Bert suffer an unchosen disadvantage through no fault of their own and have equal claims to a medical intervention that could remove that disadvantage. Moreover, if we at some point gained the ability to undertake direct genetic interventions in the natural lottery to ensure that Adam doesn't suffer a below average IQ, we should do so. Examples like this illustrate the apparent force of the brute luck interpretation of equality of opportunity since the difference between Adam and Bert with regard to their opportunities appears to be morally irrelevant.

Does this mean that brute luck theorists are committed to genetic equality and to equalizing people's natural assets? I believe the answer is no for at least two reasons. First, there are no fixed accounts of natural assets and their value because what counts as a natural asset or deficit is partly determined by the social structure and the system of social cooperation. The value of traits will change over time as a society's dominant cooperative framework changes. Second, in a free society there will be permanent differences among reasonable people about the nature of the good and of a good life. This value pluralism implies different views about what are, and
the relative value of, natural assets. Surface agreement can sometimes mask deeper disagreement; for example, one person may describe Celia as a real go-getter who takes the initiative whereas another views her as overly pushy, or some may view Doris as very altruistic in her concern for others whereas others may view her as lacking self respect and an ability to assert her own interests. Clearly, if we had to ensure that individuals had packages of natural assets of equivalent overall value, what are equivalent overall packages would be even more controversial. Even on the brute luck view then, the most that may be possible is a consensus on a “decent minimum” of natural assets for all, if that were within our powers. I emphasize that my purpose here has certainly not been to settle which interpretation of equality of opportunity is correct; that is a vastly more complex issue than could be pursued here. Instead, my point is the much more modest one that advances in genetic technology which bring us some measure of control over people’s natural assets will raise the deep, difficult, and controversial issue of how our conceptions of equality of opportunity should be applied to them.

Conclusion

I have not argued that bioethics represents a challenge to ethical theory; ethical theory is not in my view in any fundamental sense mistaken or misconceived and so bioethics does not and could not show that. But I have sought to illustrate that there are benefits to be had for moral theory from some work in bioethics. Bioethics can enrich moral theory by detailing the application of very general moral principles, and thereby bring moral theory more effectively to bear on issues of practice and policy. Bioethics can contribute to the extension or revision of moral theory by showing the need for new or revised moral principles to deal with certain bioethical problems. And finally, bioethics can contribute to extending moral theory by applying moral principles to a new domain of problems brought on by advances in biomedicine and biotechnology.

References


Parfit, Derek (1991) “Equality or Priority,” The Lindley Lecture. Copyright: Department of Philosophy, University of Kansas.


Does Bioethics Represent a Challenge to Ethical Theory?

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The question before us, “Does bioethics represent a challenge to ethical theory?” concerns the nature of ethics as much as it concerns how bioethics bears on the discipline. Accordingly, before dealing with it, I want first to consider what an ethical theory is. This is itself a controversial matter. No single position has achieved a consensus among philosophers. And, as we shall see, whether bioethics represents a challenge to ethical theory depends on which position in this controversy is understood to be in place.

The main source of the controversy is disagreement about the primary subject of ethical theory. Some ethical theories take it to be duties. Others take it to be virtues. Still others take it to be intrinsic value or the highest good, the summum bonum, of human life. Each of these positions has a long tradition. Since Sidgwick, however, it has become customary to take the primary subject of ethical theory to be right action or as Sidgwick put it, what we affirm when we make judgments of the form x ought to be done or it is right to do x, where x is a voluntary action and where ‘ought’ and ‘right’ are used in a strict and distinctly ethical sense.1 Sidgwick’s regimentation of the field has brought a degree of consensus on the primary subject of ethical theory, but it hasn’t fully resolved the question. A good deal of uncertainty still remains concerning how to construe the strict and distinctly ethical sense of ‘ought’ and ‘right’ that Sidgwick isolated and used to define the judgments that represent the primary subject of ethical theory. In other words, though there is widespread agreement on taking right action as the primary subject of ethical theory, disagreement remains about what is meant by ‘right action’.

Sidgwick understood it to mean action that is ultimately rational or reasonable. That is, for Sidgwick, to ask what ought to be done or what it would be right to do, in the strictly ethical sense of ‘ought’ and ‘right’, is to ask what would ultimately be the rational or reasonable thing to do.2 Accordingly, different ethical theories correspond, on his view, to different assumptions about the fundamental principles or ultimate ends of rational action, and he then narrowed and reduced these assumptions to three.3 One of them is now a source of controversy. It is the assumption that a person’s own happiness is always for that person an ultimate end of rational action, though it may not be for others. Sidgwick, however, did not question its validity. Common sense, he observed, as well as philosophical tradition, holds that it is never against reason to act in furtherance of one’s own happiness. It followed that egoism, the systematic exposition of general judgments concerning how best to promote one’s own happiness, counts as an ethical theory, for these judgments are judgments of the form x ought to be done, in the strict ethical sense of ‘ought’ that Sidgwick isolated. I don’t know how contentious this result was in Sidgwick’s time. My guess is that it was not especially contentious. Belief in the coincidence of the dictates of enlightened self-love with those of conscience had been a staple of British moral philosophy since Butler, and the belief lends plausibility to egoism, as an ethical theory, that it would otherwise lack. In any case, nowadays many philosophers simply deny that egoism is an ethical theory. To them, it lies beyond the bounds of ethics. Their rejection of egoism as an ethical theory thus implies a sharp disagreement.
with Sidgwick over how to understand ‘ought’ and ‘right’ when the words are used in a strictly ethical sense.

The modern source of this disagreement is Pritchard’s attack on the core problem of Plato’s *Republic*. I won’t bother to rehearse the details of Pritchard’s argument against Plato. The main thing is that Pritchard took Plato to have erred in thinking that the challenge put to Socrates by Glaucous and Adiemantus called into question the bindingness of moral obligations. If I promise to repay a loan by a certain date, Pritchard pointed out, then I am bound by the obligation I have undertaken to repay it. In other words, though I may not want to repay it, though repaying it may be inconvenient or have unpleasant consequences, I ought to repay it nonetheless. And the judgment here expresses the thought of being morally bound to do something despite its being contrary to my interests and desires. To be sure, seeing the disadvantages I would incur by repaying it, I might ask whether I really ought to repay it. Is it really necessary? Doesn’t reneging make more sense? And this question, if it has a point, is the same as the one Glaucous and Adiemantus raised about being just. That is, why should I always act justly is a question that arises in the same way when one considers the advantages of occasional injustice, or indeed wholesale injustice, if one can get away with it. But in raising this question, I use ‘ought’ in a different sense, Pritchard argued, a sense that does not express my being morally bound to do some action but rather expresses the advisability of my doing it in view of my interests and desires. And by the same token I use ‘ought’ in this latter sense, when I ask whether I really ought to repay the loan. Plato’s error, then, according to Pritchard, consisted in his thinking that a question about what it is advisable to do in view of one’s desires and interests could undermine the obligatoriness of justice, and it cannot. For what is obligatory is what one is bound to do regardless of one’s desires and interests and not in view of them.

For Pritchard, then, and for those philosophers who agree with his critique of the core problem of Plato’s *Republic*, ethical theory concerns what ought to be done and what it is right to do in the sense of ‘ought’ and ‘right’ that expresses the idea of moral obligation. It concerns, in other words, what morality binds one to do by its obligations and not what it is advisable to do in view of one’s desires and interests. This understanding of ethical theory thus opposes Sidgwick’s. While Pritchard and his followers—the Pritchardians, if I may—agree with Sidgwick that the primary subject of ethical theory is what we affirm when we make judgments of the form x ought to be done and it is right to do x, using ‘ought’ and ‘right’ in their strict ethical sense, they disagree with him on how to understand this sense of ‘ought’ and ‘right’. In opposition to Sidgwick, they take it to express the idea of an act’s being morally obligatory.

Sidgwick, it is important to note, did not overlook the sense of ‘ought’ and ‘right’ that the Pritchardians take to be the strictly ethical one. He was not blind to its existence. Their disagreement with him is therefore brute and does not represent some greater subtlety on their part about the use of ‘ought’ and ‘right’ to make ethical judgments. Indeed, Sidgwick’s sensitivity to the issue that divides him from them, is apparent in his discussion of the *Republic*’s core problem in the chapter of his *Methods* that concerns the relation between happiness and duty. Because he takes the *Republic*’s core problem to be genuine and offers a statement of it meant to be neutral on the question of whether just actions are always ultimately rational or reasonable, he is careful to distinguish what he calls “the received notions of Duty... as they are found in the moral consciousness of ordinary well meaning persons” from the notion of duty that is coincident with the use of ‘ought’ and ‘right’ in what he understands as its strictly ethical sense. For convenience’ sake, let us refer to the former as duty according to common moral consciousness. The *Republic*’s core problem, then, on Sidgwick’s statement of it, is whether one best achieves happiness by always doing one’s duty as duty is understood according to common moral consciousness. By implication, therefore, what the Pritchardians take to be the strict ethical sense of ‘ought’ and ‘right’ as these words occur in the judgments that determine the primary subject of ethical theory is the sense these words have when they are used in judgments that represent conceptions of duty according to common moral consciousness. And consequently the disagreement between the Pritchardians and Sidgwick is a disagreement over whether the primary subject of ethical theory is what is ultimately rational or reasonable in the conduct of life or what conduct is obligatory according to common moral consciousness.

The leading Pritchardian in the first half of the twentieth century was W. D. Ross. Ross’s ethical system, however, is too close to mere description of our common moral consciousness to count as a genuine ethical theory. In particular, Ross did not try to give any theoretical construction to support either his list of *prima facie* duties or his account of how to determine one’s actual duty in situations in which two *prima facie* duties called for action and nothing one did would fulfill both. His appeals to the self-evidence of these elements of his system indicate instead a lack of interest in developing such constructions and so a belief that a general and systematic description of the moral consciousness common to decent, well-meaning human beings should suffice for understanding the primary subject of ethics. Such a belief, I suspect, characterized earlier defenders of common sense morality in the intuitionist tradition that Ross inherited. At any rate, the lack of theoretical underpinning in their defenses is what Sidgwick exploited when he showed how utilitarianism can perfect common sense morality and therefore supply it with rational foundations.

The same deficiency in Ross’s system likewise left it open to similar treatment, as the subsequent development of sophisticated rule utilitarian theories demonstrated. At the same time, Pritchardians, during the last half of the twentieth century, have also developed the theoretical constructions that Ross abjured. Consequently, they too have made good this deficiency in his system. They have chiefly done so by constructing a point of view that is meant to capture common moral consciousness and is thus the viewpoint from which ethical judgments are made. Accordingly, the construction provides theoretical underpinning to Pritchard’s distinction between the use of ‘ought’ in the strictly ethical sense and its use in the sense of advisability in view of one’s interests and desires. The former is typically referred to as the moral ‘ought’, and the judgments in which it occurs are understood as judgments made from the moral point of view. And to complete the contrast, the latter is typically referred to as the prudential ‘ought’ and the judgments in which it occurs are understood as judgments made from the personal point of view or the point of view of self-interest. Ethical theories that fit this Pritchardian program are now not only familiar but also tend to dominate the field. The theory John Rawls expounded in *A Theory of Justice* is foremost among them. But there are several other important recent theories that fit this program as well, including Bernard Gert’s quasi-Hobbesian theory, the contractualist theory of Thomas Scanlon, and various attempts to work up the second formulation of Kant’s Categorical Imperative and his correlative notion of a kingdom of ends into a contemporary ethical theory.
Indeed, this program has been so successful in the last thirty years that some philosophers who think ethics is something different from the study of common moral consciousness have resorted to distinguishing what they call "the ethical" from what they call "the moral" and to referring to forms of ethics that exclude morality. 12 I can't tell whether these conceptual novelties represent an advance in the field or are just verbal dust of the sort philosophers typically stir up when they are stuck for an argument. But they are symptomatic of resistance to thinking that questions in ethics about what ought to be done and what it is right to do are questions about duty according to common moral consciousness. And as these philosophers—and here I am thinking in particular of Bernard Williams—bid us to return to the questions in Plato's Republic as to how one ought to live as a way of grasping the ethical that is extra-moral, they suggest a view to the nature of ethical theory in line with Sidgwick's, a comparison that, I suspect, Williams would not especially welcome. 13

Developments since Sidgwick in the controversy over what the primary subject of ethical theory is have thus led to the entrenchment of two main contending positions. Both, following Sidgwick, take right action to be the primary subject of ethical theory. But one of them understands right action as action that is ultimately rational or reasonable. The other understands it as action that is obligatory according to common moral consciousness. This difference in understanding of what is meant by right action bears directly, then, on how studies in bioethics and their results are related to ethical theory. Accordingly, it bears directly on the question of whether bioethics represents a challenge to ethical theory. The answer one gives to this question depends on which of these two positions one assumes.

Let us start with the first, the position on which right action is understood as action that is ultimately rational or reasonable. How could bioethics represent a challenge to ethical theory if ethical theory were primarily concerned with right action so understood? Well, presumably, some forms of religious ethics—let us call these "faith-based"—represent a challenge to ethical theory on this conception of it, since presumably faith-based ethics denies the identification of right action with action that is ultimately rational or reasonable. Hence, if bioethics were faith-based, it would represent a challenge to ethical theory. But it is safe to assume that though bioethics before philosophy colonized the field was an enterprise that fell chiefly within the domain of religious ethics and was informed by faith-based approaches, it is no longer such an enterprise, and that, in any case, what interests us on this panel is bioethics as a subdiscipline of moral philosophy. As such, it seems entirely consonant with ethical theory conceived of as primarily concerned with what it is ultimately rational or reasonable to do. That is, as a subdiscipline of moral philosophy, bioethics does not seem to represent any challenge to ethical theory when ethical theory is so conceived. Furthermore, inasmuch as bioethics is pursued in harmony with standard medical practice and medical research, where the self-understanding of people who practice and do research in medicine importantly includes an understanding of themselves as applying and extending science, there should be no opposition between it and ethical theory so conceived. For the ethos of science is the ethos of reason.

This last observation, moreover, reflects important work in bioethics, work that is exemplary of this conception of ethical theory. I am thinking here, for example, of the arguments some thirty years ago that bioethicists made for using "brain death" (i.e., the cessation of all of the brain's functions) instead of the traditional criterion of death, the cessation of heartbeat, as the marker of death that permits, inter alia, removal of vital organs from a still warm body for the purpose of transplanting them into other people. 14 In a nutshell these arguments were that one would do no harm to someone who had suffered such irreversible damage to his brain that it would never again be a functioning organ but whose heart continued to beat if one stopped his heart and removed it and other vital organs, while one could do an enormous good if one successfully transplanted these organs into the bodies of other people who needed such healthy organs to survive. And this sort of argument is essentially an appeal to what is ultimately rational or reasonable in the face of resistance due to customary or traditional ways of thinking. A second example, similar to the first, was the case that bioethicists made for instituting the practice of not resuscitating dying patients whose hearts, whenever they stopped beating, could be restarted through electrical stimulation or pounding on their chests, but whose lives as conscious beings were over. 15 Again, the argument was that no good came from restarting the hearts of such patients and a great deal of pain and suffering could be averted by not restarting them, and this argument too is a direct appeal to reason in the face of resistance owing to doctrinaire opposition to private human decision-making about whether or not to preserve a human life.

What, then, about the second position, the position on which the primary subject of ethical theory is right action understood as what is obligatory according to our common moral consciousness? Does bioethics represent a challenge to ethical theory if ethical theory is conceived of in this way? The answer in this case is different. On this position, bioethics does represent a challenge to ethical theory. For the aim of ethical theory, on this conception of it, is to give a systematic as well as accurate account of obligation according to common moral consciousness. Its aim, in other words, is to codify what philosophers call common sense morality. Doing so means articulating a complex set of relatively specific standards of conduct whose application is settled in familiar circumstances but is perforce uncertain and often puzzling in new and strange ones. Consequently, the appearance of such new and strange circumstances is often unsettling to common sense morality. Bioethics, then, regularly presents challenges to ethical theory, for the scientific and technological advances that are so characteristic of modern medicine and medical practice are a regular source of such new and strange circumstances. These circumstances regularly generate difficult questions for common sense morality. Bioethics, in other words, in virtue of them, regularly challenges our understanding of the specific standards of conduct that ethical theory, on this second conception of it, articulates.

Discussions of such challenges fill the pages of standard textbooks in bioethics. A single example, though, should suffice for grasping their nature. The example I have in mind is the challenge that is due to the significant advances in human genetics and the technology of genetic alterations that scientists have made over the last fifty years. 16 These advances have hastened the day when it will be possible to alter, early in a human being's existence, his or her genes, and this possibility raises ethical issues that test our understanding of what, according to our common moral consciousness, is an obligatory use of biomedical technology to advance human well-being. Of course, with regard to alterations that would repair a gene or gene complex whose normal expression is some fatal disorder or severely crippling deformity, it is hard
to see what could argue against making such alterations an obligatory part of medical practice. But uncertainty sets in when we consider alterations that would change a gene or gene complex so as to increase the intelligence, beauty, stature or other personal attribute of recipients in whom there was already every indication of their being normal in the degree to which they will possess these attributes. Could such alterations become part of medical practice as merely elective procedures in the way that cosmetic surgery and growth hormone treatments are often elective procedures? Or is the bearing of personal attributes on the prospects for living a decent and happy life so great in certain cases, like intelligence, as to make their distribution in these cases a matter of justice?

Traditionally, justice in the distribution of goods important to human welfare has been a matter of requiring that no one undeserving of misfortune be denied the freedom and material goods that are important to living a tolerably decent life or consequent to cooperating in socially productive arrangements. Accordingly, the obligations of justice have traditionally been obligations to respect the freedom of people to make their own way in the world within the reasonable constraints of social cooperation, obligations not to deprive people of the material necessities of life except where such deprivation is necessary for one’s own survival, and obligations of fairness in dividing among a group of people who are joined together cooperatively for common good the social product of their cooperation. This third type of obligation includes the obligation to allow everyone in the group opportunity to contribute to the common good. To be more specific, because a fair share of the social product is not always an equal share but is often, instead, a function of the extent or significance of a person’s contribution, it includes the obligation to give everyone an equal opportunity to make extensive or significant contributions. From this last obligation, then, it might seem to follow that the distribution among the members of a society of personal attributes like intelligence, volitional power, and emotional balance would become a matter of justice once the means to influence their distribution became possible. It might seem to follow, in particular, that once it became possible to make genetic alterations that enhanced such attributes, justice would require providing them to the genetically disadvantaged. For seeing that people’s genes are as much an accident of birth (or, rather, conception) as the social and economic circumstances into which they are born, one might regard the provision of such alterations as similar to a “Head Start” program and conclude that, just as there is an obligation of fairness to provide poor children with “Head Start” programs, so too there is an obligation of fairness to provide those who are genetically disadvantaged with alterations of their genes that will boost the level of intelligence, volitional power, emotional balance, and the like that they can be expected to develop.

This conclusion exemplifies, then, how bioethics generates difficult questions for common sense morality. Justice, according to our common moral consciousness, requires helping people who are undeservedly disadvantaged as a result of the accidents of birth or early childhood by removing barriers and providing resources that they would otherwise face or lack. It requires, in short, giving them a more equal start in life. But does it also require that people who are genetically disadvantaged be helped by medical interventions that, through genetic alterations, give them a more equal start in life? The question tests our understanding of the scope of the obligations that the common sense standards of justice on which programs for equalizing opportunity are founded define. It tests, that is, our understanding of what counts as an unfair advantage or disadvantage in life. Are such advantages and disadvantages, we may well wonder, restricted entirely to beneficial and adverse social circumstances that are due to chance factors, circumstances such as whether one is born into wealth or poverty or belongs to a group toward whom favorable or hostile prejudice is common and arbitrary? Or could any chance circumstance, social or not, count as an unfair advantage or disadvantage as long as it significantly affected one’s prospects in life beneficially or adversely and there was available within society feasible means for making the chances of being in that circumstance more equal? The uncertainty and puzzlement over how to interpret and apply common sense standards of justice that these questions raise exemplify the kind of challenge bioethics represents to ethical theory on the view that the primary subject of ethical theory is right action understood as what is obligatory according to our common moral consciousness.

Endnotes
2. Ibid., pp. 31-35.
3. Ibid., pp. 77-88.
5. Bk. II, ch. 5 of Methods of Ethics, pp. 162-175.
6. Ibid., p. 163.
10. See Thomas Scanlon, What We Owe to Each Other (Cambridge, MA: Belknap Press, 1998).
15. President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment (1983).
16. I here follow the excellent discussion of this challenge in Allen Buchanan, Dan Brock, Norman Daniels, and Daniel Wikler, From Chance to Choice: Genetics and Justice (Cambridge, MA: Cambridge University Press, 2000).
Is Bioethics a Challenge to Ethical Theory?

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An ethical theory should make explicit, explain, and, if possible, justify morality or the moral system. It must provide an explicit account of common morality, including its limitations. This account of morality should be given in terms that everyone can understand and, given sufficient information about the situation, use in coming to a decision or in making a judgment. It should also make clear that although morality does not always provide a unique right answer to every question, it always provides limits to the range of morally acceptable answers. None of the standard moral theories provide anything close to an adequate account of common morality. Even the best of these theories, including those of Hobbes, Kant, and Mill, provide only a misleading schema of the moral system that is commonly used. Unfortunately they are not even completely clear about the distinction between their account of this common morality and their attempt to justify it.

No one seriously holds that any of these theories will settle any of the controversial issues in bioethics such as abortion, physician assisted suicide, genetic testing, or gene therapy, not to mention the particular problems that arise in actual medical practice. The most that is done is to mention some slogans like autonomy or respect for persons, do no harm, justice or treating people fairly, and beneficence or doing good, as justifying one’s decision or judgment. These slogans have even been combined in “principlism,” which provides what passes for an ethical theory in bioethics. One reason for the irrelevance of most ethical theories in bioethics is that the solution to most actual particular problems is determined by the facts of the case. There is often no dispute about anything to which a moral theory would provide a solution, or even be of any assistance. Once the facts, including prognoses, are known and agreed upon, there is often complete agreement about what should be done. The common claim that we agree on facts, but disagree on values, is wrong in almost all real cases. Most moral theories are equally useless in dealing with controversial issues, because these controversial issues have no unique correct solution, and the theories provide no explanation of why the disagreement is unresolvable.

These controversial issues are usually such that equally informed, impartial, rational persons not only can, but do disagree about what should be done. Most moral theories do not allow for such disagreement, and even those that do, do not have the resources to explain the source of the disagreement. Partly this is due to the fact that most moral theories have not availed themselves of the resources of common morality. Indeed, many so-called moral theories are not even attempts to explain or justify common morality, but are used to generate guides to conduct intended to replace common morality. These proposed guides, those generated by most of the standard consequentialist, contractarian, and deontological theories, are far simpler than the common moral system and sometimes yield totally unacceptable answers to moral problems. Common morality does not provide unique answers to every moral question, but almost all moral theories generate codes that do provide unique answers to every question. This is one reason why those philosophers who put forward these theories have usually dismissed common morality as confused. This is also why those who take morality seriously, including many who do medical ethics, do not regard moral theory as having any practical value.

I take common morality very seriously. My moral theory begins with a detailed description of the common moral system. Although it does not provide all of the details, it provides a sufficient amount of detail to be of use in dealing with actual moral problems that arise in medical practice. Although most actual moral problems do not involve more than finding out all the relevant facts, my moral theory helps to identify which facts are morally relevant. The primary use of a moral theory is not to provide a solution to controversial problems, but to clarify how actions should be described. The usefulness of a moral theory is in providing a framework for describing actions. My explicit account of common morality, in which I list the moral rules, the moral ideals, and the morally relevant features that are part of the two-step procedure for determining whether a violation of a moral rule is justified, serves as such a framework. This framework can actually be of some help in providing the morally appropriate description of an action.

The Moral Rules

The moral rules that I list are a universally accepted part of common morality. They merely state the simple kinds of actions that are prohibited or required, unless there is an adequate justification if the prohibited action is done, or the required action is not done. The two-step procedure for justifying a violation of a moral rule makes explicit what is involved in providing an adequate justification. It makes clear what is meant by the requirement of common morality that the moral rules must be obeyed impartially. The rules are not normally used to resolve moral problems, rather they are most useful in determining whether one needs to be concerned about doing, or not doing, a particular action. If the action is appropriately described as a violation of one of these rules, then a justification is needed, if the action is not appropriately described in this way, no justification is needed.

The following is a list of the moral rules.

1. Do not kill.
2. Do not cause pain.
3. Do not disable.
4. Do not deprive of freedom.
5. Do not deprive of pleasure.
6. Do not deceive.
7. Keep your promises.
8. Do not cheat.
9. Obey the law.
10. Do your duty.

These rules are understood by all to prohibit not only actual violations, but also attempts to violate them, even if the attempt is unsuccessful. They are also understood to prohibit not only intentional violations, but also violations done knowingly but not intentionally. They even prohibit some unknowing violations. However, as will be apparent in the discussion of the two cases on which I will concentrate, these rules are in need of some interpretation. “Do not kill” does not mean simply do not do any act that has the result that someone dies. “Do not deprive of freedom” does not mean simply do not do any act that has the result that someone does not have the freedom or opportunity to do something he would have had if you had not done that act. If, in the normal course of affairs, you arrive at a parking lot before another person, you do not deprive him of the opportunity to park in that lot if you take the last parking place. You do not need to justify doing that. Knowing about the practices of a particular field or profession, especially the duties involved, is sometimes necessary to provide the proper interpretation of the rule.

Furthermore, it is knowledge of the field or profession, not knowledge of moral theory, that is essential for determining the duties that are involved. These duties are not derived from a moral theory, but from the history and practice of the profession.
The Moral Ideals

The moral ideals have the same point as the moral rules, to lessen the amount of harm suffered. Whereas the moral rules seek to lessen the amount of harm by prohibiting those actions that cause harm or increase the likelihood of harm being suffered, the moral ideals directly encourage the lessening of harm. Some moral ideals can be formulated in a way that parallels the formulations of the moral rules. The following is a list of such ideals.

1. Prevent killing.
2. Prevent causing pain.
3. Prevent disabling.
4. Prevent deprivation of freedom.
5. Prevent deprivation of pleasure.
6. Prevent deception.
8. Prevent cheating.
9. Prevent disobedience to the law.

The most important moral ideals, however, deal directly with the harms the moral rules prohibit causing. “Prevent avoidable death,” “Prevent or relieve pain.” “Prevent or relieve disability,” “Prevent or relieve loss of freedom.” and “Prevent or relieve loss of pleasure. The first three of these ideals seem to constitute the primary goals of medicine, so it is no surprise that practicing medicine is regarded as following the moral ideals. No one doubts that as long as no moral is rule is violated, morality encourages following these ideals. Following these ideals sometimes even justifies violating a moral rule. Whether it does so, depends on the morally relevant features of the violation and estimates of both the consequences of everyone knowing that a violation with these features is allowed and the consequences of everyone knowing that it is not allowed.

Describing the Kind of Act Involved

The serious work of bioethics is framing the problem so that the moral system can apply to it. A moral theory should contain an explicit formulation of the framework to be used in providing the appropriate description of an action. If the case is described in the appropriate way, applying the rest of the moral system is relatively simple. Once the appropriate description of the action has been determined, then either everyone agrees that it should be done, or not be done, or there is a further disagreement. If this disagreement is based on a disagreement about the facts, then the moral theory does no further work. If the disagreement is not due to a disagreement about the facts, including probabilities, and if it is determined that a moral rule has been broken, then a moral theory can be of some use. However, usually not in the way those putting forward moral theories think. A moral theory is best used to assure the contending parties that they are both holding acceptable moral views, and to explain the source of their unresolvable moral disagreement, rather than being used to resolve the dispute.

I was initially surprised that the part of my theory that physicians took to be most helpful was the list of morally relevant features. They regard the list as useful because it makes explicit what facts are relevant to their decision-making. Everyone knew that finding out the facts was important, but there had been no previous explicit account of how to determine which facts were morally relevant. The morally relevant features not only make explicit which facts are morally relevant, but by providing a description of the kind of act to be publicly allowed, they also make clear why these facts are relevant.

Morally Relevant Features

A morally relevant feature of a moral rule violation is a feature that if changed could change whether some impartial rational person would publicly allow that violation. All morally relevant features are answers to the following ten questions.

1. Which moral rule is being violated?
2. Which harms are being caused, avoided (not caused), and prevented by the violation?
3. What are the relevant desires and beliefs of the person toward whom the rule is being violated?
4. Is the relationship between the person violating the rule and the person(s) toward whom the rule is being violated such that the former has a duty to violate moral rules with regard to the latter independent of their consent?
5. Which goods are being promoted by the violation?
6. Is the rule being violated toward a person in order to prevent her from violating a moral rule when the violation would be (1) unjustified or (2) weakly justified?
7. Is the rule being violated toward a person because he has violated a moral rule (1) unjustifiably, or (2) with a weak justification?
8. Are there any alternative actions or policies that would be preferable?
9. Is the violation being done intentionally or only knowingly?
10. Is the situation an emergency such that no person is likely to plan to be in that kind of situation?

Once one has described the situation using only those facts that are answers to these questions, then the second step of the two-step procedure is to estimate the consequences of everyone knowing that they are allowed to break the rule in those circumstances, and of everyone knowing that they are not allowed to break the rule in those circumstances. The two-step procedure is (1) describe the act solely in terms of its morally relevant features, then (2) estimate the consequences of everyone knowing that they are allowed to break the rule in those circumstances and everyone knowing that they are not allowed to break the rule in those circumstances. The outcome of this two-step procedure determines whether one would be willing for everyone to know that they are allowed to break the rule in those circumstances.

This does not presuppose that all equally informed impartial rational persons would decide in the same way. It is important to realize that equally informed impartial rational persons, besides disagreeing on the interpretation of the rules, can disagree on (1) the scope of morality, who beyond other moral agents are protected by the moral rules, either fully or partially; (2) the rankings of the various evils involved; and (3) ideological views, such as their views about human nature that affect what they think will happen if everyone were to know that they are allowed to break the rule in those circumstances. Realizing that disagreements on these issues do not mean that either party to the dispute must be ignorant of some facts, partial, or irrational, results in that kind of productive attempts at compromise that most moral theories discourage.

Bioethics does present a serious challenge to all of the traditional moral theories, including consequentialist, deontological, contractualist, virtue theories, and others. None of these moral theories provides more than a schematic outline of our common morality. They are not only useless in making
moral decisions and judgments, they are actually harmful insofar as they encourage persons to think that all controversial issues can be settled by use of the theory. A detailed description of common morality focuses attention on the relevant facts. Also, contrary to traditional moral theories, a moral theory that emphasizes that there are not always unique correct answers to controversial moral questions, promotes moral tolerance, that is, helps all parties to a dispute realize that there is often more than one morally acceptable answer. Making this point explicit promotes fruitful discussion that may result in a compromise that will be acceptable to all the parties concerned. Failing that, it allows subordinates or those in the minority, to accept the decision of the person in charge, or the majority, without feeling that in going along with the decision they have sacrificed their moral integrity.

Two Examples
I will provide two examples of how moral theory and bioethics work together. Both examples started as individual cases, but the first can be considered on the general level without even mentioning the details of the particular case. The question is whether taking a competent ventilator-dependent patient off of the ventilator in response to his rational refusal to continue, counts as killing him or even assisting his suicide.\footnote{If a competent patient refuses treatment and there is no duty to treat, then it does not make any moral difference whether the physician stops treating by an act, e.g., turning off the respirator, or an omission, e.g., not giving antibiotics. It also makes no moral difference whether the physician stops some treatment that has already started, e.g., turning off the respirator or discontinuing antibiotics, or simply does not start such treatment. Granted that it may be psychologically easier to omit rather than act and not to start than to stop, nevertheless, there is no moral difference between these different ways of abiding by a patient’s refusal. Similarly, it makes no moral difference whether the treatment is extraordinary, e.g., involving some elaborate technology, or is quite ordinary, e.g., simply providing food and fluids, or whether or not the death is due to natural causes. If there is no duty to treat, not treating is not killing. If a competent patient rationally refuses treatment, there is no duty to treat. Therefore, if a competent patient rationally refuses treatment, abiding by that refusal is not killing. Further, since the refusal is rational, it is, in fact, morally prohibited to override the patient’s refusal by treating, and to do so is an unjustified deprivation of the patient’s freedom.} The decision in this case has some important implications for the controversial policy issue concerning the legalizing of physician-assisted suicide. The question in the second example is when not providing a patient with some information counts as deceptive withholding. This is a slightly altered version of an actual problem that was considered by an ethics committee. It, too, has general implications, but unlike the first example, the particular details of the case are crucial, and so the details must be given. Both examples require knowing what the duties of doctors are, because this knowledge is important in deciding how to interpret a moral rule. The first example involves interpreting what counts as violating the rule prohibiting killing; the second involves interpreting what counts as violating the rule prohibiting deceiving.

Killing Versus Allowing to Die
In distinguishing killing from allowing to die, it is necessary to determine whether a physician has a duty to prolong the lives of competent patients who rationally prefer to die. Although it is tempting to claim that the question of whether physicians have this kind of duty can be determined by philosophical reasoning, it is more plausible to hold that it requires knowledge of the practice of medicine. On the basis of the current practice in this country, it seems clear that physicians do not have a duty to prolong the lives of patients who rationally prefer to die. The next issue is whether not treating such patients counts as killing them. If not treating is killing, then not treating must itself be justified, for it involves killing, perhaps the most serious violation of a moral rule. If not treating is taken as simply failing to follow the moral ideal of prolonging life in the circumstances of a competent patient’s rational refusal, then it does not have to be justified. Indeed, following this moral ideal when a competent patient has refused treatment would not justify breaking the moral rule against depriving of freedom.\footnote{It might be objected that the analysis given above does not apply to providing food and fluids because providing food and fluids is not a treatment, and so failing to provide food and fluids is not merely not treating, it is killing. As noted before, children who die because their parents do not feed them are correctly regarded as having been killed by their parents. Similarly, it may objected, patients who die because their physicians do not provide them with food and fluids are killed by them. This objection is based on the mistaken view that the issue turns on the concept of treatment. Parents have a duty to feed their children, that is why not feeding them counts as killing. Physicians have no duty to override rational refusal by competent patients, so their not doing anything to prolong the life of these patients, including not providing them with food and fluids, does not count as killing. When a patient wants not to be kept alive and it is rational to want not to be kept alive, then it is morally required that a physician not force the patient to keep living. However, a physician should continue to provide comfort and palliative care. Contrary to what is widely assumed, dying because of lack of food and fluids is not painful when there is even minimal nursing care.} Not treating is sometimes correctly regarded as killing. If a physician turns off the respirator of a competent patient who does not want to die, with the result that the patient dies, the physician has killed him. In the same circumstances, the physician has killed the patient if she discontinues antibiotics or food and fluids. It even counts as killing if the physician refuses to start any of these treatments for her patient when the patient wants the treatment and there is no medical reason for not starting it. Just as parents whose children die from not being fed can be regarded as having killed their children, physicians who have a duty to provide life-saving treatment for their patients can be regarded as killing them when they do not provide that treatment. However, a physician does not have a duty to provide life-saving treatment for a competent patient who rationally refuses such treatment. Not treating counts as killing only when there is a duty to treat. In the absence of such a duty, not treating does not count as killing.

Physicians who have a duty to provide life-saving treatment for their patients can be regarded as killing them when they do not provide that treatment. However, a physician does not have a duty to provide life-saving treatment for a competent patient who rationally refuses such treatment. Not treating counts as killing only when there is a duty to treat. In the absence of such a duty, not treating does not count as killing.

If a competent patient refuses treatment and there is no duty to treat, then it does not make any moral difference whether the physician stops treating by an act, e.g., turning off the respirator, or an omission, e.g., not giving antibiotics. It also makes no moral difference whether the physician stops some treatment that has already started, e.g., turning off the respirator or discontinuing antibiotics, or simply does not start such treatment. Granted that it may be psychologically easier to omit rather than act and not to start than to stop, nevertheless, there is no moral difference between these different ways of abiding by a patient’s refusal. Similarly, it makes no moral difference whether the treatment is extraordinary, e.g., involving some elaborate technology, or is quite ordinary, e.g., simply providing food and fluids, or whether or not the death is due to natural causes. If there is no duty to treat, not treating is not killing. If a competent patient rationally refuses treatment, there is no duty to treat. Therefore, if a competent patient rationally refuses treatment, abiding by that refusal is not killing. Further, since the refusal is rational, it is, in fact, morally prohibited to override the patient’s refusal by treating, and to do so is an unjustified deprivation of the patient’s freedom.

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Contrary to what is widely assumed, dying because of lack of food and fluids is not painful when there is even minimal nursing care.\footnote{When no medical treatment is keeping the patient alive, stopping food and fluids may sometimes be the only way of allowing a patient to die. This kind of dying process is usually painless; it takes long enough for the patient to have the opportunity to change his mind, but it is short enough to provide significant relief from pain and suffering. Actually, death usually comes earlier than with any of the current proposals for physician-assisted suicide. Furthermore, stopping food and fluids is compatible with all palliative care, including permanent sedation. Recognizing that abiding by the rational refusal of treatment, or of food and fluids, by a competent patient is not killing, but, at most, allowing to die, solves most of the practical problems with passive euthanasia that have led many to recommend legalizing physician-assisted suicide or active euthanasia.}
Analysis of Killing

Some people consider abiding by a patient’s refusal of treatment when it requires the physician to perform some identifiable act, such as turning off a respirator that results in the patient’s death, as the doctor having killed the patient. This seems to have the support of the Oxford English Dictionary that says that to kill is simply to deprive of life. That the doctor is morally and legally required to turn off the respirator, one might argue, justifies her killing the patient, but it does not mean that she has not killed him. Even those who accept the death penalty, and hold that some prison official is morally and legally required to execute the prisoner, do not deny that the official has killed the prisoner. Killing in self defense is both morally and legally allowed, yet no one denies that it is killing. Similarly, one could agree that the doctor is doing nothing morally or legally unacceptable by turning off the respirator, even that the doctor is morally and legally required to turn off the respirator, yet claim that in doing so the doctor is killing the patient.

If this analogy is accepted, then it might even seem plausible to say that an identifiable decision to omit a life-prolonging treatment, even if such an omission is morally and legally required, also counts as killing the patient. Why not simply stipulate that doctors are morally and legally required to kill their patients when their action or omission is the result of a competent patient rationally refusing to start or to continue a life prolonging treatment? Isn’t the important point that the doctor is morally and legally required to act as she does, not whether what she does is appropriately called killing? However, having a too simple account of killing could cause numerous problems. Although a doctor is morally and legally required to abide by a rational refusal, it is still significant to determine whether such an action should be regarded as killing.

Many doctors do not want to regard themselves as killing their patients, even justifiably killing them. More importantly, all killing requires a justification or an excuse. When all the morally relevant features are the same, the justification or excuse that is adequate for one way of killing will be adequate for all other ways of killing as well.6 Thus, if a justification is not publicly allowed by all for other ways of killing, e.g., injecting a lethal dose of morphine, then it will not be publicly allowed by all for this way of killing, disconnecting the patient from the respirator. This means that if it is justifiable to prohibit physicians from granting a competent patient’s rational request to be killed by lethal injection, it should also be justifiable to prohibit physicians from killing competent patients by abiding by their rational refusals of life-sustaining treatments. Furthermore, since almost no one, including supporters of active euthanasia, propose that doctors should ever be morally and legally required to kill their patients, doctors would not be morally and legally required to abide by rational refusals of treatment by competent patients. Unless one favors such restrictions on patients’ ability to hasten their death by refusing life prolonging procedures, changing the way killing is understood, i.e., counting abiding by a patient’s rational refusal as killing him, would have significant risks.

Almost none of those who favor legalizing active euthanasia want to require doctors to kill their patients; they merely want to allow those doctors who are willing to kill, to do so. Similarly, for physician-assisted suicide, no one suggests that a doctor be required to comply with a patient’s request for a prescription for lethal pills. Since doctors are morally and legally required to abide by a competent patient’s rational refusal of life-sustaining treatment, abiding by such a refusal is not regarded as killing, or even assisting suicide. Providing a patient who refuses life-sustaining treatment with palliative care is not controversial either. Although some physicians feel uncomfortable doing so, almost no one wants to prohibit such palliative care. Neither killing a competent patient on his rational request nor assisting him to commit suicide are morally uncontroversial, nor does anyone claim that doctors are morally and legally required to do either. Thus it is clear that abiding by a competent patient’s rational refusal of treatment is not normally regarded as killing, nor does abiding by that refusal and providing palliative care to such a patient count as assisting suicide.

Part of the problem is that insufficient attention is paid to the way in which the term “kill” is actually used. Killing is not as simple a concept as it is often taken to be. Killing is causing death, but what counts as causing any harm is a complex matter. If the harm that results from one’s action or omission needs to be justified or excused, then one is regarded as having caused that harm. Of course, causing harm often can be completely excused, so that one can cause harm and be completely free of any unfavorable moral judgment.7 Killing, taken as causing death, may also be completely justified, perhaps even morally required. Nonetheless, it is important to distinguish morally justifiable or excusable acts of killing from those acts that need no justification or excuse because, although they result in a person’s death, they are not acts, which killed the person or caused his death.

If the act which results in death is also a violation of one of the second five moral rules, (cheating, neglecting a duty, or breaking a law) knowingly performing the act, or omission, needs justification and so counts as killing. That is why when a child dies because her parents did not feed her, they have killed her, for parents have a duty to feed their children. This is also why it was important to make clear that doctors have no duty to treat, or even to feed, patients who refuse treatment or food and fluids. However, if one does not intend, but only knows, that one’s act will result in someone’s death, and the act is not a violation of another moral rule, then performing an act which has this result might not be to cause the person’s death or to kill him.8

When a doctor abides by the rational refusal of a competent patient, she is normally not violating any of the second five moral rules, and she is not violating any of the first five rules either. The doctor’s intention is to abide by the patient’s refusal even though she knows that the result of her doing so will be that the patient dies. Even if the doctor agrees that it is best for the patient to die, her abiding by the patient’s refusal does not count as intentionally causing his death. Of course, an individual doctor might want the patient to die, but the doctor’s intention in these circumstances is not determined by the conscious desires in her own head. Rather, the intention is determined by what facts account for her action. If, given the patient’s refusal, she would cease treatment even if she did not want the patient to die, and would not cease it if the patient had not refused such treatment, then her intention is not to kill the patient, but to abide by the patient’s refusal. Most doctors do not want to kill their patients, even if such an action were morally and legally justified. Their intention is not to kill the patient, but simply to abide by their patients’ rational refusals.

Whether an act or omission which is (1) done knowingly but not intentionally; (2) does not involve a violation of one of the second five moral rules and (3) results in someone’s death, counts as killing depends on whether those in the society regard such an act as needing a justification or an excuse. In our society at the present time, doctors do not need a justification or excuse to abide by a competent patient’s rational refusal, even if everyone knows that such an act will
result in the patient’s death. When a doctor is abiding by a competent patient’s rational refusal, the cause of death is usually taken to be the patient’s disease, or it is the patient’s refusal; it is never the doctor’s abiding by the refusal. Thus, it is not usually considered killing for a doctor to abide by such a refusal.10 In our society at the present time, it is considered killing for a doctor to grant a competent patient’s rational request to do something that will immediately result in the patient’s death. No one who favors active euthanasia argues that such actions are not killings, rather some argue that abiding by patients’ refusals, is also killing, and since it is allowed, active euthanasia should also be allowed. Thus they accuse, as philosophers are wont to do, people of being inconsistent in allowing, or even requiring abiding by patients’ refusals, but not allowing active euthanasia or even assisting suicide.11

That our society does not regard the death resulting from abiding by a competent patient’s rational refusal, even refusal of food and fluids, as killing, is shown by the fact that almost all states require compliance with advance directives that explicitly direct a physician to stop treatment, even to stop provision of food and fluids. All of them also allow a presently competent terminally ill patient to refuse treatment and food and fluids. None of these states allow a physician to kill a patient, no matter what. Most of these states do not even allow physician-assisted suicide. This strongly suggests that turning off a respirator is not regarded even as assisting suicide when doing so is required by the rational refusal of a competent patient.

When Does Not Telling (Withholding) Count as Deceiving?

The second example concerns whether a psychiatrist should tell his patient that his wife is going to have him served with a restraining order. The psychiatrist is concerned that by not telling his patient that information, he might be deceiving him. He is concerned about withholding information that is relevant to the patient’s future plans. However, since the patient is at risk not only for suicide, but also for causing great harm to his wife, the psychiatrist thought that, due to the danger to the patient’s future plans. However, in such a conversation, the psychiatrist normally provides the social worker with information about the patient so that the social worker can arrange for the most suitable placement. The social worker usually does not provide information about the patient to the psychiatrist. However in this case the social worker had just talked to the patient’s wife who had disclosed that she was going to get a restraining order.

A case that seems to resemble this one has become a standard case in genetics. Before the identification of the Huntington gene, couples who wanted the fetus tested for Huntington’s would be tested themselves. In one case, the father of the husband died of Huntington’s and the fetus and the husband were tested to see if they had inherited the Huntington gene. The testing revealed that the fetus had not inherited the Huntington gene because the husband was not the genetic father. Should the genetic counselor inform the husband that he was not the genetic father? Just as in the previous case, many thought that the genetic counselor would be justified in deceptive withholding of that information from the husband. They thought that revealing the information about non-paternity would very likely have disastrous consequence for the marriage. However, others thought that concerns about the effects of the information on the marriage were not sufficient to justify deception.

Paternalistic deception in the context of medical care often presents a moral dilemma, that is, a situation in which equally informed impartial rational persons disagree about whether a moral rule should be broken. It is only a weakly justified violation. Even when following the two-step procedure makes it clear that deceiving is not justified, the fact that deception will result in much better consequences in the particular case provides a strong temptation to deceive. But deception in a situation where trust is so important, as in a medical care setting, is very difficult to justify. Thus, although those in health care are often tempted to engage in paternalistic deception, they are aware that such deception is at best usually only weakly justified, and often not justified at all. Nonetheless, they are quite reluctant to provide information when they know that this information is very likely to result in bad consequences for the people involved in this particular situation.

There is no doubt that in many cases a doctor’s not telling a patient information that she thinks would be harmful for him to have counts as deception. If she knows that the patient would refuse a much needed operation if he were told that there was even a small chance of serious disability, she may be tempted not to tell him that there is a small risk of such an outcome. However, even if she were morally justified in such deceptive withholding, which she probably is not, everyone would agree that by not telling she is deceiving. This is because a doctor has a duty to provide a patient with information that is relevant to his making an informed decision about whether to consent to the operation. Everyone agrees that information about the serious risks of such an operation is included in what counts as relevant information. Since a doctor should provide his patients with all of the information that is relevant to their making informed decisions, withholding information about which hospital has the best record of success for that kind of operation is also deceptive withholding. However, so far, that view is not universally accepted. If the courts decide that a doctor has a duty to provide that information, then it will soon become universally accepted that withholding such information counts as deception.

However, many cases of not telling do not count as deceptive withholding. If a doctor overhears some information about his patient at a cocktail party or in an elevator, she does not have a duty to tell the patient that information and not telling does not count as deceptive withholding. If a doctor discovers information about a patient that is not relevant to the patient’s making a decision about whether to consent to a medical procedure, or to what he should expect as a consequence of his medical condition, the doctor usually has no duty to provide that information. Her not telling does not count as deceptive withholding. In the case of the couple that came in to find out whether their fetus had the Huntington gene, the genetic counselor can provide that information without saying anything about the husband not being the genetic father. Although that fact was discovered as a result of genetic testing, it is not relevant to the purpose for which the couple came to have their fetus tested.

A doctor has no duty to provide information that is not discovered as part of a medical examination or an examination of the medical records of the patient. Also, a doctor has no duty to provide information that is not medically relevant. In the case of the psychiatrist who was concerned about his not telling the patient that his wife was going to have him served with a restraining order, both of these conditions are fulfilled. Although hearing this information from the social worker was
not exactly like hearing it at a cocktail party, it was analogous in that it was obtained by accident, and not as part of the psychiatrist’s examination of the patient or his medical records. Also, the information, although important to the patient, was not medically relevant in the necessary way. It was medically relevant to the psychiatrist who might want to prepare the patient for not being able to get in contact with his wife, but it was not a medically relevant in that it was not about the medical condition of the patient.

When these issues were clarified, the psychiatrist, as well as all others on the ethics committee, agreed that the physician had no duty to share the information with the patient. In this case, not telling was not regarded as deceptive, and some did not even regard it as withholding. No one regarded not telling as deceiving. With this agreement, the problem vanished. The psychiatrist did not have to justify not telling because in this case it did not count as deceiving. Clarification of the duty of a doctor to inform made clear that the doctor’s not telling was not a violation of the rule prohibiting deceiving. Although the psychiatrist might have concluded that he was justified in not telling, he was delighted to know that he was not deceiving at all and so had no need to justify his not telling. None of this was decided by application of moral theory; it was the appropriate work for those doing bioethics.

Summary
Both examples involved determining what counted as a physician’s duty, and so could be seen as interpreting the rule “Do your duty.” But discovering what counts as the duties of a profession should not be taken as interpreting the rule “Do your duty.” However, discovering what count as the duties of a profession does affect the interpretation of other moral rules. In the first example, the rule “Do not kill” was involved. Given that doctors have no duty to treat competent patients who rationally refuse treatment, the appropriate interpretation was that, given the rational refusal of a competent patient, any way in which the doctor discontinues treatment, by act or omission, does not count as killing. This made clear the moral importance of the distinction between patient requests and patient refusals, for granting a competent patient’s rational request to be killed does count as killing.

In the second example, the rule “Do not deceive” was involved. The appropriate interpretation of the rule was that not telling about the restraining order does not count as deceiving. Given that doctors have no duty to inform patients of non-medical facts that they have discovered in some accidental way, not telling the patient that his wife was going to serve him with a restraining order was not deceiving him. Not telling in these circumstances is not deceiving by withholding. One can imagine other countries in which physicians have a duty to tell all relevant information that they know about the patient’s situation, regardless of how it was acquired, and regardless of whether that information is medically relevant. In such a country, not telling about the restraining order would be deceiving by withholding. It is not knowledge of a moral theory, but knowing about the practices and duties that are actually part of the profession, which is part of what should be known by those doing bioethics, that is what counts.

Endnotes
2. It is common to describe this situation as the physician taking the patient off of the ventilator “in response to the patient’s rational request.” However, as will be apparent later, to use the word “request” in this context is misleading. See “Distinguishing between Patients’ Refusals and equests,” The Hastings Center Report, Vol. 24, No. 4, July-August 1994, pp. 13-15, Bernard Gert, James L. Bernat, and R. Peter Mogelnicki.
4. See Ibid.
6. It may be that “killing” is that the result of abiding by a refusal never has the same morally relevant features as killing that is done at the request of a patient. However, killing is such a serious violation of a moral rule, that the morally relevant features would have to be dramatically different for one way of killing to be justified and the other not.
7. Contrary to one’s initial inclination, what counts as “causing harm” is not determined by some scientific analysis, but rather by whether it is held that a justification or excuse is needed for such behavior.
8. One can kill a person unintentionally, even when one is not negligent, as when one’s car skids on some black ice and hits a person resulting in his death. Such a killing may be completely excusable, but it is still killing.
9. It also might. It is morally relevant whether a person acts knowingly but not intentionally, but often if doing something intentionally is immoral, doing it knowingly but not intentionally is also immoral.
10. In our society not everyone uses or extends the paradigms or prototypes in the same way, and so there will be disagreements on whether a given act counts as killing. Nonetheless, there is usually substantial agreement on most cases. However, in trying to change a long standing practice, it is not uncommon for people, especially philosophers, to try to change the ways of extending the paradigms, so as to justify the change they are promoting. And sometime these efforts are successful and what counts as killing does change.
11. See “Voluntary Active Euthanasia,” D. W. Brock. Hastings Center Report, 22, 1992, pp.10-12. People would be inconsistent if such concepts as “killing” were as simple as some philosophers claim them to be. However, some philosophers confuse complexity with inconsistency.

Parental Authority, Children’s Rights, and Health Care
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1. The Problem of Parental Authority
In order to set the stage for a discussion of the specific rights and responsibilities of parents and children in the medical context, it would be helpful to present a general framework for thinking about the ethics of parent-child relations. I will do this in the next two sections and then move on to some comments on its implications for issues that arise in the provision of health care to children.

Philosophical writing on the ethical foundations of the family has a distinguished history. Among writers of the modern period, like Bodin, Hobbes, and Locke, the family served as the focal point of debate on the nature and justification of political authority. Admittedly, the relationship between familial and political institutions was not a totally new concern in this period. It had been a recurring theme of social and political philosophy since Plato’s Republic and Aristotle’s Politics. But in the modern period the concern with parental authority did not leave philosophical reflection on the family unchanged. It reoriented thinking about the family and raised questions about the grounds of filial obedience and familial discipline that had not been raised in this way before. In
contrast to the ancient Greeks, for whom features of family
life were largely regarded as given, natural aspects of human
life, parental authority now became something requiring
ethical justification. It became, to use the fashionable
terminology, “problematized.”

For many of us today, who are living in the shadow of the
modern period, parental authority is also seen to be something
requiring not only explanation, but also justification. Many
parents today are uneasy about their right to exercise authority
over their own children. They believe that, as parents, they
are entitled to their children’s obedience, but they worry that
their use of authority may actually be inhibiting their children’s
development. As a result of this insecurity, parents are
frequently inconsistent in their use of authority, alternately
failing to set limits for their children when they need to have
demands imposed on them and then reacting to their
children’s perceived rebelliousness with excessive discipline
and other authoritarian measures. Arguably, much of our
current perplexity about the family stems from the tension
between two fundamental ethical norms that are widely
shared within liberal democratic societies. First, there is the
right of parents to raise their children in accordance with their
own conceptions of what is best for them, and to do so within
a protected sphere of familial privacy that for the most part is
to be free of coercive state interference. Second, there is the
right of children to become independent adults who have their
own conceptions of the good and can make their own
decisions in accordance with them. Parents quite
understandably want their children to share their most
important values, to participate with them in forms of life that
rest on and develop around common values. For these aims
to be realized, a measure of control and discipline is needed,
and since these aims are regarded as legitimate, parents are
held to have rightful authority over their children. But as we
have come to realize as well, though children in some sense
“belong” to their parents, they are not their property, in anything
like the usual sense of this term. They have distinguishable
interests in need of protection and these interests do not
necessarily coincide with those of their parents. How to
achieve the correct balance between exercising and relaxing
authority, between asserting one’s rights as a parent over one’s
children and according them their rights as persons, is a
problem well-known to parents in societies like ours.

The following propositions are commonly accepted by
philosophers of children and the family who are writing in a
broadly liberal tradition. First, parental authority cannot be
justified only, or even primarily, in terms of the interests of
parents. There is among liberals some disagreement about
the extent to which parents’ own interests may legitimately
be served by the exercise of authority over children, that is,
about whether serving children’s interests is to be thought of
as the exclusive or only the overriding responsibility of parents.
But no liberal seriously argues that parental authority exists
solely for the benefit of parents. Rather, parental authority,
while inevitably benefiting parents in various ways, is chiefly
if not solely for the good of children, and justified only to the
extent that children cannot yet be presumed able to make
decisions for themselves. Second, parental authority, if justified
at all, must encourage and adjust to the developing capacity
of children for independent judgment. It must be aimed at
guiding children to become independent, self-directing
individuals (insofar as this is possible) so that they no longer
require continual adult protection and supervision and can
care for themselves. And it must be take account of and adapt
itself to the child’s increasing ability for mature selfdirection.
Moreover, parental authority — which importantly is to be
distinguished from parental concern and guidance — is no
longer warranted when the child has achieved this status.

The classic statement of the liberal view of parentchild
relations is found in John Locke’s Second Treatise:

Children, I confess, are not born in this full state of
Equality, though they are born to it. Their Parents have
a sort of Rule and Jurisdiction over them when they
come into the World, and for some time after, but ’tis
a temporary one. The Bonds of this Subjection are
like the Swadling Cloths they are wrap’t up in, and
supported by, in the weakness of their Infancy. Age
and Reason, as soon as they grow up, loosen them
till at length they drop quite off, and leave a Man at
his own free Disposal.

The key elements of the liberal theory of parenthood are
all here. “Jurisdiction” (i.e. authority) is necessary in order to
bring children to a place of equality with their parents, where
they (the children) are left at their “own free Disposal.”
Moreover, parental authority is or ought to be temporary and
should progressively reduce the need for its exercise.

Adolescence, of course, poses special problems. It both
challenges our beliefs about the appropriateness of parental
authority and complicates our understanding of its scope.
Indeed, over the past three decades, an expanding body of
professional literature has questioned our traditional
assumptions about the boundaries of adolescent decision
making in general and health care decision making in
particular. The point is that the biological and psychological
differences between children at different stages of
development are enormous, and coming to maturity is a
gradual and uneven process. Ethical generalizations that apply
to children at one stage of development will not always be
applicable to children at another.

2. The Moral Status of Children

Discussions about the moral status of children are typically
couched in the language of moral rights. (I note in passing
that philosophers are not the only ones who have been
attracted to the language of rights. Arguments about children’s
rights have also played a significant rhetorical role in political
debate.) It is useful to begin with some relevant distinctions
that appear in philosophical discussions of moral rights.

Though the term “rights” is used in diverse ways and plays
diverse roles in moral discourse, the rights that concern us
here are claim rights. Claim rights can themselves be divided
into negative rights to noninterference and positive rights to
services and assistance, and imply corresponding obligations
on the part of others. The negative claim rights are held against
the world at large, and imply obligations of all others to refrain
from interfering with the right holder in the exercise of his or
her right; hence, they are called general obligations. The
positive claim rights (for example, children’s rights to food and
shelter, and medical care) are held against some specific
individuals (their parents) and imply obligations only on their
part to meet certain needs of the right holder; hence they are
called special obligations. Every claim right implies a
respective duty, and this is referred to in the literature as the
correlativity of rights and duties thesis.

To add a further wrinkle to the analysis, the primary
function of claim rights can be explained in either of two ways.
To quote L.W. Sumner, “The interest conception treats rights
as devices for promoting individual welfare... On the other
hand, the choice conception treats rights as devices for
promoting their freedom or autonomy.” The former depicts
rights holders as “passive beneficiaries,” the latter as “active

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managers.” Although people have an interest in being free and autonomous agents, the exercise of free and autonomous choice does not always promote welfare. For this reason, these should be viewed as distinct conceptions.

The prevailing view in the philosophical literature is that children have a number of positive claim rights that can be broadly understood as rights of nurturance (in contrast to rights to free choice). These include the means for ensuring survival and healthy physical growth, affectionate care by adults, and an education that equips them to participate in the life of adult society. These rights can be straightforwardly justified on welfare grounds: children have needs that, without the active assistance of adults, they cannot meet on their own. Things become more complicated when we consider whether the choice conception can be applied to children to yield additional rights. Arguably, children are entitled to some measure of autonomy during childhood, and not just because, as future autonomous adults, they currently have an interest in developing capacities for selfdirection and selfdetermination. (This argument is based on the interest conception.) But the extent to which and the matters about which children should be allowed to make decisions for themselves is a contentious matter, especially since in the normal course of events a child’s capacities for selfdirected choice are evolving. With young children, it seems clear that the rights that are most important for them are positive claim rights, which do not allow much moral room for independent decision-making. But over the course of a child’s development, the psychological capacities underlying the possession of rights to make decisions for oneself gradually mature, so that by the time a child reaches adolescence, there is no longer a bright line separating children from adults with respect to the possession of rights to autonomous choice.

Not all philosophers agree that the interest conception of claim rights should be the dominant one among young children, however. Some so-called child liberationists such as John Holt and Howard Cohen have taken a radically different view and have argued that children (even very young ones) have all the moral rights of adults. As a consequence, moreover, fundamental revision of our traditional notions of parental autonomy and familial integrity is needed. But this is definitely a minority position among writers on children’s rights and family ethics, and it is extremely implausible as well, given a realistic understanding of the biological, cognitive, and psychosocial development of children.

3. The Decisional Capacity of Children: Consent to and Refusal of Medical Treatment

Decisional capacity is a measure of an individual’s ability to make autonomous choices and its assessment is a critically important element in medical decision making. Decisional capacity, in contrast to the more legalistic notion of competence, is a taskspecific conception. Different situations call upon different repertoires of skills: some decisions, by virtue of the complexity of the information that needs to be understood and assimilated, or their more farreaching consequences, require more sophisticated powers of deliberation and reasoning; in some cases, a fair degree of experience and judgment is needed to make a sound decision; and so forth. Willard Gaylin has argued for combining this decisionspecific conception of capacity with a riskbenefit approach to decision making for children. He proposes that when the risks of treatment are low and the benefits are high, the child should have to meet a higher threshold of capacity when declining treatment than when agreeing to treatment. Likewise, the child should have to meet a higher threshold when agreeing to a highrisk, lowbenefit treatment than when declining such treatment. In other words, decisions that seem suspicious on their face, considering the patently more favorable riskbenefit ratio of another declined option, would have to meet a higher standard of decision making capacity and be subjected to greater scrutiny than others. Determinations of capacity, Gaylin argues, are to be made by employing what is called a sliding scale.

A sliding scale is utilized clinically with adults. Typically, of course, when dealing with apparently competent adults, no indepth assessment of capacity is initiated or required, and even when the expected consequences to adults of accepting their decisions are adverse, we tend to give patients the benefit of the doubt, in accordance with the high value our society places on personal autonomy. The situation with respect to young children, and perhaps to some extent with respect to adolescents as well (I will return to this case below), is quite different. Our society does not place a high value on the personal autonomy of young children, or rather, it does not place nearly as high a value on this as on their wellbeing, and I have already given reasons supporting this. There is no presumption that young children say below the age of 10 have the capacity to decide for themselves about matters affecting their vital needs. Moreover, the higher threshold of capacity that a young child who refuses medical treatment with a patently favorable riskbenefit ratio would have to meet, will rarely be met in fact. So, we normally do not initiate an indepth assessment of the child’s capacity in such situations, since there are good and compelling developmental reasons for believing that were such an examination conducted, the child would fail to pass the test. A fiveyear old’s refusal to be vaccinated, for example, should be taken seriously, since forcing treatment over objection can adversely affect his wellbeing. But it should not be taken seriously in the same way as a 30 year old’s refusal to consent to a blood transfusion that might be necessary during an appendectomy.

The situation with adolescents is not as straightforward as this, however. Developmental research has shown that at about the ages of 12 to 14, the normal adolescent can conceptualize the cause of illness, comprehend that present discomfort can result in future reward, and balance the risks and benefits of various courses of action. In important respects, they have achieved the cognitive capacity of the average adult. Indeed, it has become increasingly common for clinicians to grant greater weight to adolescents’ wishes concerning treatment after this age and to include them to a greater degree, even accord them a controlling position, in decisions about their care. Some commentators have argued that there should be a presumption of decisional capacity in these adolescents, but this is a very controversial position. Alternatively, we might apply the sliding scale to their decisions, but in a different way than we apply it to the decisions of competent adults. As Buchanan and Brock have argued, the sliding scale represents an attempt to balance two principles in determining whether a patient will decide about his or her own treatment — the principle of respect for patient autonomy and the principle of beneficence.4 The difference between adolescents and adults might be said to be this: the former principle has significantly greater weight than the latter among competent adults, whereas this is not the case among adolescents. Thus, among adults, a contrary decision in the face of a patently favorable riskbenefit ratio should be grounds for an indepth individualized assessment of capacity. (By “indepth,” I mean roughly an assessment to determine whether the patient possesses a high level of decisional capacity — i.e., understanding, ability to weigh risks and benefits by
applying a more or less stable set of values.) Because the principle of respect for patient autonomy has significantly greater weight than the principle of beneficence among adults, we should not initiate such an assessment of capacity unless the riskbenefit of the rejected treatment is extremely favorable. In the case of adolescents, by contrast, the relative weighting of the two principles is different. In other words, the threshold for the riskbenefit ratio that should trigger an in-depth assessment of capacity is lower for adolescents than it is for adults.

This distinction can be justified on the ground that the developing moral selfhood of the normal teenager renders the authenticity of his or her judgment more suspect than that of the normal adult. A teenager’s oppositional stance, while perhaps not defective in a purely cognitive sense, is typically not based on values that constitute a stable and recognizable moral self.

To sum up, we have the following three guidelines for adults and children of different ages:

- For competent adults: an in-depth individualized assessment of capacity should be done when they refuse medical treatment with an extremely favorable riskbenefit ratio or choose medical treatment with an extremely unfavorable riskbenefit ratio.
- For adolescents: an in-depth individualized assessment of capacity should be done when they refuse medical treatment with a somewhat (but less than extremely) favorable riskbenefit ratio or choose medical treatment with a somewhat unfavorable riskbenefit ratio.
- For young children: an individualized assessment of capacity is rarely indicated (and for newborns, never). In this case, rights are to be understood according to the interest conception.

There is of course no mechanical formula for determining when ratios are extremely or only somewhat unfavorable. There is some room for reasonable disagreement here. However, I believe the combination of these principles represents a reasonable compromise between liberationists and protectionists. The principle pertaining to adolescents in particular accords them significant autonomy rights while at the same time it recognizes that they may have special needs for protection in virtue of age-appropriate vulnerabilities.

4. The Parents’ Role in Medical Decision Making

Children’s claim rights are correlated with obligations on the part of their parents to respect their needs for basic human goods, including a sense of identity and worth, physical and mental health, as well as knowledge and skills that will equip them when grown for effective participation in the life of adult society. Parents have significant latitude with respect to how they will fulfill these obligations. With respect to medical treatment, parents not only make routine medical decisions for their minor children. They also consent to or decline treatments when such decisions involve more complex weighings of risks, burdens, and benefits. To a large extent, although with restrictions, we allow parents to make these balancings in accordance with and on the basis of their own set of values. It would be wrong to suppose, however, that the interests and good of the individual child are the only values at stake in family life. In any society that counts individual freedom and close personal relationships among its fundamental values that should be protected, there are other values at stake as well, including the interests and good of the parents and of other family members for whom the parents are responsible. The modern family in Western industrialized countries is childcentered, but a relentlessly childcentered focus turns parents into mere stewards of their children’s interests. Moreover, when there is more than one child in a family, the interests and good of one must be balanced against those of the others. This intricate web of interests and goods that are served by family life constitute it as an intensely valuable form of personal relationship, but it also complicates the process of parental decision making in all sorts of areas, including that of health care.

Though I began this paper discussing parental authority, I certainly do not want to leave the impression that this is all there is to the role of being a parent. Parents (at least good ones) also provide guidance, emotional support, love, and encouragement to their children, and much else besides. But authority is certainly a hallmark of the role, and how a parent deals with his or her authority, in particular how much latitude the maturing child is allowed over time to make his or her own decisions, will have a bearing for better or for worse on other valued dimensions of family life. There is no algorithm that tells us when, how and under what conditions a parent should relax authority to permit his or her children to make independent choices, and different ethicists may propose different timetables.

Lainie Ross, for example, argues against health care autonomy for minors under the age of emancipation because, she believes, it “places the emphasis on shortterm autonomy” instead of giving children a “protected period” in which to develop their potential for selfcontrol and other characteristics that advance lifelong autonomy. In her view, parents’ interests in “raising a family according to their own vision of the good life” are weighty enough to override their children’s shortterm autonomy. My own view of the parental role, as I suggested in discussing the sliding scale notion of decisional capacity, is that this does not strike the right moral balance between the exercise of parental authority and respect for the rights of children.

While there is substantial agreement between Ross and me concerning younger children, and while I agree with her that decisional capacity narrowly construed is not tantamount to the possession of autonomy, I think I am more inclined than she is to check my protectionist instincts and to accord older adolescents autonomy rights in health care. However, I realize that these are difficult issues and it will be enough if I have at least raised doubts about some of our traditional assumptions concerning children and the parents who care for them.

Endnotes

Ethical Issues in Home Health Care

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Background

Since its beginning, the literature in bioethics has addressed itself primarily to the physician and to ethical decisionmaking in the acute care hospital. Yet, with recent changes in the health care system, spurred by efforts to reduce costs, hospital stays are fewer and shorter, with the result that patient care is increasingly the responsibility of nurses and increasingly takes place in a home setting.

Home health care is not immune from ethical concerns, but because of the marked differences in the environment between hospital and home, ethical concerns arise in quite different ways. The conditions which make going home attractive to hospital patients are often the very conditions which present ethical challenges for the home health care nurse. Thus, it is appropriate for philosophers in bioethics to turn attention to the particular kinds of issues which health care professionals encounter in home health care.

The following is a summary of some typical ethical concerns, highlighting the ways in which the home setting changes the picture for the nurse:

a) Privacy and confidentiality. Most commonly family members or friends serve as caregivers with the home health care nurse in attendance only a few hours a day or a few hours a week. Since clients depend on the good will of their caregivers, they may be reluctant to ask them to step outside while conferring with the nurse. In many cases, caregivers need information about the medical condition of the client in order to give good care. In addition, nurses inadvertently reveal information about the progress of the client merely by the frequency and duration of their visits, which are publicly observable by attentive neighbors.

b) Decisionmaking. The hospital patient, somewhat isolated from family and friends, is in a good position to exercise autonomy and consider his or her own best interests. In the context of home health care, however, clients’ decisions may have a direct impact on others; thus collaborative or compromise decisionmaking seems more appropriate. A client’s desire to be cared for at home rather than in a nursing home, for example, depends on the ability and willingness of a spouse or son or daughter to serve as caregiver and this must be negotiated before a decision can be implemented. In some cases, the caregiver will automatically try to assume the role of decision maker, even though the client is competent. For these reasons, it is very important that those involved in discharge planning and in carrying out clients’ decisions, give careful consideration to the particular circumstances and the web of relationships of the individual patient.

c) Truth-telling. Information about the client and information given to the client is much more easily controlled by family caregivers in the home setting. Health care professionals must rely on reports, records, and observation by others, since they are able to make direct observations only intermittently. Since family caregivers are not bound by the same code of ethics as professionals, they may believe it is acceptable to withhold, manipulate, or reinterpret information as they see fit. This can cause serious problems between nurse and caregiver.

d) Adherence. Health care in the informal atmosphere of the home lacks the regularity and supervision that hospital routine virtually guarantees. Clients on their own may forget to take their medications or their caretakers may decide to modify the treatment plan. While competent clients may always refuse medication or treatment, this is less likely to happen under the eye of hospital staff. The home health care nurse must work out a balance between respecting the autonomy of the client and promoting medically appropriate care.

e) Cultural differences. Hospital patients wear the same johnnys, eat the same food, wake and sleep on the same schedule. Cultural differences tend to fade into the background. In the home, however, cultural practices pervade all the daily activities of life and these may not be compatible with good nursing care. For example, caregivers may not be knowledgeable or willing to change cooking habits to meet the client’s special dietary needs.

f) Safety issues. Sometimes a patient wants to be discharged home but refuses or cannot make arrangements for an informal caregiver, and there are real concerns about safety. How paternalistic should the health care team be, if the patient is competent? Other times, even with a caregiver in place, some homes pose unacceptable safety risks in terms of physical environment, unclean housekeeping practices, the presence of smokers, etc. In the extreme, home health care nurses must be alert for signs of elder abuse. These kinds of safety issues simply do not arise in a hospital setting and they pose real quandaries for the nurse who wants to respect a client’s desire to be at home, yet wants to protect the client from high risk situations.

g) Shift in power. As a hospital patient, a person is on alien turf. At home, the home health care nurse is a guest on the client’s turf. Also, she is alone on the scene without the back-up of a whole hospital team. Clients and families may feel empowered to challenge the nurse’s treatments in ways they would not do in the hospital. Thus, home health care nursing calls for special awareness, diplomacy, and sometimes creativity to assure the safety and best interest of the client.

Methodology

The home setting establishes an intimate relationship between client, family, and nurse. This fact suggests that in addition to the usual ethical questions about rights and consequences, ethical analysis should pay special attention to the particular context in which health care is given, the relationships which help define the identity of the individual client, including the triadic relationship between client, nurse, and caregivers, and questions about character, that is, the professional and personal integrity of the home health care nurse. Thus, borrowing from some of the feminist ethics, it seems especially well suited to the unique features of home health care bioethics to approach discussion of cases from a broad-based methodology which goes beyond traditional ethics.
To gain insight into the special ethical issues in home health care, the authors interviewed fifty practicing home health care and hospice nurses, in both urban and rural settings, asking them to reflect on those aspects of their work which present real ethical challenges. In addition, the authors conducted a series of interactive workshops with small groups of the 150 attendees at a state nursing conference. Topics included end of life decisions for home health care clients, noncompliance, cultural differences, and the limits of professional responsibility, and ethical and practical issues posed by managed care. From this background, they developed fictionalized case studies with analysis of the ethical issues and recommendations of strategies that nurses might use in other similar cases. This work has now been published, adding to the small amount of literature on the topic written by philosophers.1

The following case and discussion illustrate some of the unique aspects of home health care that pose special ethical concerns.

Case and Discussion
Let me tell you what happened last week. I went for a first visit on a new case. I was met at the door by the client’s daughter. The daughter said, “I want you to understand. My mom doesn’t know her diagnosis and unless you promise not to tell her, I'm not going to let you in. I’m her primary caregiver and I couldn’t handle it if she knew she had cancer. She would have to go to a nursing home and I know she wouldn’t want that. So, do I have your word on this?”

It is clear that the daughter totally controls access to the client; the nurse cannot even see the client to assess her competency, ask her wishes about how much information she wants to have, or find out if she is voluntarily ceding to her daughter her right to make decisions for herself.

Appeal to rights in this case will not be very helpful. The client has a right to know, but the nurse has at least a prima facie obligation to provide care. The particular situation, as the daughter has arranged it, makes it impossible to fulfill both of these demands.

Appeal to consequences will also prove not very helpful. The harmful consequences of disclosing information could support the decision to withhold a diagnosis from a client on the grounds of therapeutic privilege. In this case, the nurse has no good grounds for thinking that the truth per se will harm the client, although she does believe it may harm the client indirectly by causing the daughter to back out of the role of caregiver. Other nurses will also most likely be reluctant to accept the daughter’s conditions, with the possible consequence that the family will not be able to hire any nurse to care for this client.

One reason this case presents such a difficult situation is that the nurse needs more information before she can decide what she should do. She must take into consideration not only the particular situation created by the daughter, but even more importantly, the nature of the relationship between mother and daughter. How important is the relationship to the mother? Is it more valuable than knowing the truth about her diagnosis? Is it possible that the mother already knows her diagnosis, but is protecting her daughter and their relationship by letting it remain in a state of “closed awareness?” Will trust be lost if the mother later finds out that the daughter has been withholding information?

The front steps are not, physically or psychologically, the most comfortable place to talk. Yet, it is important that the nurse engage the daughter in conversation, try to assess the nature of the mother-daughter relationship, and try to find a way to care for the client while maintaining her ethical integrity.

While she should not, of course, agree to lie or deceive, she might agree to hold off in offering information until after the first visit. The first visit allows the nurse an opportunity to gain more insight into the situation. It also provides an opportunity to educate the daughter about the benefits of disclosure and offer support in coping with her mother’s knowing. Keeping the door open to further conversation with caregivers is a good strategy in most cases. It allows time for further reflection and lays the foundation for building good nurse/client/caregiver relationships.

Conclusion
In general, insights into the way ethical issues arise in the home setting can be helpful in addressing ethical issues in the hospital or office setting as well. Extending moral reasoning beyond traditional principles to pay careful attention to context, the role of a patient’s important relationships, and the character and integrity of the professional will enhance the process of ethical analysis.

Endnotes

Movie and Book Reviews

Minority Report, movie by Stephen Spielberg
Reviewed by Arthur Caplan
University of Pennsylvania

If you are interested in the ethical problems raised by advances in science, then you are likely to find Stephen Spielberg’s new movie, MINORITY REPORT, a bit disappointing.

It is not a bad movie. It has plenty of action with Tom Cruise in the role of a mid-21st century federal cop. He spends most of the movie on the run from a hi-tech police force that comes complete with retinal scanning technology, intelligent robots and, most interestingly, forecasts of who will commit a crime, and where and when.

If you are enamored of Hollywood and special effects fueled by high-speed chases, you will leave the Cineplex happy. But if you want a more philosophical, nuanced examination of the ethical choices your grandchildren are likely to have to grapple with as technology advances, then you are going to leave hungry for more than MINORITY REPORT delivers.

The film, based on a story by Philip K. Dick, presents a dark and even haunting image of where science may take us. The future, or at least the future of murder, can be seen by genetically engineered telepaths. They are linked to a police agency whose job it is to stop the killing before it happens.
The residents of big cities spend their days in highly controlled environments in which identification scans using retinal imaging are ubiquitous. Big business has linked to this technology, personalizing its advertising for each individual. High-tech drugs provide an illicit escape for those who find order boring and can afford the prices. Virtual reality can provide you with a very good time at very little personal risk.

So far, so good. The explanations, however, of how the technology works that lets us see into the future, are lacking. The explanation of the powers of the telepaths is ludicrously incoherent. Their link to the police uses a technology so Rube Goldberg-like as to be downright silly. The scanning technology can, with some serious bioengineering, be too easily defeated. The possibilities inherent in brain imaging and virtual reality are underexplained and underutilized in favor of magnetically powered police cars and cops flying around powered by rocket packs.

The core ethical message of MINORITY REPORT is that technology will crush individualism in favor of social goods such as safety, security and happiness. Scientists in the movie are constantly seduced and entranced by technologies that cause them to make immoral choices, as when the pre-crime cops and their technical helpers keep the telepaths imprisoned and dehumanized in the name of the public good and personal glory.

All of this leaves plenty of room for ethical rumination. But the amount of time spent in the man/robo hunt for Tom leaves little room for ethics. Would it really mean the end of individualism if human beings gave up a great deal of their privacy? Is it true that we find violent crime so horrific that we would give up all of our civil liberties to stop it? That is hardly the case today in the U.S.A., where guns, drugs, and due process for those accused of a crime are all flourishing. Would it really be ethically wrong to lose ourselves in drug experiences that do not addict the user or in virtual reality worlds that would allow us to make our fantasies come true? Wouldn’t our ancestors from a century back say that is what we do today with Prozac, television, CDs and Dolby Sound?

And who is really the enemy when it comes to using technology to destroy freedom — the government and its police, as the movie contends, or is it more likely to be corporations, or even religious movements? In many contemporary societies, fundamentalist practitioners of Islam, Judaism, Hinduism or Christianity are as likely to want to put technology to use to scan and identify non-believers or those who have engaged in “sin” as are governments. Culture and convention exert tremendous influence to get us to conform, even without the power of the state behind them.

All of these issues are worth thinking hard about. Rapid progress in the neurosciences, radiology, cognitive science and bioengineering means that the ability to investigate our brains and intervene electrochemically to modify them is not far away. We will need to know whether consent is always a requirement for a brain scan. Policies should be put in place to determine what information about our propensities and requirement for a brain scan. Policies should be put in place to determine what information about our propensities and should be made by looking inside our heads can be kept private and what should be available to third parties. And the brain sciences will have to decide if they are simply in the business of diagnosing and treating mental illness and disorder, or whether they will follow the lead of cosmetic surgeons and sports physiologists in making improvement and enhancement a key part of what they do.

MINORITY REPORT, while not providing much insight into these questions, is still a timely reminder that it is not too soon to begin looking ahead.

Arthur Caplan is the Emmanuel and Robert Hart Professor and Director of the Center for Bioethics at the University of Pennsylvania.


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**Reviewed by Erin Schwartz**

Horace Mann School, Bronx, NY.

Genetic Engineering: Science and Ethics on the New Frontier is introduced by the presentation of four preeminent ethical theories (Ethical Intuitionism, Virtue Ethics, Utilitarianism, and Deontology). Boylan and Brown then proceed to examine the Hippocratic Code-derived professional responsibilities of the physician-researcher, potential conflicts of interest, and obligations to the environment and to future generations. Both dictates of ethical theory and specific professional duties are reiterated throughout the book so that readers can effectively connect the dots when evaluating the moral complexities of genetic engineering issues.

Part Two of the text provides a college level foundation for understanding molecular biology, genetics and evolutionary theory. Although the authors propose a detour for the “scientifically challenged,” this part of the book is nevertheless quite clear. The addition of just a few basic diagrams and flowcharts, however, would have enriched this section and made it easier to follow.

Armed with fundamental concepts of moral theory and biology, the reader is then presented with the quagmire of genetic engineering and the ethical issues inherent in its pursuit. The chapters touch on critical topics such as the limits of science, genetic testing and screening, somatic gene therapy, cloning, germ-line therapy and the intersection between business and science. The reader is guided through this maze with sound and reasoned analysis. With this grounding support, judgements can be made and morally justified.

For example, in the chapter on germ-line therapy, Boylan and Brown argue against the reckless pursuit of progress. “Despite the prudential good that might be performed if we moved more aggressively, the long-standing harm that could occur if we made a crucial mistake is decisive.” (158) No where is the delicate balance of medical duty and ethical theory more apparent than in germ-line genetic therapy for humans. Boylan and Brown discuss the risk of a change in the germ-line from four standpoints: Do No Harm, The Principle of Precautionary Reason, The Duty Not to Harm Nature, and The Duty to Future Generations. They invoke these four
principles to question whether our ethical duty to rescue and the duty to promote the well being of the sick can justify the elimination of single-gene disorders. The authors outline a practical, professional, and moral guideline to evaluate the "threshold of risk for research that might impact the germ line." (159) They argue that the all-embracing mission statement for science, that "whatever could be known should be known," (158) should not be taken as a moral imperative.

This approach to reconciling science and ethics through an orderly progression of reasoning provides even a high school reader with an invaluable framework from which to tackle bioethical issues. Genetic Engineering: Science and Ethics on the New Frontier should be commended for the range and depth of the subject matter. Practically any chapter could stand alone as a complete treatise. Additionally, the book includes an exhaustive bibliography, websites to surf, a glossary of terms, and clear, useful charts and illustrations.

In a field replete with conflicts of interest, foxes guarding the henhouse and ends that justify the means, Boylan and Brown have provided a substantive framework of analysis to counter irrationality and rationalization. This book takes an intelligently moderate and practical approach to a very controversial subject. The text would be of great value to students and researchers in the fields of molecular biology, philosophy and medical ethics.

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**ANNOUNCEMENTS**

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**Committee on Philosophy and Medicine Graduate Student Prize**

The APA Committee on Philosophy and Medicine announces that it will award an annual prize for the best essay by a philosophy graduate student on some topic in Philosophy and Medicine. It is our intention to announce the first such award by the end of the 2002-2003 academic year. For more complete information on the award and submission requirements write to kkipnis@hawaii.edu and place “P&M Prize” at the beginning of the subject line.

Submissions will be judged on the basis of the quality of the writing, the salience of the issue addressed, and the cogency of the student’s argument. In addition to a cash prize, the top entries will receive detailed critiques from the judges, as a part of a mentoring process.

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**Conference**

**Issues In Medical Ethics: 2002**

**Seventeenth New York Regional Conference**

**Special Challenges Of Emergency Medicine**

Wednesday, October 23, 2002

Sponsored by the Institute for Medical Education, Mount Sinai School of Medicine

Mount Sinai School of Medicine, Hatch Auditorium, Guggenheim Pavilion 100th Street & Fifth Avenue, New York City

**Morning Session**

How Are Emergencies Different? - Heather Gert, Ph.D.

Emergency Research Without Consent - Lynne Richardson, M.D.

What Part of “No Don’t You Understand?”

Capacity to Refuse Treatment - Arthur R. Derse, M.D., J.D.

**Afternoon Session**

How to Prepare for a Disaster

The Case of 9/11

Disaster Preparedness & Triage: Justice and the Common Good - Robert M. Veatch, Ph.D.

Police Requests & Mandatory Reporting

Cases & Doubts: Challenges of Confidentiality

Registration is required. Registration fee $20 (includes lunch).

For further information, contact: KAREN SMALLS, Bioethics Education, Box #1108, Mount Sinai School of Medicine, One Gustave Levy Place, New York, NY 10029. Telephone: (212)241-6602; Fax: (212)241-5028; Email: Karen.Smalls@mssm.edu.

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**Conference**

October 24-27, 2002 ASBH 5th Annual Meeting

LOCATION: Baltimore, MD, Wyndham Baltimore Inner Harbor

Meeting will include: Preconference Workshops, Plenary Sessions, Paper and Panel Sessions, Affinity Group Meetings and Art Events.

For additional information and the conference brochure go to http://www.asbh.org.

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**Call for Papers**

For a special issue of *Theoretical Medicine and Bioethics* focusing on the topic of parents, children and the state in relation to health care decisions. Publication expected in early 2004. Please contact Mark Sheldon at sheldon@northwestern.edu.

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**Course**

March 31 - April 2, 2003 Death Without Suffering

Three-day intensive course on ethical issues of palliative care at the University of Nijmegen, The Netherlands. Speakers include Diego Gracia (Complutense University Madrid, Spain) and Henk ten Have (University Medical Center Nijmegen).

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