FROM THE EDITOR

Rosamond Rhodes
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This issue of the Newsletter includes a special feature, a set of papers presented as a session at the American Society for Bioethics and Humanities meetings in Philadelphia last fall. This controversial session, organized by Anita Silvers, focused on Peter Singer's position on severe impairment at the beginning of life. The papers in this issue are by the panelists, Peter Singer, Adrienne Asch, Anita Silvers, and Eva Fedder Kitzay.

In addition to those provocative pieces, this issue also includes a thought-provoking paper by Martin Harvey which raises questions about prescribing placebo medication for autonomous patients. We are also lucky to have another entertaining short story by Felicia Ackerman. "Break, Break, Break" tells the story of a heart disease patient coping with his disability. In the book review section, we have Julie Zilberberg's review of Expecting Miracles, a stirring book on assisted reproduction by Christo Zouves.

Please feel free to volunteer your papers, comments, stories, poems, your book reviews, or your comments on papers IN THE LITERATURE. Please continue to send in notices of events and activities that you would like to have announced in these pages. Anything to be announced in the Fall 2000 issue should reach me by July 15, 2000. Items should be sent to me at the address below. Submissions should follow the Guidelines at the front of the Newsletter. Please include both a disk and a printed copy and a telephone number or e-mail address.

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FROM THE COMMITTEE

Leonard M. Fleck
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Let me begin this column with some words of welcome to our new committee members. Mark Sheldon, from the Philosophy Department at Indiana University—Northwest, joined the committee last July. We are pleased to report that he has hit the ground running. He will have primary responsibility for the program sponsored by the Philosophy and Medicine Committee at the APA Central Division Meetings in Chicago this April. He will also be assisting Rosamond Rhodes with organizing the Eastern Division program in New York this December.

Our other new committee member is Glenn McGee, who comes to us from the University of Pennsylvania Center for Bioethics. He too is no slouch. He is the author of The Perfect Baby: A Pragmatic Approach to Genetics, and is the coeditor with Arthur Caplan of a new series of volumes in basic bioethics from MIT Press, the first of which is Pricing Life: Why It's Time for Health Care Rationing, by Peter Ubel. Glenn will join the committee officially this July.

The Philosophy and Medicine Committee has been very productive during this past year. We sponsored two programs at the Eastern Division meetings in Boston this past December. The first of these had as its theme "Philosophical Challenges in Teaching Bioethics." Larry McCullough deserves the credit for putting together a very fine program. The main presenters in that program and the titles of their presentations were as follows: (1) Robert Baker, "The Role of History in Teaching Biomedical Ethics"; (2) Maureen Kelly, "Profound-Religious Ethic and the Role of Moral Judgment: Teaching Across the Health Professions"; (3) Rosemarie Tong, "Teaching Bioethics in the New Millennium: Holing Theory (ies) Accountable to Actual Practices and Real People"; and (4) W. Richard Momeyer, "What Conception of Moral Truth is Communicable and Defensible in the Classroom?" We hope to see all these papers in print very soon; and we thank these speakers for their contributions to the program.

The other program with which we were involved in Boston was one that we cosponsored with the Philosophy and Law Committee. The theme of that session was "Citizens Who Are in Extended Medical Dependence: Virtue, Obligation, and Federal Law." This program was actually precipitated by the U.S. Supreme Court Olmstead decision earlier in 1999. Anita Silvers deserves the credit for taking the initiative and putting together an excellent program in very short order, the result being a timely assessment and interpretation of the Olmstead decision in relation to the concerns of advocates for individuals with disabilities. Leslie Francis and I cochaired that session. Presenters included Eva Kittay, Aisduair MacArtney, Mary Mahowald, Thomas Pogge, Anita Silvers, and David Wasserman.

We have coming up two programs that we will be sponsoring at the Pacific Division meetings in Albuquerque this April. The first of these is a symposium under the title "Medical Genetics and Philosophy: Mutating Concepts, Evolving Disciplines." Lisa Parker, another energetic committee member, gets the credit for organizing this session. Speakers and their presentation.
ARTICLES

Severe Impairment and the Beginning of Life

Peter Singer
Princeton University

I. Introduction

As the title of this session makes clear, we are talking about a juxtaposition of two issues: severe impairment, and the beginning of life. To take a position on either the theory or policy that should govern our ethical decision making here, we need to consider both the moral status of the newborn, and the relevance of severe impairment. In the brief time available, I will try to say something about both of these issues.

II. The Status of Newborn Human Life

The idea that it is always wrong to take the life of an innocent human being is something that we scarcely dare question. Yet philosophers ought to question just those beliefs that we routinely take for granted, including this one. So here is one way to look at this problem.

Ask yourself:

Is it worse to kill a human being than it is to kill, say, a chicken? Unless you are a vegetarian, you are certainly going to say yes, it is.

And even if you are a vegetarian—as I am—you are very likely going to think—as I do—that when someone kills people randomly in a church or school, that is a greater tragedy than what happens daily at a slaughterhouse. But why? Unless we take refuge in religious teachings, which not all of us share, the answer has to be because of some difference between humans and animals. That difference, however, cannot merely be the fact that we belong to one species and chickens, for instance, belong to another. To think that mere species membership alone could make such a crucial moral difference would be a kind of species-racism—more briefly, speciesism. Suppose there were intelligent Martians, very like us, and entirely peacable and friendly to us, but of a different species.

Would it be acceptable to kill them, just because they are not members of our species? Surely not.

So if it is worse to kill human beings at random than to kill nonhuman animals, the difference must have something to do with the kinds of beings that humans are. And I would suggest, more specifically, that it must have something to do with the higher mental capacities that humans have—capacities that nonhuman animals do not have. This cannot be merely the capacity to feel pleasure or pain, or to suffer from the severing of a relationship like that between mother and child, for all mammals have such capacities. To give us a reason for thinking it much worse to kill typical humans than it is to kill beings of other species, the capacities must go beyond these—they might include not merely awareness but self-awareness, or possibly the capacity for making plans for the future. Here we have, I believe, a reason for distinguishing between the wrongness of killing beings that is based on something that is clearly morally relevant. The fact that a being is capable of understanding that it has a "life" does make it worse, other things being equal, to end that life. Then, and only then, are we ending the life of a being that knows it is alive, and can see itself as existing over time. Then, and only then, does the being have any conception of what it might lose by being killed, or have any capacity to have desires for the future that are thwarted by being killed.

I use the term "person" to refer to those humans who have the higher mental capacities, whatever we may decide they are, that make it much worse to kill someone like you or me than it is to kill a chicken. Here I follow the Oxford English Dictionary which defines "person," in one of its senses, as "a self-conscious or rational being." This sense has impeccable philosophical antecedents, for it was used by John Locke. Understanding this will help you to understand one of those notorious Singer quotations that is so beloved by the media: "killing a disabled infant is not morally equivalent to killing a person." [2nd ed., 191].

In fact I could have left out the word "disabled" altogether. For the reason I have just quickly sketched, I do not think that killing any newborn infant is morally equivalent to killing a rational and self-conscious being. This does not mean, of course, that killing infants is a matter of moral indifference. On the contrary, to kill an infant is normally very wrong indeed, but normally it is wrong primarily because of the

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harm it does to the parents, who have conceived the child, and already love it and wish to nurture it. The death of a newborn infant is generally a tragedy for the parents, not for the infant who has not even glimpsed the prospects of the life that might have been in store for it.

You might immediately object that even if a newborn infant is not a person, a newborn infant has the potential to become a person. But if this is supposed to be the reason why it is as bad to kill a newborn infant as it would be to kill an older human being, we shall have to acknowledge that the human fetus also has a very similar potential to that of the infant, and hence the same reason would make it very seriously wrong to kill a human fetus.

Some of you, of course, will endorse this conclusion. But let us note here that a lot of people do not, and without the influence of religion, even fewer would endorse it. To most people, there is nothing especially shocking about the statement that killing a disabled fetus is not morally equivalent to killing a person.

I do not think that the potential of a being is enough to make it wrong to kill that being. The world’s population has passed six billion and is heading for somewhere around 9 or 10 billion—a figure that will strain our planet’s resources to the limits of their capacity. We do not think it obligatory, or even desirable, for fertile couples to bring as many human beings as possible into existence, even though each one of them would, in all probability, become a unique, rational, self-aware human being. And on the same grounds, I do not think that the fact that a human fetus would, in all probability, become a unique, rational, self-aware being is a reason against having an abortion.

That is all I have time to say today about my views on the taking of infant life. I turn now to the significance of disability.

III. The Significance of Disability

Disability is an important issue for ethics, and it is right that it should receive our concentrated attention. But it is a difficult issue, because on the one hand we are naturally sympathetic to the claims of a disability rights movement that models itself on movements defending the rights of women and ethnic minorities, and, on the other hand, we all accept that to have a disability is to be worse off than to be without the disability.

Let me elaborate. Disabled people are discriminated against in various ways. They may be denied education, employment, or housing on grounds that are irrelevant to their disability. This is simply wrong, and should be stopped, just as discrimination in those areas on grounds of race, sex, or sexual orientation is wrong and should be stopped. We should all support disability advocacy groups in opposing such discrimination.

Slightly different, but still definitely something we should support, are the claims of disability advocacy groups to a reasonable effort to remove obstacles to the full participation of disabled people in everyday life. This may range from wheelchair access to buildings, to the provision of signing for the deaf, or audible signals on pedestrian traffic lights for the blind. I say “reasonable efforts” because obviously there are limits on the resources that societies can spend on such matters. But they are of vital importance to a significant proportion of the community, so the effort should be substantial, even if it cannot be infinite. Again, we should support the efforts of disability advocacy groups to ensure that societies, especially wealthy ones like the United States, do these things.

Thirdly, people often have prejudices against people with disabilities, based on irrelevant or factually erroneous information. For example, many people think that people with the lack of muscular control associated with cerebral palsy are intellectually disabled. Such prejudices should be combated through educational programs, and again, we should support disability advocacy groups in their efforts to do this. But here we need to take care. At the extreme end of the spectrum of disability advocacy groups, there are some who deny that to have a disability is an inherent disadvantage at all. They may claim either that the disability is only a disadvantage because of the way our society is constructed, or they may claim that our perception that it is a disadvantage to have a disability is itself a prejudice. I do not think we should accept either of these claims.

Consider, for example, the common disability of being paralysed below the waist. Is this disadvantage only because our society is so constructed as to make it one? Surely not. There are many things that people who are paralysed below the waist could not do in any society, no matter how constructed. They cannot visit untracked wilderness, go ice skating, or play football. And many other things that they can do, they can do only with difficulty, and with more time than it would take those who have the use of their legs. None of these things means that they cannot have a worthwhile life, of course, but they are things that many people like to do. And there is no lack of evidence about this. Why would we spend money in trying to find ways of overcoming spinal injuries, if we did not believe that it is better to be able to walk than not to be able to walk? And the same goes for almost everything that we currently regard as a disability.

Admittedly, there are some disabilities about which it is possible to argue. Some deal people have rejected treatment to restore hearing in their children, arguing that if they become able to hear, they will no longer belong in the community of the deaf. This raises an interesting issue, somewhat akin, I believe, to the wishes of some religious communities to raise their children in ignorance of a world in which there are people who do not share their religious beliefs and way of life. Is this child abuse, or justifiable community autonomy, in regard to which the state should remain neutral? But I will not pursue these issues here, because for most of what we regard as disabilities, there can be no doubt. For parents in wheelchairs to permanently cripple their children, so that they too would be in wheelchairs all their lives, would be child abuse.

At this point, of course, someone is going to think: Peter Singer says that it would be child abuse for parents to cripple their children. Yet he thinks that it is all right for parents to kill their children. Why is that not also child abuse? Isn’t it worse to be killed than to be crippled?

Here, I need to draw together the two threads of my argument. We are talking about severe impairment at the beginning of life. If a life is going to be lived, then it is wrong to make that life worse than it would otherwise be—and to injure children so that they cannot walk is to make their lives worse than they would otherwise have been. To kill a newborn infant, before it is a person, is to prevent a life being lived. And that is something that can be done in many ways—by not having a child at all, or by having a child but using genetic counselling to avoid having a child with a disability, or by having prenatal diagnosis and terminating the pregnancy if the child will have a disability, by
withdrawing life support from a baby born with a disability, or by killing the child soon after birth. These acts are different in various ways, and some of these differences are morally significant, but they do all have the outcome that a life will not be lived.

In thinking about these issues, we should not forget that most couples today, at least in the developed world, plan their families. They will have perhaps two or three children. The decision to abort a fetus that has, say, Down syndrome, is not a decision that is “antichildren,” still less “anti-life.” It is a decision that says: “Since I will only have two children, I want them to have the best possible prospects for a full and rich life. And if, at the outset, those prospects are seriously clouded, I would rather start again.”

This is surely a reasonable view to take. Does it reflect a prejudice against the idea that life with a disability can be worth living? No, no more than putting money into medical research to find cures for disabilities does. In both cases, we are not denying that people with those disabilities can have lives worth living, we are just saying that, other things being equal, they would be better off without those disabilities. It is curious that many of us seem to accept such reasoning when it comes to ending a life during pregnancy, and yet we are shocked by exactly the same reasoning as soon as the baby has been born. I am not sure why. If there is one thing that the opponents of abortion are right about, it is surely that birth does not mark any decisive change in the nature of the being itself. The development of the fetus into infant is a gradual one. Perhaps the most significant difference that birth makes is that the infant can more easily be given up for adoption. Hence where the disability is not a very serious one, if there are couples keen to adopt a child, that is a better outcome than ending its life.

Apart from that distinction between the late fetus and the newborn, I can see no reason for drawing the line at birth—unless it is the need to have some nonarbitrary line that compels us to take our stand with birth. I have suggested that the real moral dividing line occurs later, when self-awareness begins. But here too there is no sharp line to be drawn. That is why, at one point, my colleague Helga Kuhse and I proposed that a breathing space of 28 days should be allowed after birth, in which parents and doctors together should have discretion to make life and death decisions about a newborn child. But I now think this is too arbitrary to work—so I will merely say that these decisions should be made as soon after birth as the accurate diagnosis of the infant's condition, and the parents' need for due consideration, permits.

In closing, let me acknowledge that many people have written to me telling me that they have a child with a disability, and that the child has enriched their lives, and had a good life her—or himself. I have no doubt that this is often the case. But it is also quite often not the case. I have had some heartrending letters from parents who support my views. Here is one example, from a woman I shall call Mrs. B:

My son, John [not his real name], was born almost 2 1/2 years ago 11 weeks premature and weighing only 1 lb., 14 oz. They assured me that because he was already 29 weeks and had no intracranial hemorrhages that he would be fine; he would just need to catch up with other kids his birth age. That is not the case. John has spastic diplegia cerebral palsy with underlying right hemiplegia, sensory problems, and speech delays. We don't know what his level of intellectual functioning will be, although people tell me he will probably be of "normal" intelligence with perhaps numerous learning disabilities. He is certainly more functional than some children with CP and has at least a small chance at a reasonably "normal" life, but that is not the issue.

My husband and I love our son [middle of three], but had someone told me, "Mrs. B., your son will have numerous disabilities down the road. Do you still want us to intubate him?" my answer would have been no. It would have been a gut-wrenching decision, but it would have been for the best. It would have been in the best interest of John, of us, and of our other children. I am saddened beyond words to think of all he will have to cope with as he grows older.

If some couples find their lives enriched by bringing up a child with a disability, I would not wish to prevent them doing so—in fact, as I have said, I would want to ensure that they had the best possible support services. But I also believe that couples like Mrs. B. and her husband do not think this is best for them, the disabled child, or her family as a whole. Others should not force it upon them.

Comments on Severe Impairment and the Beginning of Life

Adrienne Asch
Wellesley College

Peter Singer and I agree on at least one facet of his views regarding infants with disabilities and people with disabilities more generally: They are not his alone; parts of those views are shared by many within the fields of medicine and bioethics, not to mention the public at large. Therefore, if we are to deal with "the monster," it is not Peter Singer, but the views he champions. With most of these views I do disagree.

Before examining Singer's views about the moral status and quality of life for the three classes of infants Singer considers, let me comment on a view that underpins all of his assertions about the parent-infant relationship, regardless of the health status or moral status of the infant under discussion: the "replacement thesis." Singer contends, as do others, that newborn infants (and fetuses during gestation) are replaceable. If one fetus is aborted, say for reasons of prenatal diagnosis of a disabling trait, or if an infant dies shortly after birth of a condition incompatible with life, no great psychological or social loss has occurred to the parents or family into which the fetus or infant might have come and been raised. If, however, we are discussing a wanted pregnancy or a longed-for birth, such an idea is utterly contrary to the experiences of most women and their partners and families. During pregnancy, and surely at the time of labor, delivery, and birth, almost all women who plan to raise the child they have carried, feel that they are already in some kind of psychological relationship with the baby they have borne. So, too, may their partners, who have spent months planning for the new member of the family. Thus, if a wanted child dies at birth, or if a parent chooses not to treat the medical conditions of a child that she or he has looked forward to raising, virtually all will experience great sadness and disappointment that will not
be simply compensated by a subsequent pregnancy and birth of a purportedly "better" child, one without a diagnosed disability. I would suggest that Singer should spend some time listening to what people say who have experienced pregnancies, abortions for fetal impairment, and stillbirth or death of an infant shortly after birth. He might realize that his ideas do not comport with the lived reality of most people he wants to reach.

Let me turn now to Singer's three classes of infants: those he thinks of as "normal," those with disabilities that will render them less than persons in his view, and those who will be persons but who will never have a quality of life that will be comparable to an infant or adult without a disability. Singer argues that infants of whatever health status cannot be persons in the moral sense because, like fetuses, they do not have capacities for self-awareness, self-reflection, or for thinking in any rudimentary way about the past, the present, or the future. He argues that if it is acceptable to abort fetuses for any reason of a woman's choice, it should be morally acceptable to kill a newborn infant because that newborn, for at least several months, has none of what he believes are the attributes of moral personhood. Singer fails to recognize that the "geography" of birth matters; an infant, once born, needs care, but not any one person's, or one woman's, body for survival. The moral grounding of abortion is not in the lack of moral status of fetuses but in the greater moral status of women, who should not be required to use their bodies for the purpose of sustaining life they do not wish to bear. In this, women, like men and women who are parents, do not need to donate blood, marrow, or kidneys to their children even if the children could benefit from them. Thus, Judith Jarvis Thomson's 1972 argument about the morality of abortion still has some force. Newborn infants do not need any one particular woman, or person, and thus they deserve a chance at life because of who they can become. Singer accepts that if biological parents don't want a "normal" child, that child can be adopted and can provide happiness for someone else and have a happy life and thus, the reason to keep the child alive is for that happiness. He doubts that the child with the disability either can be adopted or can have a satisfactory life and that killing the disabled child will ultimately result in less harm and more happiness. Again, his views do not conform to the experiences of people with disabilities or those of most of their families.

Although Singer is not always clear on just which infants he believes are sufficiently impaired that they will never achieve moral personhood, he is clear that most infants with disabling conditions will never have lives that are as satisfactory as infants born without those conditions. "It is obvious that it is better not to have a disability," he says, because the disabled person can never run around, go to the desert, play football, or read bioethics papers (depending on whether we are talking about mobility or cognitive disabilities), and these activities are valuable components of a good life. First of all, Singer fails to recognize that plenty of people with mobility disabilities can enjoy various forms of physical activity, and indeed, they have gone to the desert and returned. Yet again, time spent with people who have disabilities, or at least reading what people with disabilities say, would make a difference. Second, just as the infant or adult with Down syndrome or some other cognitive impairment may not read articles about bioethics or engage in abstract discussions about life and death, this failure to engage in abstract discourse is not synonymous with having no views or preferences about what goes on in one's life or about life as against death. Singer also is unaware of the way in which people with significant cognitive impairments succeed in expressing their views and preferences through means other than abstract discourse.

One should question, moreover, just why Singer selects the capacity for reasoning as the hallmark of moral personhood. Those of us who have relationships with domestic animals as pets value the love and loyalty they offer and might prefer such love and loyalty to the calculated cruelty of humans who plot the destruction of others. The class of infants who will never be able to grow up to engage in this discussion about the merits of their lives will almost all be able to communicate who and what they value in the lives they lead, and they are also able to contribute meaningfully to the lives of others who know them.

The third class of infants, those who as adults would surely be moral persons, but would have less satisfactory lives than nondisabled adults because of their disabilities, should only be killed, according to Singer, if their parents don't want them and if no one can be found to adopt them. As adults, they are moral persons. Singer thus wonders why people with disabilities find his views alarming, since he claims that his views apply only to "severely disabled infants" and not to adults. In the 1993 edition of his book *A Practical Ethics*, Singer discusses infants with disabilities such as spina bifida, hemophilia, Down Syndrome, and other sensory and physical impairments as being in the class of people whose lives would be less satisfactory than the lives of "normals." Again, Singer, like all too many people in bioethics, medicine, and the public, assumes that what is species typical is essential to a satisfying life and that any departure from that typicality dooms or thwarts life interests. It is time for people in medicine and bioethics to listen to people with disabilities and their families who consistently report that their lives are not tragedies, that often their lives are as satisfying as those of nondisabled people, to the extent that scores on self-report standardized psychological measures can be trusted. Furthermore, when people describe their lives as problematic, whether disabled or not, the reasons have to do with disappointments in such realms as relationships, work, financial security, or community life. These disappointments are faced by everyone in life, and Singer and others falsely attribute problems to the having of an "impairment" rather than to the human situation in which everyone finds herself or himself, and to the social conditions that may make life for people with impairments more difficult than they would be if the society were organized to truly include everyone. The root of Singer's (and most people's) difficulty in understanding disability is that people cannot accept the idea that most of what is disabling about impairment is socially created and not intrinsic to the impairment itself. Although not everything about the inability to see or walk would be changed by a society that assumed that some people could not see or walk and properly included methods of mobility and reading that did not require legs or eyes, most of the problems people with disabilities experience could be alleviated by a truly barrier-free society. Bioethics, however, like medicine, has swallowed the notion that unless people with disabilities can be "fixed" they cannot be happy and cannot contribute to themselves or others. Bioethics must start paying attention to
what people with disabilities and their families have been saying for years about the problems of life with disability, and must join with disabled people to call for changes in the society and changes in the health care system that could vastly improve lives.

My last problem with Singer is one that is larger than his erroneous views about the quality of life for people with disabilities or the reasons that life can be problematic. It has to do with his unmodified utilitarian view of the world, of life, of happiness as the sole or most important value. People with disabilities, like anyone else, can find one facet of their lives problematic, disappointing, frustrating, and not derive the whole of their lives. There are other moral values than happiness: loyalty, integrity, striving for self and world improvement to name a few. Singer would probably not dispute the claim that other values exist, but by trying to reduce them all to “happiness” and to measure the value of a life by calculating happiness and pain, he misses the richness and complexity that exists in all life.

Arguing with Singer is arguing not only about the meaning of disability but about the meaning of life for everyone.

**Super Villainous or Mild Mannered?**

**Does Singer’s Position Threaten Real People or Only Philosophically Constructed Ones?**

*Anita Silvers*

*San Francisco State University*

In an op-ed piece in *The Nation* [Katha Pollitt, “Peter Singer Comes To Princeton,” *The Nation*, May 3, 1999, v 268, n 16, 10] Katha Pollitt asks why, with such opportunity to confront real wrongs done to real people, disability activists choose to direct their wrath at a philosopher. Philosophers have little real world impact, she says, and this one has done no more than look cross-eyed at theoretical, philosophically constructed babies. After all, she observes, the only existence these babies have is to star in extreme bioethics dilemmas that pit one large abstract idea against another.

Pollitt raises an important question. What makes Singer such a target? After all, the majority of the arguments he advances are not original with him. Further, although Singer’s conclusions are by no means as commonsensical as he represents them to be, neither are they unique. So what is so provocative, what seems so threatening, about Singer’s position? And does the reaction to Singer hold a lesson about the exposure philosophers risk when they apply their discipline to the practical issues of life?

When we see who they have chosen as friends, the way the disability activists position themselves against Singer is even more puzzling. Pollitt says that the activists’ main ally, the pro-life movement, has yet to stir a finger on behalf of real-life disabled babies and their older counterparts. There is no surprise here, for allegiance to the sanctity of life entails no further obligation about making people glad they’re alive. In this regard, for example, sanctity of life adherents are not identified with efforts to improve the quality of the lives of children with disabilities. In fact, there are negative correlations between the influence of sanctity of life advocates on public policy and how generous policy is to children with disabilities. As a recent study showed: “The evidence was overwhelming that antiabortion states were far less likely . . . to support children with physical or mental handicaps” [William Claiborne, “Anti-Abortion States Deny Benefits to the Disabled,” *The San Francisco Examiner*, Oct 10, 1999, A-5].

This is not to say that all sanctity of lifers reject supporting the disabled. It is simply to note one impact of insisting that life, but not disability, matters. Lori Andrews and Michelle Hibbert find a similar phenomenon in a familiar pattern of legal reasoning in wrongful life suits. Typically, when courts hold that life is the preeminent benefit, they refuse to compensate children born with disabilities when a physician failed to recommend a prenatal test or to report the test’s results accurately (Lori Andrews and Michelle Hibbert, “Courts and Wrongful Birth: Can Disability Itself Be Viewed as a Legal Wrong?” in Leslie Francis and Anita Silvers, *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions*, Routledge, forthcoming Spring 2000). Had the physician done so, the courts reason, these children would not have been born at all. As one court declared: “Life—whether experienced with or without a major physical handicap—is more precious than non-life. . . . By virtue of her birth, [the child] will be able to love and be loved . . . emotions which are far more valuable than the suffering she may endure.” In other words, the suffering any life imposes is the price of whatever benefits are conferred by that life. The belief that life is worth any degree of suffering, so unfortunate people should be glad they’re alive, mitigates the responsibility of other people to compensate the unfortunate one.

Affirming that life is preeminently valuable by no means precludes being generous to those whose lives are filled with suffering. But neither does it make generosity an imperative. On the other hand, to take avoiding suffering as a preeminently valuable end leads to a requirement for generous resource distribution to relieve those who suffer. In this vein, Singer’s “equal consideration of interests” principle recognizes that more than an equal or typical share of resources may be due community members whose physical or mental impairments necessitate heightened support to avoid or alleviate their suffering. Thus, unlike the disability activists’ sanctity of life allies, Singer takes a principled view in regard to disabilities mattering in the allocation of public resources.

Are people with disabilities advantaged by such a principled acknowledgement that disability matters? This depends first of all on whether their disabilities forestall their being treated as community members who matter. In this regard, disability activists could perceive Singer as offering them support with one element of his theory but jerking it away with another. Because he denies that being biologically human is enough to make an individual a person, they read him as elevating people with disabilities from the community of morally connected persons. But of course no logical necessity conjoins these two positions.

While being biologically human creates a strong presumption of community membership, I agree with Singer that there is no entailment between being biologically human and moral community membership. After all, “moral community member” is a value-laden, essentially contested concept. Any definition of "moral community member" is vulnerable to counterexamples. Singer’s best-known argument against the equation of moral community members
with being biologically human is that individuals who are not self-aware have no moral status as persons. How then can they participate in a moral community? But what counts as self-awareness remains obscure, I think. On some versions, any aversive reaction to discomfort counts as self-awareness, while on other versions various manifestations of higher-order reason are required. Further, the margins of awareness and of higher-order reasoning are both so replete with puzzling and troubling examples and counterexamples that to draw the line in any particular place seems nothing more than an act of faith. Similar degrees of vagueness or levels of contestedness becloud all of these other proposals about the essential properties of persons. For practical purposes, then, theoretical proposals about which biological humans do not count as persons and thereby are not qualified to be moral community members should be distanced from public policy decisions. That is, the view that neonates are not persons should be separated from public policy, as the U.S. Constitution requires for any religious belief.

However, three other, more concrete contraindications of the community membership of some biologically human individuals are appealed to repeatedly in Singer's work. While all of them seem to have been extrapolated from Singer's biologitarian premise, each also has a commonsensical flavor. In what follows, I will examine each to ascertain both what it means for the treatment of people with disabilities and whether it suffices to compromise acknowledging them as peers in the context of public policy.

**CONTRAINDICATION ONE: An individual's community membership is contraindicated if the community's ministrations would prolong or exacerbate the individual's suffering.**

What should we do in cases in which an individual does not flourish but instead suffers when subjected to the responses we are required to make to peers? If treating someone as a peer harms that person rather than helps her, it seems commonsensical to refrain from doing so. For instance, although we are obligated not to stint in taking lifesaving measures on behalf of our peers, we might reasonably exempt certain individuals—those for whom heroic measures would be both painful and futile—from the community in which such measures are categorically prescribed.

Our question, then, is whether we increase the suffering of people with disabilities by treating them as peers should be treated. Declaring that disabilities are inherent disadvantages is not a true claim, but even if it would not resolve the point. For most disadvantages are so only in relation to certain purposes and circumstances; they are not categorical. For instance, overcoming the disadvantage of having small breasts currently commands expenditure of a great deal of money. Yet for the purpose of fashion modeling, small breasts are not a disadvantage. So it would be a mistake to think that small breasts are inherently disadvantageous.

A similar case can be made for disability. When this point is made, non-disabled people usually object by citing life-enriching activities they imagine to be precluded if one is impaired. They believe, for instance, that mobility-impaired individuals are unable to ski. I do not ski because I cannot see the advantage in spending so much money and time to get cold, but many of my younger friends with quadriplegia enjoy adaptive skiing. Anomalous biological conditions become limitations in respect to personal taste and in circumstances where social arrangements preclude or omit adaptive modes of performing activities. Every individual is disadvantaged in some ways, but not every disadvantage imposes suffering, and the same characteristic may be disadvantageous in some contexts but neutral or even advantageous in others. In many cases, the suffering associated with disability is contextually induced. Hostile environments cause it, and hostile environments are largely remediable, often readily remediable.

Clearly, until such exclusionary social practice is altered, we really cannot measure the extent to which the suffering we have come to associate with disability is merely transient. Too often, when we mistakenly identify their biological anomalies with inferiority, inherent disadvantage, or unalterable limitation, we are doing nothing more than rationalizing the contextual disadvantages we wrongly impose on people with disabilities.

There are, after all, counterexamples to almost every example of limit advanced to prove the disadvantageousness of disability. There are deaf professional classical musicians, blind visual artists, and paraplegic rock climbers. In sum, when applied to real cases, the idea that a disability is a limitation, an inherent disadvantage or a source of suffering very often proves no more than a stereotype.

It is difficult, but very important, to take great care in assessing the potential any condition has for imposing suffering. As Elizabeth Spelman observes, "Claims of... human suffering can do as much to reinforce claims of superiority and inferiority as they can to undermine them" (Elizabeth Spelman, *Fruits of Sorrow: Framing Our Attention To Suffering*, Boston: Beacon Press. 1997, 9). As yet, we have no adequate understanding about how to judge suffering accurately. Our measuring instruments—the so-called quality of life scales—are ad hoc, uncalibrated and abysmally primitive. Nor have any quality of life measurements now in use been demonstrated to be unbiased, objective, and reflective of thorough community agreement.

So we are not positioned to discover whether their suffering contraindicates disabled people's community membership. We could, of course, settle the matter arbitrarily by defining disability as a state of ineluctable suffering. But surely it is biased to stipulate rather than demonstrate that their suffering precludes embracing people with disabilities within the community and frustrates treating them as peers. Moreover, this strategy rests on an absurdity, namely, the notion that we can define away or stipulate against our obligations to attempt to relieve suffering. The line of thought we have just explored gives no ground for holding that disability matters because it narrows the principle that biological humans are peers. Although it is logically possible to build a case for excluding particular individuals from the principle to avoid heightening their suffering, in the cases in which the burden of proof for doing so can be met are much, much rarer than Singer usually admits (although over the years he has come to acknowledge some of the difficulties in doing so).

**CONTRAINDICATION TWO: An individual's moral community membership is contraindicated if no community member bonds with the individual.** Impaired neonates, unwanted by their parents and unacceptable, figure largely in Singer's illustration of how this consideration should operate. Singer quite rightly insists that individuals should not be imagined to be protected by the moral community's bonds if community members...
must be coerced to connect to and care for them.

However, for this contraindication to be a principled one, neonates rejected by community members for any other reason should be accorded the same status. That is to say, if community members do not want to engage with a neonate because it is a twin (the most common reason for rejection of neonates worldwide; Benedicte Ingstad and Susan Reynolds White, Disability and Culture, Berkeley: University of California Press, 1995, 11), because it is a girl, because it is a slave, because it has some other mark of supposed inferiority, their right to self-determination should equally suffice to relieve them from responsibility for its care. It is biased to make disability the lone mark of a moral outsider by supposing that it, alone of all stigmatized characteristics, justifies exclusion from the community. Other views of how disability affects moral status abound. An important one, which casts individuals with disabilities as the quintessential moral insiders rather than as pariahs, can be found in Alasdair Macintyre's Dependent Rational Animals (Open Court, 1998).

Also, for this contraindication to be principled, the failure of people to bond with children who have disabilities must emanate from something more than current fashion. That parents now happen to prefer average-size children to achondroplastic children is a matter of taste; not all parents do so now, and in cultures in which achondroplasia is the mark of a man of power, parents' preferences are very different. And notice how extensive the list of morally unshielded kinds of people would become if all such tastes are allowed to justify abandonment by and exclusion from the community. Nothing I have said here suggests that all children must be embraced. But the discussion suggests that the problem of rejected children—those whose parents would prefer not to have them—is not intrinsic to disability.

CONTRAINDICATION THREE: An individual's moral community membership is contraindicated if the individual will be so needy that, on balance, the collective interest is best served by considering her not to be morally connected so that no obligation to relieve her neediness burdens the community.

But there is little practical difference between withholding support from a needy individual because she has no claim on the community, and withholding it because her claim is weaker than everyone else's claims. Moreover, it is unprincipled to detach the disabled from the community of those whose interests deserve equal consideration just to dispose of their claims for care. So this position collapses into another one, which is that the collective interest trumps an individual's interest regardless of her moral status. The question then turns to ascertaining the extent to which sustaining the public good involves trumping the claims of the disabled.

For example, how should principled collective interest respond to various kinds of stigma? Should caring for distant individuals with such stigmatizing characteristics as third-worlder or immigrant be assigned a higher priority than caring for our own children who are stigmatized by disability? The thought that seems to guide Singer's work is that supporting distant and needy people rather than individuals who are near to us and needy is more conducive to the collective good because it is less personally burdensome to individuals and to society as a whole. After all, committing to the near and needy may require changes of personal practice, while caring for the distant needy usually demands no more than going without whatever resources we agree to reallocate to them. But precisely because relieving our intimates is more demanding personally, we must be sure expediency is not the reason that doing the right thing for distant people is more attractive than doing so for more intimately connected ones.

One source of obfuscation comes from using allocation models designed to help us select between two immediate options for considering choices between actual individuals and abstract, potential, or imagined ones. For instance, the triage model, in which the immediate circumstances of emergency or war force us to abandon one patient in favor of another, often is used to consider the propriety of allocating resources so a disabled baby shall live. (The important insight that the triage model impermissibly dominates our reasoning about medical resource rationing was introduced by Rosamond Rhodes at the World Congress of Philosophy, Boston, August 1998.) The question about caring for the disabled child is posed as if the perfect child and the disabled child are in competition for resources. It is cast in terms of whether to keep the disabled child or, instead, discard it so that a perfect child can be conceived in its place. Singer often formulates the question of how disability matters in this way.

But it is bizarre to apply guidelines for well-formulated choices between two real patients to ill-formulated choices between a real but imperfect baby and an imagined alternative philosophically constructed perfect baby. After all, in classic triage we would never refuse treatment to an injured person simply because we can imagine a patient we would prefer. Yet far too often, the case that people with disabilities are intolerably burdensome is made through misleading suggestions that their presence potentially deprives us of the presence of other, better individuals.

Singer and his opponents thus agree that "disability" is a category that introduces resource allocation issues. They agree that people with disabilities may claim more than the usual resources because of their atypical needs. But they disagree about how many such claims should be honored. Singer's view appears to be that the principle of equal consideration of interests is curtailed when the collective interest conflicts with the individual interest of a person with a disability. Singer therefore says that only some disability claims should be honored because there are many cases in which responding sufficiently supportively to a disabled individual is too burdensome for others in the community. Disability activists adopt the political stance that all such claims should be honored.

Disability activists sometimes represent the minority group in whose name they speak by proposing that honoring the claims of the disabled categorically is the moral way to make disability matter. As the previous discussion indicates, however, their difference with Singer is not abstract moral debate about what kinds of people are morally deserving. It is a concrete political dispute about whose interests should be satisfied in allocating resources. It is evident, then, that Singer is a political target. Notice that in politically charged debates, no one is reassured by clarity.

Therefore, Singer's clarifying his position is no more likely to be effective in winning over his opponents than Dan Quayle's doing so. Singer rightly complains about the fallacy of charging him with opposing
the existence of disabled people categorically simply because he urges us to avoid bringing children with disabilities into the world (Peter Singer, "A German Attack on Applied Ethics: A Statement by Peter Singer," Journal of Applied Philosophy, v 9, n 1, 1992, 88). However, his opponents rightly read him as suggesting that their burdensomeness to others sometimes makes the disabled unwelcome and therefore as threatening the public benefits on which their way of life depends. (It is no accident that political opposition to Singer first emerged from the left in Germany, where social welfare policy confers generous benefits on people who are classified as disabled.)

CONCLUSION: Singer advances several distinct reasons to show that disability weighs against prolonging people's lives. But as we have seen, his arguments that disability is burdensome to the disabled individual and that it impedes communal connection with others do not warrant the conclusions he draws. The phenomena he cites are familiar, of course. He reminds us that some parents of disabled children want their offspring not to be alive. Similarly, in the Nazi concentration camps, mothers killed their babies to save them from worse suffering. And as Toni Morrison describes in Beloved, mothers killed their children rather than have them exist as slaves. Yet in these cases we do not conclude that the children were best off to die. Instead we acknowledge pressing obligations to repair any circumstance so evil as to make mothers believe that destroying their babies is the least worst choice. So should we for disabled children.

This leaves Singer's last contention, namely, that disability matters so much we must be wary of its compromising nondisabled people's good. It is hard to imagine that Singer's advancing this view will alter the allocation of health care or other U.S. benefits to people with disabilities, even were he able to command all of the vast influence Princeton exercises on our nation's public policy through trustees like Steve Forbes and Bill Bradley. Nevertheless, philosophers should view the political protests held at Princeton with more concern than they have evinced so far, especially if they take the construction of resource allocation schemes to be a main objective of scholarship in philosophy and medicine. Such allocation schemes are inherently political, so philosophers who address them inevitably will be viewed as affixing moral imprimatur to political positions. The fact that Princeton, a private first-tier university, withstood an attempted intervention (including intervention by the official who chairs the National Council on Disability, a federal agency) into its faculty appointment process should not lull us into supposing that the abstractness of philosophical positions always insulates us from the effects of political action.

Relationality, Personhood, and Peter Singer on the Fate of Severely Impaired Infants

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"The one thing having a child does is make a philosopher out of a parent." So opens an op-ed piece in the aftermath of the infamous Baby Doe case, an infant with Down's syndrome whose parents reluctantly made a decision to let their infant die. If having a child makes every parent into a philosopher, having a child with cognitive disabilities makes a philosopher who becomes a parent into a far humbler philosopher.

I was a philosophy graduate student when my daughter Sesha was born. She was picture-perfect at birth. It wasn't until Sesha was four months old that we suspected a problem. At six months, our pediatric neurologist suggested that we visit another doctor for an assessment. This neurologist gave us the news straight—straight up, no soda, no ice, no palliatives. A two-minute exam, and the words: "your daughter is severely to profoundly retarded." When we returned home, I was violently ill. My poor husband had to care for both Sesha and me that terrible night.

Now, I am not suggesting that I took the news worse because philosophy was my chosen trade. But loving Sesha and loving the life of the mind forced me to think—to feel—differently about that latter love. My own child could not share its treasures, could not even remotely approach that which had, I had thought, given my life its meaning. I had to reassess the meaning and value of cognitive capacities as the defining feature of humanity. I discovered that a love for one's child transcended any denumerable set of defining characteristics. What it meant to be human, to have value as a person, would never be the same for me again.

The yardstick I bring to the truth and value of a philosophical position is its ability of to embrace a person such as my daughter. Professor Singer's views, I think, fall short. But first let me say that my views are not always at odds with Singer's. Like Singer, I reject the sanctity of human life ethic when it insists on the moral impermissibility of abortion. This ethic also insists that hastening the death of infants and adults who persist in a vegetative state or whose condition is terminal and who face a lingering and painful death is always morally impermissible. I think these positions are wrong and cruel, and that Singer is perfectly correct to challenge them and is courageous to force the argument. Singer takes a quality of life ethic in place of a sanctity of life ethic. I agree that this approach is preferable. But as Singer deploys it, I find it problematic.

I contrast my views with Singer's, by:

1. Disputing that the concept of personhood is given by a denumerable set of attributes, especially ones that privilege cognitive capacities.

2. Questioning Singer's coupling speciesism with questions concerning severe human impairments.

3. Challenging the primacy of the impartialist ethics that guides Singer's project.

Instead I argue for a view of personhood in which our relationships to others figures centrally, which affirms species membership as having moral significance, and which affirms partiality as appropriate for certain ethical considerations. I take from a feminist ethics of care a number of key concepts that contrast with the ethics, old and new, that Singer both attacks and adopts. An ethic of care stresses the actual relations we have to particular others and the need to maintain connection and to avoid harm. To posit given an abstract sanctity of human life above the particular concerns of the individuals whose lives these lives is to fail to attend to the needs, to fail to be responsive, to those whose lives are affected. The embryo may be human but it is not a human life. To
exclude embryos from moral considerability doesn’t commit one, on pain of contradiction, to give up a commitment to the moral specialness of membership in the human species. One can privilege species membership without having to include all forms of human life, only all those humans who live these lives.

An ethic based on the quality of life is less abstract because it is always someone’s quality of life that is under consideration. But what is a good quality of life? Whose notion of quality is under consideration? The philosopher’s? The physician’s? The as-yet-unhumbled philosopher answers as Locke did to the question of what constitutes personhood. With Locke, Singer offers to define a person as one who is “a thinking intelligent being that has reason and reflection and can consider itself, the same thinking thing in different times and places.” The physician is hardly less invested in cognitive capacities.

Few would think to say that a good quality of life, getting wonderful hugging and kissing, clapping to your favorite song, giving endless joy to your parents and caretakers, teaching love without uttering a word. Not that the philosopher and the physician couldn’t accept this as a life with quality when seeing the joy, but joy—giving it and experiencing it—somehow has rarely made the list of attributes that confer personhood.

From whence does that joy derive? Largely from loving, caring relations with others and with what is beautiful in life, what we can find of beauty in life. A smile, a penetrating look, a mournful strain of music, the cool fluidity of water. Well, the philosopher responds, animals can appreciate some of this as well—isn’t Singer right after all then? Isn’t it simply speciesism that favors your daughter over the gorilla, Koko?

Singer (in Rethinking Life and Death) attempts to convince us by conjuring up an institution for the retarded, which it turns out, is not for mentally disabled humans, but for full-functioning chimpanzees. However, the preferred setting for a person with retardation is in the community, in the home of her family, or living near where her relationship to her family can be maintained, where she can develop relations with others in the community. If there is no call to integrate chimps into the (human) community, it is because chimps do not have a human community into which to integrate—instead they have a community among “their kind.” In contrast, segregation of retarded persons, it has been argued, is no more morally benign than racial segregation. So there seems to be a moral difference, after all, between humans who are retarded and chimpanzees. What has gone wrong? Is it that the discrimination against the disabled is not akin to racism or is it that preference for members of the human community is not akin to racism?

What is left out of the talk of morally relevant attributes is that they, like the ethic they are called upon to overturn (that is, the ethic of the sanctity of life), are abstracted from the actual lived lives of those who bear them. It is a flawed view that derives, at least in part, from a philosophical hubris, a hubris which vanishes with the birth of a child with severe impairments—impairments which cut directly to the set of attributes put forth in abstraction of the individuals to whom we relate, and whose lives and well-being are constitutive of our own identity and happiness.

Living for nearly thirty years with a daughter who arguably does not fit the list of attributes that Singer adopts from Locke, I would have to reject the notion that my child is a person, or reject the criteria. It’s a simple choice. Sesha, and the many children and adults I have met in these many years who have similarly severe impairments, are persons. Their personhood gives rise to the definitional claims of the list Locke and Singer provide. Perhaps it’s just the wrong list. The burden of proof is on the proponent of an attribute criterion of personhood to come up with a better list. But, to borrow from Tolstoy, “all unimpaired humans are alike; all humans with severe impairments are impaired in their own special way.” We can retain some characteristically human capacities and lose others. What is lost and what is retained determines how much of the scope of human existence we can partake in. It does not and should not determine our personhood.

Who we understand to be persons, I suggest, begins (but does not end) with those to whom we stand in relation, not as generalized others, but as concrete others. Feminist theorists, have argued that an “encumbered” self, a self for whom relations to others is not constitutive of identity is an abstraction masking multiple dependent and interdependent relations to others. They have argued that the very formation of a self depends on the interrelation with the earliest caregivers; that both our desires and our second-order desires are inextricably shaped by the communities in which we live, and the relationships in which we find ourselves. There is no coherent sense of self, or oneself as a person, that does not rely for its very constitution on relations with others, beginning with those with whom we are closest. What it is to be a self, what it is to be a person is to be enmeshed in a network of relations that are constitutive of that self.

Just as we come to understand ourselves as persons in and through relations with others, so we come to understand others as persons in and through relationships. But here relationship need no longer be confined to those with whom we are in actual relationship. I propose that this extension is properly made to all those whose possibilities are also our own possibility. Imaginatively extending my relations to those others in whom I see their situation as a possibility for myself is a (if not the) crucial move to seeing our connection to all human beings. Here species membership returns as having moral relevance, and distinguishes itself from racism. Any human being—of whatever race, sex, religion, age, ability, or limitation, etc.—presents a field of possibilities, which the moral imagination grasps as my own possibilities. This is true even as I understand myself in relational terms. While I am white, I could have a child or grandchild that is black or of a religion or ethnicity that is not my own. But even the nearest ape does not stand in this relation to me (unless it turns out, as Singer speculates in Rethinking Life and Death, that chimpanzees and humans are sufficiently close genetically that they can interbreed). This species partiality in no way suggests that I have any right to wantonly kill, imprison, injure, or mistreat chimpanzees, or any other beings—no more than a partiality to my own child gives me a warrant to mistreat another's child.

The utilitarian principle of the equal consideration of interests seems to suggest that such partiality to our own children is not warranted. Yet, even on consequentialist grounds, one could argue that partiality is required in certain sorts of distributions, that an equal consideration of interests in certain contexts would serve everyone rather badly. Imagine having each of us give of ourselves equally to each and every child, whether or not they be our...
own [biological or adopted]. It isn’t clear that any child would receive the sort of intense concentration of attention and care that it requires to survive and thrive. So, at the very least, this form of distribution would not be very efficient or effective. Much better to have these vulnerable persons assigned to the care of a relatively few persons who behave not in impartial ways to them, but with partiality.

I understand the above arguments to mean that we cannot claim humans are not properly persons if they do not have the appropriate attributes. Therefore, we cannot claim that infants, whether not impaired, and severely retarded human are not persons by pointing to their lack of the stipulated attributes. Then, defending the appropriateness of letting infants die or killing them, whatever their condition or ability, by claiming that they are not persons, will not do. This of course means that the justification of killing or letting severely impaired infants die because they are not persons also fails.

Singer recognizes that while the attributes necessary for personhood are not fully acquired until well after infancy, there are social considerations that demand that the baby be considered a person prior to their attainment. Yet, birth, he claims, is an arbitrary place to mark the beginning of personhood, for the full-term fetus is indistinguishable from the newly born babe, and other cultures often chose a time after birth to confer personhood.

If we take personhood to consist of satisfying a list of attributes, then birth is arbitrary. The full-term fetus differs from the newborn only in its physical separation from its mother—and to the extent that it depends on mother’s milk for nutrition, it isn’t even all that separate. If personhood is conferred, at least in part, by relationship, then it is less arbitrary. While this being is still within, we don’t know it yet. The moment of birth establishes a point where relationship can begin in earnest, so to speak; it is the moment after which the care of a mothering person is necessary to sustain it and bring it into the human community.

Yet, birth is arbitrary even for forming a relationship with the baby. Relationship may be established prior to birth. Before birth, prospective mothers will speak of the fetus as “the baby.” Alternatively, relationship may be postponed until the infant is welcomed not only by the mother and father, but by the community.

Membership into the community solidifies personhood.

The question of whether our own society should move from accepting birth as the socially agreed-upon dividing line should perhaps be split, as it is in Hebraic law—into the case of the full-term baby and the very premature neonate.

I think a close look will reveal that the reasons for which other societies have postponed and still postpone personhood either fail to apply to our own situation (for instance, when the justification has to do with scarcity, harsh living conditions, or the need to space children) or are morally unacceptable on other grounds, such as sexual discrimination (as when infanticide is selectively practiced on girls). An affluent society, with access to birth control, with resources to care for disabled persons, and a commitment to gender equality, such as our own, does not share the bases on which traditional societies have justified infanticide. The only remaining justification is based on the emergence of new medical technologies for premature neonatal care. As one mother Singer quotes puts it, “[sometimes] it is hard to distinguish a premature birth from a late spontaneous abortion.” Even here, I am not so sure. Many parents look at the tiny being in its sterile bubble with tubes and wires—looking so unlike a baby—and still see their son or their daughter. Once a parent sees the infant as her child, she sees the infant as a person.

If there are not very strong justifications for moving the line, decisions about the fate of the infant have to be made in light of the infant’s personhood. Then, who decides why a very ill and disabled infant should continue to fight for life? I agree with Singer that it must be the parents, together with the physician (although the role of the physician is very problematic). I think that a relational conception of personhood would demand that those who have the responsibility for the care of the child, usually the parents or the mother, must have the first, if not also the last word, about the fate of the infant. If they [and especially the mother] do not or will not take on this responsibility, they can, in generosity, relinquish it to another. Even then, it remains the prerogative of the mother, in particular, to relinquish her responsibility to another. The mother who has made the connection to the child, whose own personhood and interests are now (and so forever) entwined with the child may judge—perhaps incorrectly, but it must be her judgment—that the child cannot have a worthwhile existence with her or another.

Parents faced with a child with severe impairments at the start of its life have to make terrible decisions in a very short period of time. And they have almost no time to educate themselves. The society at large aggravates the situation by providing so little in the form of understanding what a life with disabilities is like, what a family with a disability is like, and worse still, by providing so few resources to persons with disabilities and to their families. This makes the prospect of having to handle this situation so much more frightening than it need be. Furthermore, society does the family and the child a major disservice in so poorly preparing physicians to understand what it means to raise a child with severe disabilities, what sort of life a person with cognitive disabilities can lead. Such a person, in the best of all worlds can have a very wonderful life and can be the source of enormous joy for others as well. My daughter has a wonderful life and she, along with my son, is the light of my life, and my partner’s and her grandmother’s, and a person of central importance to the many who have helped care for her.

What would I say if I were in the nursery with the mother who, learning that her otherwise healthy infant has Down’s Syndrome, says to her husband, “I don’t want it, duck.” Do I think it was appropriate for the physician, hearing this, to sign the orders “nursing care only” and allow the child to quietly starve while under heavy sedation? Or, do as Singer suggests would be still better, to actively kill the infant with a lethal injection?

Although I could not say to a mother faced with a very premature infant with severe medical complications, whose survival was uncertain and whose outcome would surely involve significant cognitive damage and medical problems, “Without a doubt, do everything to save this child,” I find it very hard to accept the actions of this family and this physician. It seems based on ignorance and prejudice and not a realistic assessment of the hardships of the family or the life prospects of the child. Furthermore there are increasing numbers of persons who could relate to a child with Down’s Syndrome, who could find joy here. In this case it would be more decent and generous to allow this particular infant the opportunity to form its connections to
another—for the parents to relinquish him to others who could love him.

Birth matters here because birth allows the infant to form relations to others than the mother, and when there are others there to fill the void left by the biological parents, there is some very important violation. Perhaps it is that all the consideration here is for the family and none for the infant. If the alternative were to consign the infant to an impersonal and inadequate institution, perhaps such a decision might be justifiable—because the concern was for the happiness or misery of the child that would grow up.

To insist on a relational concept of the person is not to say that when the relationship is not made there is nothing there—one can only create a relationship that makes personhood possible to the sorts of beings who can become persons. Those sorts of beings, I argued earlier are those whose possibilities are always our own possibilities. I may not become a person with Down’s Syndrome but I could become a person with the diminished cognitive faculties. Once we understand that such a life can still be a fully human life, one well worth living, it is harder to accept the fate of the child of the mother who whispered to her husband, “I don’t want it, duck.” But hers is a failure of moral imagination that incites our society and its failure to acknowledge the full personhood and humanity of the many disabled persons. Although I do not mean to accuse Singer of excluding disabled adults from personhood, the marking of severely impaired infants as so easily excluded from personhood works to reinforce a prejudice which, as all prejudice, is vicious and harmful. When we conclude that sometimes an infant’s life is best ended, it is a person whose life we are thinking of, just as we sometimes come to this conclusion at other moments in persons’ lives. And as in the latter case, it is never only one individual’s life that is involved—the decisions are decisions for those individuals whose own personhood is intertwined with the life that hangs in the balance. When we make that choice, when we determine whether that life is a quality life, we must think beyond narrow prejudices.

The life of the mind surely has its charms—and is even indispensable as a part of the human project. But thinking, rational reflection, the high cognitive skills required even for rudimentary speech remain a part only, and most surprising to the philosopher, not even the most important part, of what it is to be human and what it means to participate in the highest value. I gleaned this in my early days with Sesh, while still a graduate student. In time, I became a philosopher. Graduate school, colleagues, books, writing, a lot of disciplined thinking turned me into one. However, Sesh, my profoundly cognitively disabled child has taught me my most important philosophical lessons—if she has not made me a better philosopher, she has surely made me a humbler one.

Note
1. This idea was recently affirmed in a Supreme Court decision; see Olmstead v. L. C. and E. W.

Autonomy, Informed Consent and the Use of Placebos

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Imagine the following scenario. You are ill and require medical attention. Upon reaching your physician’s office you are lead down a brightly lit sterile hallway and told to sit quietly in a drab examination room. After some time, your physician enters and proceeds to inquire after your health, asking various perfunctory questions such as ‘Where does it hurt?’ ‘How long have you had these symptoms?’ etc. She continues with a comprehensive physical exam and then leaves the room. Some time later she returns and informs you that surgery has been scheduled to remedy your condition. Any questions you might have are either brushed off in a most cursory fashion or elicit an extremely technical response. Importantly, no other treatment options are discussed. In short, your physician has already determined the best course of treatment—at least, she is the expert—and it is your duty as the patient to submit, unflinchingly and without hesitation.

What upsetting us about this picture? Prima facie, the most troubling problem is that the patient is given absolutely no voice in the choice of care, i.e., about what is to be done and not done to her body.

This situation, of course, strikes us as morally abhorrent. After all, the patient, an adult of sound mind, is an autonomous being and not simply some sort of object in whom a medical change is to be effected. In contrast to the tradition of benevolent (or, as the case may be, not so benevolent) paternalism, wherein the physician was taken to be the best judge of a patient’s welfare, the locus of such judgments has now shifted to the patient. That is, because of our sentience, and more importantly, our sapience, each person is viewed as bearing a bundle of inalienable rights, most crucially the right to determine what happens to one’s body, over which no one, including physicians, may wantonly trample. Clothes are shed upon entering examination rooms; rights are not.

While its praises may be loudly sung, the value of the principle of respect for patient autonomy is largely negative in scope. The ethical fruits it brings to bear are largely preventative, in that, when consistently and universally acted upon, the likelihood of patient manipulation and exploitation is greatly diminished. Consider the radical information asymmetry between doctor and patient; knowledge, after all, is power. In this sense, a patient is potentially at the mercy of his or her physician. As such, the patient must trust that the physician will act for his or her good—the very essence, as it were, of a fiduciary relationship. Respecting patient autonomy insures that this trust will not be abused—indeed it demands that the patient is ultimately the one who makes all major medical decisions. Once the physician comes to view his or her patients as autonomous beings who have the right to determine their course of medical treatment, he constrains his behavior accordingly. The physician may champion various treatment modalities and may even decry the patient’s choices as irrational (e.g., the hemorrhaging Jehovah’s Witness refusal of a blood transfusion), but, so long as the patient retains sufficient capacity, treatment may, under no circumstances, be forced

In turn, the primary means of protecting patient autonomy has been reliance on the rigorous and stringent doctrine of informed consent. As is well known, in obtaining patient approval for treatment, simple acquiescence is, morally speaking, not enough. A genuinely informed consent requires that the patient be provided with the medical facts of the case and the various treatment alternatives available. Full disclosure appears essential. Furthermore, obtaining a freely given and...
informed consent requires that information be delivered in such a way so as to ensure that the patient has sufficient understanding of his or her medical condition. In brief, ignorance, in its own way, can be as much an impediment to autonomous action as coercion. None of this entails, however, that a physician must sit idly by and passively accept whatever her patient decides. As above in the case of our hemorrhaging Jehovah’s Witness, the physician in many cases ought to challenge her patient’s decisions if she views them as irrational. Clearly, a physician who meekly accepted a patient’s demand for antibiotics as treatment for a case of raging appendicitis would be both morally and professionally remiss. Indeed, the vast majority of the time, a patient willingly follows doctor’s order’s precisely because he trusts that his physician has his best interests at heart. Nonetheless, when the two parties conflict, a competent patient refusal of treatment trumps further medical action on the part of his physician. The doctrine of informed consent thus forms a moral bulwark against the unjustified infringement upon patient’s rights.

Given the above, it appears that truth telling is one of a physician’s most basic moral duties. In that lying paints a false picture of reality, lying to a patient renders the patient’s exercise of autonomous informed choice impossible. Unless one’s beliefs correctly connect with reality, it is hard to see how a truly free and informed choice is possible. Indeed, one’s behavior can be easily controlled and manipulated by someone who manipulates her beliefs. If I, as your physician, tell you that everything is fine, when in fact you have terminal cancer, you will eventually discover the truth (presumably when you don’t respond to treatment). But until then you will be living in delusion. Egregious sins of omission also fall into this category—for example, if you are informed that you have cancer, but your physician neglects to tell you that it has metastasized. Your decisions will not be made in light of the facts, but in spite of them.

To claim, of course, that a patient’s autonomy ought to be preserved and respected through arduous adherence to the doctrine of informed consent is no longer revolutionary. Nonetheless, ethical conundrums still rear their stubborn heads. Consider the use of placebos. Clearly, employing treatments with no known therapeutic value is as old as the practice of medicine itself and the existence of a ‘placebo effect’ is well documented. One would expect, however, that given the ever-burgeoning tide of medical technology, the ‘placebo’ option would have fallen by the wayside (aside from double-blind experiments in medical research). Nevertheless, as evidenced by a recent in-depth article in the New York Times Sunday Magazine (January 9, 2000), interest in the employment of placebos has recently revived. Driven by the need to control costs, skepticism about complicated new treatments, and the inability to cure many common ailments, some physicians are turning to an old, but deceptively deceptive, standby. Is the use of placebos compatible with the duty to respect patient autonomy by eliciting a genuinely informed consent for treatment? As with most interesting ethical questions, a clear and concise answer remains elusive.

On one hand, the use of placebos ought to be prohibited: such deception, regardless of its benevolent basis, undermines any meaningful notion of informed consent and robs patients of autonomy. On the other, so long as patient suffering is substantially reduced, then autonomy, at least in this instance, is damned. In what follows, I want to steer a middle course between these two opposing camps and argue that the limited employment of placebos neither endangers patient autonomy nor poses any serious threat to the doctrine of informed consent.

Before proceeding further, however, some conceptual clarification is in order. According to the Mosby Medical Encyclopedia, a placebo is an “inactive substance” with no known causal efficacy to bring about a desired therapeutic effect. It can take the traditional form of sugar pills and saline injections or the more modern version of prescribing antibiotics for viral infections. More recently, the concept has been extended to include medical procedures of a more invasive sort, such as pseudoarthroscopic knee surgery for chronic arthritis. In turn, whether as pills or procedures, placebos, when successfully deployed, induce a ‘placebo effect’, i.e., a reduction or elimination of suffering on the part of the patient which cannot be explained, at least in strictly clinical terms, by reference to the action of the substance or procedure involved. Clearly, the impetus behind the use of placebo is benevolent—there is perhaps nothing worse than being told by a physician that “nothing more can be done.” Placebos, one could argue, instill hope in otherwise hopeless patients, providing potential palliation against the unrelenting desirae that so often accompanies chronic and ultimately incurable illnesses.

The difficulty lies in the fact that the successful use of placebos necessitates deceptive behavior on the part of a physician towards this patient. Specifically, it appears highly unlikely that completely informed consent concerning the use of a placebo could ever be achieved. It will not do to say to one’s patient: “The pill that I am about to give you is pure sugar. There is absolutely no clinical evidence to suggest that sugar will in any way alleviate your symptoms.” Obviously, in order for a placebo to produce its desired effect, the patient must in some sense believe that the treatment in question is real. Such a belief, however, in light of the clinical evidence, is patently false. By definition there is no known physiological connection between the treatment’s mechanism of action and the desired effect. As such, it appears that the successful employment of placebos involves an act of deliberate deception, and, regardless of the benevolent intentions, the patient’s autonomy is thereby violated.

Still, one wonders, can it really be right to send a patient away depressed and empty-handed? A very qualified “No,” strikes me as the most measured response. To wit, I tentatively propose that when the following three conditions are met, placebo use is morally permissible:

1) The Exhaustion of Medically Relevant Therapies. This condition is essential. Medicine, after all, is an empirical science and its results are accepted precisely because they conform to the methodological canons thereof. The magnificent advance of medical knowledge and technology in the twentieth century bears more than sufficient witness to the fruitfulness of a scientific approach to medicine. Thus, before considering the use of placebos, physicians are obligated to rely on scientifically approved modes of treatment. Hence, it would be wrong to treat a patient suffering from prostatitis by solely prescribing saw palmetto extract. Nonetheless, once all medically indicated therapies have been exhausted, and the patient is still exhibiting symptoms of disease, the use of placebos may be allowed.
2) Minimal Nondisclosure. As noted above, the efficacy of placebo treatments presupposes that a certain amount of information not be disclosed to the patient. Importantly, however, the extent of this nondisclosure must be minimized as much as possible. In general, one could claim that the more elaborate the deception, the more difficult it is to justify. In the case of placebos, only minimal deception is permissible. Sugar pills and herbal extracts are one thing, pseudo surgery is quite another. Crucial knowledge concerning the gravity of a patient’s overall prognosis must not be withheld and the placebo itself must not be sold as a ‘miracle cure’. The purported benefits of any placebo must be qualified if unreasonable, and ultimately unrealizable, expectations are to be avoided. The aim should be to provide the patient with a kernel of hope for at least a slight improvement in their state of physiological and psychological well being. Permissible nondisclosure in the case of placebos is akin to the nondisclosure of minute risks of death in the case of general surgery. Each involves a slight loss in the ability to make a fully informed choice—the latter for the sake of security, the former for the sake of hope. So long as the scope of the nondisclosure is strictly minimized, the ultimate impact on patient autonomy appears to be negligible at best.

3) Minimal Threat of Harm. As any physician will assert, the most basic guiding practical principle in medicine is ‘first do no harm’. The purpose of medicine is to heal, not to hurt. This is particularly relevant to the use of placebos. Any placebo—whether pill or procedure—must carry only the most minute risks. This condition places strict limits on the extent of placebo use. For instance, placebos involving general anesthesia or very invasive procedures are impermissible. A placebo must be physiologically innocuous because the risks of allergic reaction and infection, while low, are not low enough.

In sum, if all medically relevant therapies have been attempted, if the scope of nondisclosure is minimized, and if there is little potential for any significant harm to the patient, then placebo use is morally permissible. Clearly of course, this position is a compromise, albeit biased in favor of patient autonomy but nonetheless allowing a strictly regulated inroad for benevolent minor deceptions in the form of placebos. Advocates of strict adherence to the principle of respect for autonomy are apt to find this account overly permissive. To them, any crack in the dike is more likely than not to turn into a flood. The fear is that positions such as the above will allow the physician to be the best judge of what information will best enhance patient autonomy and what will not, leading to a slide down a very paternalistic slope. So long as one sticks to the conditions set down above such worries can be allayed. The extent to which a false belief undermines autonomy depends, more or less, on the extent to which the belief is divorced from reality. The emphasis on minimal distortion requires that physicians do not grossly mislead their patients.

Those who take benevolence to be the defining and fundamental moral value for medicine will view my constraints on placebos as too strong. If this were the case, however, the previous autonomy objection would, indeed, be well founded. Any genuine doctrine of informed consent would fall by the wayside and any conception of genuine patient autonomy would be rendered a hollow shell.

As argued, I believe that, granting the satisfaction of certain basic conditions, the use of placebos may be morally permissible. As with almost any compromise position, the possibility of abuse remains. The best way of preventing abuse in the case of placebos, however, is not to institute an absolute proscription on their use. Instead, judicious training in clinical bioethics on the part of future physicians holds much greater promise. The key, of course, is to develop a physician’s capacity to grasp the nuances of any complex moral decision. Physicians have to be able to weigh the advantages of limited placebo use for desperate patients on a case-by-case basis. This approach would retain the benefits of moderate placebo use while insuring that patient autonomy is not unduly sacrificed.

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**SHORT STORY**

**Break, Break, Break**

Felicia Ackerman
Brown University

“No, thanks, it’s too early in the day for me,” Dean Nakamura told the waiter, raising her eyebrows a bit; so of course Stephen Ferris couldn’t have a drink, either. But food attracted him more—it always did—and now he was ordering the most voluptuous foods on the faculty club lunch menu: fettuccine Alfredo and garlic bread. “And oh, yes,” he added before the waiter could turn away. “I’d also like cream of tomato soup, a bowl, please.”

“Nice to see you have such a hearty appetite, Professor Ferris,” the dean said in a pleasant tone, and Stephen, conscious of the paunch that made him sit conspicuously back from the table, wished he had the courage to say equally pleasantly that it was nice to see his appetite being so carefully monitored. He glanced around the room, wondering what else was being monitored. Maybe people thought the new dean of faculty was eating alone with him because she wanted his experienced advice about some university matter. And maybe she did; why shouldn’t he tell himself that as long as he could? It might even be true, and besides, he had found that if he imagined something tenaciously enough, he could often come to believe it. In a way, it worked best when he was at ease, though.

“So when can we expect to see your Tennyskom book?” Dean Nakamura was asking. Her face had an anonymous, generic prettiness that reminded Stephen of how, when he had come to California from the Midwest thirty-one years ago, all Orientals really did look alike to him. Now it was all deans who looked alike, all three of the university’s women deans, anyway, with their well-tended haircuts, efficient, attractive faces, and slim, ostentatiously healthy bodies. Probably they all were joggers, certainly not smokers like him. And they were all over a decade his junior, and any two put together quite possibly weighed less.

“The book will be finished soon,” Stephen said, hoping she wouldn’t ask how soon or point out that it had already taken nearly fifteen years. But of course she did both these things, her tone pleasant as ever; so he said, “A life’s work is supposed to last a lifetime,” only to realize that this didn’t sound right at all. Hadn’t the dean published her two-volume study of sociological survey techniques before she was forty? Through the window behind her head, he could see a high cloud, soft and white as a bedsheet. As his bedsheet. A wave of exhaustion threatened him, and it suddenly seemed almost miraculous that before the sun rose again, he would have a whole night under the covers, where even
in his dreams he could smell the honeysuckle outside his bedroom. How lucky he was; how incredibly fortunate was everyone in this room, everyone in the world, to be able to spend one-third of life in bed! He felt sorry for poets who called sleep oblivion. His dreams, so often, were wonderful and vivid. So many nights he was important and powerful, admired and loved, and now the prospect gave him strength to tell the dean he had a number of Tennyson articles about to be sent off for publication, and to assure himself he wasn't actually lying; zero was a number.

"Why don't you send me copies? I'd like to read them. I'm fond of Tennyson myself," said the dean, and Stephen silently replied, 'I'll bet. But then she gazed past him with a strange little smile and recited softly, "But who hath seen her wave her hand? Or at the casement seen her stand? Or is she known in all the land, / The Lady of Shalott?"

So I was right that there's nothing to fear; she just wants to talk about Tennyson, Stephen thought, with such a rush of girly relief that his voice trembled slightly as he supplied the next lines of the poem. And soon the waiter came, bearing Stephen's soup and garlic bread like a gift. Immediately Stephen took a spoonful of soup and felt warmth course through his body; at least in this way his circulation could hardly be better. And who were those fools without the sense to see why heart patients broke their diets? Once he had read an Ann Landers column headlined "A heart attack survivor with a death wish," and he'd been tempted to write and tell her how ridiculous it was to suppose you needed a death wish to eat T-bone steak and chocolate cream pie; didn't she know that rich food made bad days bearable and good days glorious?

"I've been betrayed by time," he said, dipping his spoon into the soup again.

"Is that also from Tennyson?" the dean asked.

"Oh, no," said Stephen, but now he was holding his spoon unsteadily in midair, sending orange soup droplets onto the white tablecloth. He put the spoon hastily back in the bowl. "Did it ever occur to you that one could write a social history of academic life by studying changing patterns of faculty club eating behavior over the past half-century?" he said.

"No," said the dean.

Stephen was sorry he had started on this line. He particularly regretted the "half-century," which might suggest he had been hanging around faculty clubs for that long, although, he reminded himself, surely the dean would know better. "In the good old days, you could look fifty-eight when you were fifty-eight," he said. "You could be overweight. You could smoke." He had been aiming for the detached, urbane air of a social critic, but he heard his voice coming out bitter and almost wheezy. He took a deep breath and tried to lighten his tone. "You didn't have to live as if you were in training for the Olympics. Intellectuals cultivated the mind, not the body," he finished, and resumed eating his soup.

"The good old days weren't so good. Dean Nakamura's voice was flat as a slap. "I was born in an internment camp in Arizona."

"How terrible," said Stephen, thinking how unfair it was of the dean to play such a trump card. Was he really expected to consider this hotspot an underdog because of where she was born? Clearly, the conversation had been going downhill since "The Lady of Shalott." "Do you know Idylls of the King?" he asked, starting on his garlic bread and realizing a moment later that he could have pointed out that having a paunch didn't exactly mean you were the type to lock up Japanese Americans in internment camps. He considered saying this anyway, accompanied by an ironic little remark about how he was apt to come up with a rejoinder just a trifle too late. But he quickly discarded the idea. This obviously wasn't his day for ironic little remarks.

"Very apropos of this conversation," the dean was saying. "The old order changeth, yielding place to new. Not that I'm pretending to be a Tennyson scholar," she added with a disarming flutter of her hand. "You'd catch me out in a flash. I've just been quoting some bits I know."

Stephen had read about police interrogations that paired a nasty cop with a nice one. Now he wondered whether the dean was trying to play both parts herself. He watched her spear a mushroom in her salad and noticed that she wore a moonstone ring. The sight gave him a jolt. A moonstone ring had been his fourteenth anniversary present to his wife—now his exwife, another way time had betrayed him. He had married Paula expecting to take care of her in the old manner, and she had wanted that, too. They had both wanted a life of poetry, privacy, and possessiveness about each other; his good fortune had amazed him. When she decided to take up painting, it had seemed an extra blessing. He loved her paintings. He was surprised they never sold, but he grew to enjoy comforting her. But then the '70s had come, and Paula joined a women's consciousness-raising group and started graduate school, turning slowly but implacably into a feminist art-therapist who in the end announced that she was leaving him. "I want to support my sisters," she said, and for an instant there he thought she meant her own sisters, who were older and prettier and had never been kind to her. "Why would you want to support Isobel and Barbara? When did they ever support you?" he had nearly asked. "Why did you decide to become a dean?" he asked Dean Nakamura now. "I mean, speaking of the old order changing. . . ."

"There were two reasons," said the dean, stabbing an olive. Academic administration had always interested her, and she wanted greater visibility as a role model.

Stephen managed not to wince. 'Role model' might be everywhere these days, but he'd heard it first from Paula. Had she learned it in her consciousness-raising group? They had certainly learned plenty from her. Somewhere in the Bay area there were half-a-dozen women who knew that Stephen Ferris's blood-pressure pills made it difficult for him to maintain an erection.

"I try to keep one day a week for my own research," Dean Nakamura continued, "but it's no easy matter combining research and administration. Do you find it hard to combine research and teaching?"

He almost smiled. Whenever he gave examinations, he included one question any idiot could answer, and now the world was returning the courtesy. "I find that teaching and research complement each other," he said, feeling as if he were giving a speech at Parents' Weekend. "I love teaching," he said, and it was true. Who wouldn't love expounding on his favorite subject to his sole remaining audience, an audience that was not only captive, but obliged to be at least minimally polite and attentive? And that asked just the right kind of question—stimulating, but answerable without undue effort. He had not prepared new lecture notes in more than a decade. Year after year, his lectures hardly varied; they were an annual celebration of his favorite poetry. And the students had seemed to like them and like him. Until last spring. But he wasn't going
to think about last spring. Their waiter was approaching, this time with the main course. But no sooner had he set the plates down and gone away than the dean remarked, in the sort of carefully even tone Stephen’s father had used for explaining sex, that she gathered Stephen hadn’t published anything in over ten years.

“I am not the type of academic who believes in publication for publication’s sake.” Stephen took a forkful of fettuccine.

“Besides, I told you, I’m about to send off a number of articles,” he added, thinking that his current moral code held that misleading statements weren’t as bad as outright lies. A compromise in order to deal with a world of hostile questioners, he frequently reassured himself, and sometimes almost an interesting challenge, although not today.

“Did you hear about the university where they stack every professor’s publications in a pile and measure each pile with a ruler? Somewhere in the Midwest, it’s supposed to be,” he said, watching the dean eat her chicken.

“Yes, that’s a popular story,” said the dean. Her eyes were shiny and dark, like pebbles under water. Break, break, break,/ On thy cold gray stones, O! Stephen thought. It was the first Tennyson poem he had ever learned, back in seventh grade, when any verse you memorized turned into a jingle. “Why haven’t you been publishing?” the dean was asking.

Stephen knew why. He had always delighted in the start of a project, when ideas swirled like colored streamers and anything seemed possible, before revising and refining became as tedious and exhausting as swimming in a weed-choked pond. For years he had managed to see his papers through to the end, rewarding himself for each completed article with a special meal or weekend trip with Paula. Then she left him, and he decided he wasn’t going to be one of those ferociously well-adjusted paragons who took adversity in stride, getting on with their lives as if disaster hardly mattered. Certainly he hadn’t wanted to look for another woman as though Paula could be replaced like a cat that had died. And he’d felt entitled to take a break from publishing. Why compound catastrophe with drudgery? Shouldn’t misfortune justify self-indulgence, at least for a while? But later, when he tried to get back to publishing—and he still sometimes tried—he found that he couldn’t. He supposed this meant that on some level he no longer wanted to, not enough to get him through the hard parts. He had grown too accustomed to languor and to spending his free hours daydreaming, reading poetry, and eating. And imagining endless future paths for his research; often he could still believe he would one day find the magic topic that would not clog his mind with a ghoulish layer of fatigue once he got past the agreeable early stages. In the twelve years since Paula’s departure, he had gained seventy-five pounds, started a dozen never-finished articles, and developed a repertoire of fantasies that were enticing and always ready for consumption, like fresh pastries on a tray. Most of these fantasies he could tell himself would someday come true, fantasies about discovering lost Tennyson manuscripts, writing important books, or being reunited with Paula, wondrously transformed into the old Paula, who read poetry with him and painted fields of flowers on the bedroom walls. Other fantasies were too preposterous for any sort of belief, but irresistible nonetheless. Frequently he imagined having tea with Tennyson, who was gently amused to hear that nowadays it was not enough to enjoy poetry; you had to write critical studies of it as well. Or instead, when Stephen told Tennyson that the latest fashion was to center these critical studies on race and what people seemed to like to call gender, Tennyson assumed this was a joke and replied that as long as Stephen still had his sense of humor, the situation could hardly be unbearable. All these scenes Stephen would envision in detail, down to the expression in Paula’s eyes and the color of Tennyson’s cravat. And often, after teaching his classes, Stephen would go driving along the coast, giving himself over entirely to his daydreams, and for hours he would be happy, so much happier than anyone glancing at the surface of his life would ever suppose. Just when had the idea silted into his head that the contempt of his colleagues might be a small price to pay for doing whatever he wanted, all the time, for the rest of his life? “I believe in perfecting my work,” he said. “I am not the type of academic who is willing to compromise his standards in order to publish.”

And was the contempt of his colleagues such a small price to pay? There was no shortage of contempt; that much was certain, even if he usually managed to avoid thinking about it. Once he had overheard another professor call him a mental and physical wreck, and he’d felt like screaming that he wasn’t, really wasn’t, a mental wreck, and as long as the blood was circulating adequately to his brain, what business was it of his colleagues if he was a physical wreck? But he knew the obvious rejoinder: the blood wasn’t circulating adequately to his brain, not in the only way that counted here, the way that resulted in publications. Soon after that, he got into the habit of pretending he had to use the second-floor men’s room on the way to his third-floor office; he hoped this would hide his wanting a break before tackling the next steep flight of stairs. He decided against combing his hair over his bald spot, though. People couldn’t blame you for going bald. And just last week, he had learned about the graduate students’ joke that ending up like Stephen Ferris was the worst thing that could happen to a professor; so all the English department bighots probably hung pictures of him in their studies at home to keep themselves plugging away.

“I am pleased to be able to tell you,” said Dean Nakamura, “that we can offer a special arrangement for faculty in your situation,” and for a moment Stephen actually thought she would offer something good—an extra sabbatical, maybe, or a reduced teaching load at full pay. But she was offering to reduce his teaching load to zero. At retirement pay. And it wasn’t exactly an offer.

It was like being pushed underwater; you had to make it to the surface before you could begin to focus on who had shoved you below and why. Stephen’s fork clattered from his fingers to the floor, but he ignored this except to put his suddenly shaking hands in his lap. “I don’t want to retire,” he said. His voice, at least, was fairly steady. “I need the stimulation of teaching in order to do my research. I love teaching. I’m a good teacher.”

“Oh, come now.” The dean’s face was calm, reminding Stephen of a quotation he had once read and never forgotten: “We all have strength enough to endure the misfortunes of others.” “After last spring,” the dean was saying.

“Last spring wasn’t my fault.” Stephen longed for more fettuccine, but, with his fork on the floor, what could he do? Requesting a replacement would call the dean’s attention to his clumsiness, and besides, no waiter was nearby. He took a gulp of water and felt oddly invigorated. “What I said was true. My feminist students
"That's a lie," Stephen said truthfully. "I imagined myself playing the game all the time. I imagined myself being a star, a success, a winner. But it was never like that. It was just a dream." He looked down at the floor, his eyes glassy and his voice hollow. "I guess I was just a fool, thinking I could do it all. But I couldn't. I was just a dreamer, a fantasist, a fool."

"But you were so successful," I said, trying to安慰 him. "You were so good. You were so loved." I reached out to touch his shoulder, but he shrugged me off. "Don't you see," he said, his voice rising, "that's the problem. I was successful in the end, but I was just a dreamer. I was just a fool." He laughed, a bitter, hollow laugh. "I guess I was just a fool."
reminders and go where he could set
himself up as a distinguished retired
scholar, Costa Rica, maybe, where he had
read the warmth was eternal and
Americans lived like kings. But he wanted
it to be a professor, not a king. He didn't
know Spanish. He loved his house with its
view of the hills and with Paula's
wildflower murals still on the bedroom
walls. Besides—how could he have
forgotten—wasn't he supposed to be a
racist? What color were the Costa Ricans,
anyway? I'll work it out, he told himself,
panting; fantasy never fails me. The brain
is deeper than the sea. But then he felt
thunder in his chest and lightning down
his arm and terror everywhere, too much
terror to walk, too much terror to
breathe. And who were those healthy
thirty-year-olds who said you weren't
supposed to be afraid of death? This is it,
his mind gasped, and he tried to think: at
least, Dean Nakamura will be sorry. But
he couldn't really believe that he could even
envision her saying it was all for the best,
just as people had said when his father
died after the stroke, when his mother
died after the cancer, just as they said
about the death of anyone who had no
reason left for living except for wanting to,
so desperately wanting to.

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BOOK REVIEW

Christo Zouves, M.D., with Julie Sullivan,
Expecting Miracles: On the Path of
Hope from Infertility to Parenthood,
Henry Holt, 1999, Foreword by
Rosamond Rhodes, Ph.D., 266 pages.
Reviewed by Julie M. Zilberberg, The
Graduate School of the City University
of New York.

Expecting Miracles is not a bioethics book,
nor is it meant to be. It is instead a book
written for the general public describing
some of Dr. Christo Zouves' success stories
in his battles against infertility.
Dr. Zouves is the medical director at
Pacifi c Vity Center in San Francisco
and a member of the medical advisory
panel of RESOLVE, a resource organization
for patients battling infertility. In the book
he shares case details of patients who
genuinely seem to expect miracles.

The title is catchy and provides
opportunity for reflection. These patients
are expecting miracles in several senses that
vary with the different senses of 'expecting'
and 'miracles.' First, they are expecting
miracles in that they represent some of his
toughest cases and must undergo lengthy,
risky, and burdensome treatments with the
hope that they will finally have a baby. In
this way they are hoping for a near miracle
since the deck is strongly stacked against
them. Further, they typically expect these
miracles. Most have come to Zouves
expecting that they, too, will have a baby,
and they have expected this all along.
Zouves is well aware that these patients
have expected a pregnancy to have already
occurred. Part of the pain infertility
patients feel is finding out that the
expectation of pregnancy should not have
been taken for granted. And of course they
are expecting miracles when they finally do
become pregnant, or participate in the
impregnation of a surrogate, or find an
expectant mother who would like them to
adopt her baby. In this sense, the babies
themselves are the miracles.

In the introductory chapter, Zouves
shares his own personal experiences to
explain why he values life so deeply. His
strong feelings have led him to help
seriously infertile patients who realize how
important it is for them to create a life now
that pregnancy has proven so unattainable.

Throughout his book, Zouves gives the
reader excellent insight into the experience
of those who struggle with infertility. For
the patients described here, infertility has
become a genuine life crisis. The thoughts
of a patient called Susan summarize the
desperation.

Infertility is like driving through the
desert and having your car break
down. You tinker with the car, and
when that doesn't work, you start walking.
As you head toward town, you take your
purse and your bags with you because you'll
want them when you arrive. But as you
walk in the killing heat, you start leaving
things behind, just to survive. You
realize that what you thought was
valuable once and what you need to
give where you are going are two
different things. Susan began to see
that she would leave almost every
vestige of traditional childbearing
behind in order to be a parent.

Later in the book, an egg donor named
Bonnie comes to understand the pain of
infertile couples through a comprehension of the “hierarchy” of infertility.

The ones needing egg donation seemed the most vulnerable, the most victimized. . . . They saw themselves at the bottom of the fertility ladder. At the top of the ladder were people who needed a little assistance to have a family, say, through in vitro fertilization and get pregnant with their own eggs on the first or second try. Below them were couples needing numerous attempts. And at the bottom, it seemed, were the women who needed another woman to provide the uterus or the eggs if they were to become parents. Few people understood how much grief there was on the bottom.

The book does an excellent job of presenting the infertility patient’s perspective. As such, I recommend it to anyone interested in the ethics of reproductive technologies, especially those interested in the ethics of the fertility industry. Expecting Miracles encourages our empathy for people who seek out this technology.

I found the book to be engaging, suspenseful, and difficult to put down. It is sensitively written and enables the reader to care about what happens to the patients, and to share in their tremendous joy in finally having babies.

On the other hand, there is no discussion of the ethical issues involved with infertility treatment. Here and there Zouves makes comments indicating his awareness of some of the ethical issues. But he does not engage in discussion or debate about the ethics of any of the fertility treatments. The book would be enhanced by the addition of a chapter in which ethical questions are raised.

At the very start of the book, Zouves speaks of the desire to have children as a biological urge. According to him, we have a Darwinian biological urge to perpetuate our genes, just like other species. It is important to recognize that unexamined hypotheses can serve to justify developing and implementing invasive techniques with a relatively low success rate.

The desire to have a biologically related child is, indeed, the bottom line for patients who seek fertility treatments, or is at least their first choice. But, because the moral justification of some aspects of infertility treatment is related to such desires, they are worthy of further examination.

Indeed some argue that we place too high a priority, or value, on having genetically related offspring. Regardless, it is unclear whether the desire for a child is wholly socially conditioned, somehow hardwired into us, or is comprised of elements of both. On the one hand, women and girls are encouraged (more strongly than men and boys) by society and existing social structures to want to bear children. Toys, games, occupations, etc., that are seen as traditionally female and to which girls are frequently directed reinforce the idea that a key role, if not the supreme role, in a woman’s life is having a baby. It is easy to see how the desire for a child could be socially conditioned or socially enhanced.

On the other hand, one would expect that human beings, like other animals, have some stake in reproducing themselves. So, the desire to have a child could be biologically hardwired into us.

If the desire to have a child is entirely biological, then there is little place for ethical discussion. Like survival, we might be programmed for it. But, if the desire to have a child is at least partially socially constructed, then ethical debate about reproductive technologies and the infertility industry is appropriate and necessary. And, going back a step further, ethical debate over these constructs, which play a role in reproductive technologies and the growth of infertility industry, is appropriate and necessary too.

ANNOUNCEMENTS

FIFTH WORLD CONGRESS
OF BIOETHICS

Sponsored by the International
Association of Bioethics

September 21–24, 2000
Imperial College, London

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Issues in Medical Ethics: 2000
"Understanding Professionalism and
the Implications for Medical
Education"

Friday, November 3, 2000
8:30 a.m.–4:00 p.m.
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