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# Stem Cell Research as Innovation: Expanding the Ethical and Policy Conversation

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In 1998, researchers established the first human embryonic stem cell line. Their scientific triumph triggered an ethics and policy argument that persists today. Bioethicists, religious leaders, government officials, patient advocates, and scientists continue to debate whether this research poses a promise, a threat, or a mixed ethical picture for society.

Scientists are understandably excited about the knowledge that could come from studying human embryonic stem cells. Most of them believe these cells offer a precious opportunity to learn more about why diseases develop and how they might be prevented or attacked. In their quest to gain support for stem cell research, scientists and others have claimed that the research could generate cures and treatment for everything from heart disease to cancer.

Although most people are now familiar with claims about the diverse medical benefits stem cell research might deliver, they are less familiar with the diverse ethical issues relevant to the research. Most of the ethics debate focuses on the morality of destroying human embryos for the benefit of others. This is an important issue, but stem cell research raises other important ethical issues — issues that have received relatively little attention in the public arena. After more than a decade of narrowly focused analysis, it is time to expand the discussion.

The debate over embryonic stem cell research should consider a diversity of ethical and policy issues. Many of the ethical and policy issues that stem cell research presents apply to biomedical research in general, such as questions about appropriate research priorities and allocation of limited resources for research and health care. In this sense, the debate over stem cell research offers an opportunity to examine a variety of ethical and policy issues raised by biomedical innovation.

In this article, I place stem cell research in a broader ethics and policy context by describing three considerations that merit more attention in the debate. These include the following: (1) truth-telling and scientific integrity; (2) priorities in resource allocation for research and health care; and (3) responsibilities in civic discourse about bioethical controversies.

## **Truth-Telling and Scientific Integrity**

New breakthroughs in biomedical science are often hailed as potential cures for the diseases that plague modern society. In many cases, however, the breakthroughs fall short of initial expectations. Innovations such as the artificial heart, fetal tissue transplantation,

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and gene therapy proved disappointing when they were tested in humans.

A similar result could occur with stem cell research. The excitement over stem cell research is unprecedented, and this creates fertile ground for exaggeration. Researchers, patient advocates, and politicians promise stem cell remedies for nearly every major health problem in the United States. And the promises come from both supporters and opponents of embryonic stem cell research. Supporters stress the advances possible through embryonic stem cells, while opponents emphasize potential therapeutic benefits from adult stem cells and other alternative sources.<sup>1</sup>

The predictions on both sides violate the ethical responsibility to be accurate in describing the state of scientific exploration. Although there are a few established therapies that employ adult stem cells, most of the claims about stem cell therapies lack a solid evidentiary foundation. Much of the existing data comes from laboratory and animal studies. The first human trial of an embryonic stem cell intervention did not begin until 2009.<sup>2</sup> It will be many years before

could impede efforts to devise therapies using stem cells from cloned embryos.<sup>5</sup> More work is also needed to determine whether induced pluripotent cells, the latest potential substitute for embryonic stem cells, could be safe and effective sources of replacement tissue. Novel uses of other kinds of adult stem cells also need further investigation to determine their clinical utility.<sup>6</sup>

These and other scientific uncertainties make unqualified or barely qualified claims about therapies and cures from stem cell research ethically suspect. Ordinary people, including patients and their families, may be misled by such claims. They may develop unfounded hope for relief in a matter of months or years, rather than a more realistic understanding. They will be sorely disappointed once they become aware of the “significant technical hurdles... that will only be overcome through years of intensive research.”<sup>7</sup>

Inflated promises about stem cell benefits can harm vulnerable people and can harm the research endeavor, as well. When members of the public real-

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researchers can gather the human data necessary to determine whether stem cells will live up to their promise.

Much remains to be learned about the therapeutic abilities of stem cells. The cells' treatment potential lies in their capacity to develop into different types of specialized human cells. The hope is that they could replace cells damaged through illness or injury. For this to work, however, scientists must understand more about how transplanted cells behave in the human body. They must also develop the power to control how the cells develop. Without this power, the cells could cause cancer or other harm to the recipient.

Because the immune system rejects foreign tissue, immune rejection is another possible barrier to effective therapies.<sup>3</sup> In theory, the problem could be solved by using stem cells created from a cloned embryo made with an individual patient's somatic cell, but this procedure appears to present significant scientific challenges.<sup>4</sup> Moreover, economic and practical difficulties

ize that much work remains before effective therapies can be devised, their support for stem cell studies may diminish. They may become less willing to urge government support for the research, and less willing to contribute to nonprofit organizations supporting stem cell research.

The hype about stem cell research threatens scientific integrity, too. The field was undermined when the world learned of the fraud committed by South Korean researchers who claimed they had created stem cell lines from cloned human embryos. Besides dismay at the research team's failure to observe basic standards of scientific integrity, there was speculation that editors and peer reviewers at *Science*, the journal that published the research, were too eager to publish the cloning reports. Some wondered whether scientists' enthusiasm for the stem cell field led them to be less demanding than they should have been in their scrutiny of the research claims.<sup>8</sup>

Other threats to scientific integrity arise when stem cell research becomes the basis for exaggerated claims

by interest group lobbyists. Scientific organizations have claimed that limits on government funding for embryonic stem cell research could damage U.S. scientific preeminence. In the funding controversy's early years, critics predicted a huge "brain drain" as U.S. scientists migrated to other nations offering generous support for the research.<sup>9</sup> Yet few scientists actually left this country to engage in stem cell research.<sup>10</sup> Several states stepped in to offer substantial funding, and nonprofit and private-sector support became available, too.<sup>11</sup> Even before the Obama administration revised the federal funding policy, U.S. researchers had many opportunities to pursue embryonic stem cell research.

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Stem cell research has become a hot-button political issue, and this development could tarnish the public's respect for and trust in science. Traditionally, science has enjoyed bipartisan support in the U.S., and in many respects, it still does. The debate over government funding for embryonic stem cell research does not divide along party lines. At the same time, however, politicians and their supporters have used the stem cell cause to advance partisan objectives. As one observer reported in 2006, "Politicians from both major parties are trying to use such research as a 'wedge issue' to woo voters."<sup>12</sup>

During the past decade, stem cell research became enmeshed in partisan politics from the national to the local level. Senator John Kerry made his support for federal funding of embryonic stem cell research a major theme in his 2004 campaign for the presidency.<sup>13</sup> For his part, former president Bush used his opposition to embryo destruction for research as a means to advance his campaign.<sup>14</sup> In the 2008 presidential election, both candidates claimed to support expanded federal funding for embryonic stem cell research, but the issue became politicized when research advocates warned that Senator John McCain's position might change if he were elected.<sup>15</sup> Stem cells have also taken center stage in some state elections. In my own state of Missouri, where an initiative about stem cell research was on the November 2006 ballot, U.S. Senate and even county

council candidates made stem cell research central to their election efforts.<sup>16</sup> The topic was a major issue in the 2006 New York governor's race as well.<sup>17</sup>

Stem cell research has joined abortion as a controversial matter on which politicians are expected to take a stand. It has become impossible to insulate this type of research from political debate. If stem cell research becomes identified with a particular political party or with specific candidates, then its fate could be determined more by politics than by substantive results in the laboratory.<sup>18</sup>

There is one positive development in the public discussion about stem cell research. Many stem cell research supporters have begun to convey more realistic messages about the prospects for stem cell therapies.<sup>19</sup> In an ironic twist, one of the cautionary voices is James Wilson, who led the gene transfer trial in which Jesse Gelsinger died. Recounting the problems that came from the hype and haste surrounding clinical trials of gene transfer interventions, Wilson wrote in 2009, "I am concerned that expectations for the timeline and scope of clinical utility of [human embryonic stem cells] have outpaced the field's actual state of development and threaten to undermine its success."<sup>20</sup> He called on stem cell researchers and professional organizations, like the International Society for Stem Cell Research, to "steadfastly discourage" the exaggeration characterizing many claims about medical benefits from stem cell research.<sup>21</sup>

Like Wilson, more experts and journalists express caution about the potential for stem cell therapies and focus instead on the value of stem cells as basic science tools that could help researchers understand how and why diseases develop.<sup>22</sup> But it is still easy to find examples of hype about stem cell therapies, such as in the publicity surrounding the first human trial of an embryonic stem cell intervention.<sup>23</sup>

Like the Human Genome Project, stem cell research is most likely a form of scientific inquiry whose benefits will emerge slowly and incrementally. (Indeed, the Human Genome Project is now criticized as a costly research effort that to date has produced few actual medical benefits.<sup>24</sup>) Rather than presenting stem cell research as a short-term answer for today's patients, supporters should portray it as a promising scientific development that might, after many years of investigation, contribute to new medical interventions.<sup>25</sup> Just as physicians should be honest in disclosing a poor prognosis to a patient, scientists and advocacy groups should be honest about the lack of certainty

that stem cell research will produce cures and effective therapies.

### **Social Justice and Allocation of Limited Resources**

Stem cell research raises general questions about the appropriate allocation of government and private resources in biomedicine. One set of allocation questions addresses priority setting in biomedical research. The other set of allocation questions concerns the relative priority of research versus health care in funding decisions. These are questions that apply to biomedical research in general, but stem cell research nicely illustrates the relationship between research funding choices and social justice considerations.

Stem cell research is just one form of promising research. The National Institutes of Health (NIH), the largest public funder of biomedical science, supports many kinds of research offering opportunities to advance knowledge. The research portfolios of industry and nonprofit organizations also reveal an array of promising research areas. But neither the public nor the private sector can support every promising research project. Every research funding source has limited resources. As a result, these entities face hard choices about where to invest their limited dollars. How should funding agencies, nonprofit organizations, and private companies decide where to channel their resources?

According to NIH officials, five considerations play a role in the agency's spending choices: (1) public health needs; (2) scientific merit of specific study proposals; (3) potential for advances in a particular area; (4) distribution across diverse research areas (because it is impossible to predict exactly where advances will occur); and (5) national training and infrastructure needs. The first criterion, public health needs, is determined by the following factors: (1) number of people with a specific disease; (2) number of deaths a specific disease causes; (3) degree of disability a specific disease produces; (4) how much a specific disease shortens the average lifespan; (5) a specific disease's financial and social costs; and (6) the threat posed to others by contagious disease. According to the NIH, all of these considerations play a role in allocating research resources; none is rated as more important than another.<sup>26</sup>

In the private sector, industry tends to allocate funds to research on conditions and products offering the greatest potential for financial reward. Many nonprofit organizations represent a single disease or demographic group and use their limited funds to support research that could benefit their specific constituencies.

The choices these entities make about research funding allocation raise social justice issues. As a publicly funded agency, the NIH has a duty to distribute its resources in a just manner. People disagree about whether private organizations have justice-based obligations, but a growing literature on corporate responsibility contends that even for-profit entities have a duty to consider the public good in their decision making.<sup>27</sup>

What qualifies as a just approach to allocation of resources for research? The NIH priority-setting criteria incorporate justice-based considerations, but they are quite general. Moreover, officials have been unwilling to rank the criteria in order of importance. This means that the agency takes no position on the relative importance of, for example, research aimed at conditions that shorten the average lifespan and research aimed at conditions affecting the most people. In reality, critics say, the priority-setting criteria are so loose that congressional politics often determines where NIH dollars are directed.<sup>28</sup>

The NIH criteria also leave open a significant social justice question, which is whether the U.S. has obligations to support research primarily aimed at helping people in poor nations. Some would contend that research funded by the U.S. government should address only domestic health concerns, but for many years, NIH has funded some international health research. There has been little public discussion of whether this approach is appropriate, however, and if it is appropriate, what portion of the NIH budget should be devoted to the health problems of people in other countries.<sup>29</sup>

Although the proper approach to research priority setting is contested, the NIH criteria offer a framework for evaluating stem cell research. Much stem cell research is aimed at understanding and treating chronic diseases of aging, such as heart disease and neurological diseases. Indeed, some advocates proclaim that stem cell research will pave the way to "regenerative medicine," in which the tissues and organs that deteriorate with age will be replaced with new ones created from stem cells. According to this group, interventions developed through stem cell research will substantially extend the human life span.<sup>30</sup>

Not only are these predictions inconsistent with the duty to acknowledge the uncertainties accompanying early-stage research, they also raise resource allocation questions. Should extending the average U.S. life span be a high priority in research funding decisions? Would it be more defensible to give conditions that cause premature death a higher priority? Should strat-

egies targeting prevention rather than treatment have a higher priority?<sup>31</sup>

Another factor is the costs of the treatments that might emerge though stem cell research. Although basic science studies involving stem cells might help researchers develop new drugs and other relatively affordable medical interventions, the stem cell therapies that regenerative medicine enthusiasts describe could be relatively costly. As one group considering justice issues raised by stem cell research observed, “It seems inevitable, and of serious moral concern, that there will be significant economic barriers to access to new therapies utilizing stem cells or other cell-based preparations.”<sup>32</sup> If stem cell research produces expensive treatments, how many people will be able to benefit from the research investment?<sup>33</sup>

Even more dramatic social justice questions arise when one considers biomedical research in an international context. Research is concentrated in wealthy nations and much of it focuses on the health problems of people fortunate enough to live in those nations.<sup>34</sup> Stem cell research is a prime example of this phenomenon, since much of the research (although not all of it) targets conditions arising later in life. But does justice require that prosperous nations devote more of their research funds to conditions that cause premature death in poor countries?<sup>35</sup>

Questioning the justice of research funding allocation decisions may seem sacrilegious, given how popular biomedical science is in this country. But bioethicist Daniel Callahan presents the following thought experiment:

[C]onsider — as an imaginative exercise — what we would get if there was no progress at all from this point forward, and medicine remained restricted to what is now available. The rich countries would remain rich. Most of their citizens would make it to old age in reasonably good health. There would continue to be incremental gains in mortality and morbidity, the fruits of improved social, economic, and educational conditions, and improvements in the evaluation and use of present therapies. No prosperous country would sink from the lack of medical advances.<sup>36</sup>

Another startling take on research priorities comes from neuroscientist Floyd Bloom. In his 2003 presidential address to the American Association for the Advancement of Science, Bloom declared that the quest for improved health care should focus more on health outcomes research than on the genomics research so often portrayed as a vehicle to medical advances.<sup>37</sup> These points provide a basis for considering stem cell

research in a broader research context. Although stem cell research might eventually deliver benefits to some patients, benefits could also be achieved by investing resources in other kinds of research.

The social justice inquiry is relevant to many areas of biomedical research, not just stem cell research. Indeed, such an inquiry might support research on some conditions that are the focus on stem cell research, such as juvenile diabetes and spinal cord injury, which affect many young people. Nevertheless, it is important to see stem cell research as simply one of many scientific opportunities that could deliver health benefits. Investments in stem cell research will reduce the funds available for other types of biomedical research. In stem cell research, as in other research areas, the relative value and likely cost of any potential therapeutic benefits should be part of the decision making about research priorities.

A second matter of social justice concerns the relative priority of research needs and health care needs. Is it more important to conduct research aimed at improving care for future patients, or to provide better health care to today’s patients? In the U.S., as Daniel Callahan observes, “[T]he research drive has received an awful lot of money and great attention, but we have done less well with the delivery of health care....”<sup>38</sup> Because millions of people lack health insurance coverage and millions more have inadequate coverage, many patients are unable to benefit from the clinical interventions developed through past research efforts.<sup>39</sup> Is it ethical to devote large sums of money to research while so many people lack access to medical care that could give them longer and better lives?

Supporters contend that stem cell research is needed to aid patients with conditions that cannot be treated with existing therapies. From this perspective, there is a social justice basis for channeling limited resources to stem cell research. But those defending a moral duty to conduct stem cell research should consider another social justice perspective. Expanding access to health care would assist a currently disadvantaged group of people. Most standard health care interventions have been studied and found to be reasonably effective. Many are also relatively affordable. For these reasons, directing limited resources to health care delivery might achieve social justice objectives more efficiently than directing resources to stem cell research. This argument has even more force in the international context. Lack of access to basic health care, clean water, and other public health services produces high death rates in poor countries.<sup>40</sup> In this situation, small amounts of money can make huge contributions to improving and extending human lives.

What justifies our nation's substantial investment in biomedical innovation, when millions of people here and abroad are denied access to proven medical interventions?<sup>41</sup> Once again, the stem cell controversy opens a window to a larger moral problem. The social justice inquiry raises questions about the priority that stem cell and other basic science studies should have in the competition for limited resources. If government officials and health advocates want to help patients, meaningful help would also come from a system that supplied adequate health care to more people, both across the nation and worldwide.

### Responsibilities in Civic Discourse

People have passionate views on stem cell research. Their passion has had two detrimental effects on the public debate. One is the exaggeration about therapeutic benefits I referred to earlier. The other is disrespect for people with opposing positions. Too often, people caught up in the debate portray those with different positions inaccurately and unfairly.

Opponents of embryonic stem cell research use the slippery slope to cast aspersions on the morality of research supporters. According to some opponents, research supporters will accept almost anything to advance science and human health. Thus, for example, those who would allow the creation and destruction of human embryos to advance knowledge will also accept a world in which human beings are "grown for spare body parts."<sup>42</sup> And any move to allow early embryos to be destroyed in research "will provide the leverage to thrust the research door open for Frankensteinian experimentation on the most vulnerable of our species."<sup>43</sup>

On the other hand, people supporting embryonic stem cell research belittle those assigning a high moral status to early human embryos. Underlying this attitude is disdain for anyone who would let religious and other moral beliefs influence their positions on science policy. Some scientists and advocates recognize that scientific considerations alone cannot determine appropriate state policy on embryonic stem cell research.<sup>44</sup> Others, however, seem to assume that morality has no place in the debate, or alternatively, that no rational individual could assign a high moral status to the early human embryo. As a columnist who supports embryonic stem cell research put it, "Only Bush bitter-enders and the pope are in the perverse position of valuing the life of an ailing human being less than that of a tiny clump of cells no bigger than the period at the end of this sentence."<sup>45</sup>

Misleading terminology also characterizes the stem cell debate. For example, many embryonic stem cell research supporters deny that they endorse human

cloning.<sup>46</sup> Implicit in this claim is a narrow definition of human cloning that covers only the creation of a child through cloning. But the initial process of creating the cloned embryo (which research supporters prefer to call somatic cell nuclear transfer) is the same in research cloning and cloning to have children.<sup>47</sup> People who believe that the early human embryo has a high moral status do not differentiate between the two activities. Yet speakers often fail to clarify which definition of cloning they adopt, which leads to confusion in the public debate.

Also misleading is the term "therapeutic cloning," which suggests to the layperson that this is a procedure with proven clinical benefit, rather than one that remains theoretical at this point. And in yet another form of terminology manipulation, embryonic stem cell research supporters characterize their proposals for liberal federal funding policies as efforts "to promote all ethical forms of stem cell research."<sup>48</sup> This characterization avoids what is at the heart of the policy controversy, which is the question of whether or not research requiring embryo destruction is ethical. Such language games fail to give due regard to the moral disagreements underlying the policy disputes over stem cell research.

Decisions about U.S. stem cell research — whether to prohibit, regulate, permit, or financially support it — occur in the democratic context. The ongoing debates over stem cell research ought to reflect a better deliberative process than we have seen so far. In their work on deliberative democracy, political scientists Amy Gutmann and Dennis Thompson offer guidance for improving the deliberations over stem cell research. Below I describe their general framework for deliberative democratic policymaking and then apply it to stem cell policy formation.

Gutmann and Thompson describe four deliberative democracy characteristics relevant to stem cell research policy. First, policy arguments and choices must be supported by reasons. The requirement for reason-giving rests on a moral principle that underlies democracy: the principle that citizens should be regarded as agents participating in their society's decisions. To participate in a democracy, citizens must understand why certain choices are made. Learning the basis for official actions allows people to challenge decisions that rest on false or misleading reasons. The reason-giving requirement also demonstrates respect for all citizens, no matter what their economic or political power happens to be. All are entitled to an explanation for the policies their officials impose.<sup>49</sup>

Gutmann and Thompson describe a second feature of deliberative democracy, which is that the reasons underlying a policy must be accessible to all affected

by that policy. Accessible reasons are understandable not only to those agreeing with the policy, but also to those opposing it. To fulfill this requirement, decision makers must publicly articulate their reasons for a specific policy choice and those reasons must have an acceptable public content. This means that reasons should rest on facts, rather than false information. Members of the public should also be able to evaluate the beliefs supporting a policy choice: "It would not be acceptable, for example, to appeal only to the authority of revelation, whether divine or secular in nature."<sup>50</sup> In a deliberative democracy, Thompson and Gutmann maintain, individuals can disagree with a policy and at the same time conclude that the policy has a legitimate basis.

Deliberative democracy's third characteristic addresses the status of policies over time. Deliberations are aimed at a specific policy decisions, and at some point those decisions must be made. Policies then become binding on citizens. But deliberative democracy requires that policies remain open to revision. If new facts are discovered that undercut the initial policy choice, officials should reassess their original choice. If emerging discoveries or events provoke people to new value judgments affecting their policy views, officials should take these changes into account. People should be free to challenge existing policies, and officials should make revisions when they are justified. As Thompson and Gutmann observe, those disagreeing with a policy choice will be more likely to accept it if they know they can in the future work to alter that choice.<sup>51</sup>

Thompson and Gutmann discuss a fourth dimension of deliberative democracy with special relevance to the stem cell research debate. Participants in deliberations should aim for what Thompson and Gutmann call "economy of moral disagreement."<sup>52</sup> This concept comes from the deliberative directive to respect those with values and positions that differ from our own. The concept "does not ask us to compromise our moral understandings in the interest of agreement, but rather to search for significant points of convergence between our own understandings and those of citizens whose positions, taken in their more comprehensive forms, we must reject."<sup>53</sup> Deliberative democracy asks parties in disagreement to seek common ground, sometimes forgoing their ideal policies for ones that elicit greater agreement.<sup>54</sup>

Policy debates about stem cell research should incorporate these features. Proponents of different policies should offer accessible reasons for their positions. For example, research supporters should go beyond simplistic slogans linking stem cell research with lifesav-

ing cures. They should supply clear and accurate information about potential clinical results, tempering the promises of effective therapies with realistic accounts of what must be achieved before therapies become available. In turn, people promoting alternatives to embryonic stem cell research should supply clear and accurate information about adult stem cells, induced pluripotent cells, and other alternative sources that avoid embryo destruction. They too should speak of therapies as possibilities that remain uncertain and

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probably many years away. Both groups should emphasize that most stem cell work remains in the laboratory and that no one can say whether or when medical applications will emerge from that work.

Both advocates and opponents of embryonic stem cell research should also do a better job of confronting the moral questions raised by their positions. Those whose views reflect religious beliefs about the moral status of early human embryos should offer reasons for their positions that can be accepted by people who fail to share those beliefs. Those who claim to see the human embryo as an entity owed special respect should explain why embryo destruction is consistent with this moral status position. People worried about risks to women providing eggs to create embryos for stem cell research should explain why the usual human subject protections are inadequate in this situation. And those who think the risks to women are justified should consider how they will respond if women experience harm from the egg production process.

Adversaries in the stem cell debate should aim for an economy of moral disagreement as well, seeking to develop policies that individuals with differing positions could accept. For example, if people on both sides agree that the goal of improved health care justifies government funding for stem cell research, federal officials could decide to pursue that goal in a manner that demonstrates respect for those opposed to embryo destruction. Officials could for a limited time period fund only stem cell research using cells from alternative sources. If suitable alternatives failed to emerge during that time, government support could be redirected to research involving stem cells from destroyed embryos. A similar policy approach could be taken

to research cloning, with support initially directed to research aimed at developing patient-matched stem cells through methods that avoid the need for donated eggs.

Policies incorporating the reverse presumptions might also be devised. Such policies would authorize financial support for embryonic stem cell research from IVF and cloned embryos for a limited period, but would cease such support once alternative sources became available.<sup>55</sup> Policies like these would demonstrate respect for those holding different positions on the ethics of creating and destroying embryos for research. And these options are not the only possibilities. A deliberative commitment in policy development could yield a variety of options that accommodate to some degree the different moral positions on stem cell research.

How does the latest development in federal policy look through the lens of deliberative democracy? In the 2009 revision of the federal funding policy for stem cell research, some features of deliberate democracy were evident, but there were deliberative shortcomings as well. In announcing his plans to liberalize the policy, President Obama cautioned against exaggerating the possibility of medical benefits from the research. At the same time, he characterized the research as a step toward the “day when words like ‘terminal’ and ‘incurable’ are potentially retired from our vocabulary.”<sup>56</sup> He recognized the moral opposition of “thoughtful and decent people” to embryonic stem cell research and spoke of avoiding the “perils” the research presents through “proper guidelines and strict oversight.”<sup>57</sup> But he neither defined those perils nor explained how guidelines and oversight would avoid them. Thus, the president gave a nod to the moral dispute and the importance of supplying accessible reasons for the position he endorsed, but the deliberative effort was relatively superficial.

The final NIH Guidelines on Human Stem Cell Research<sup>58</sup> also exhibit deliberative strengths and weaknesses. The guidelines permit federal funding for research on stem cell lines created from embryos donated by couples who have completed their infertility treatment. But the guidelines rule out funding for research using lines created from embryos produced purely for research. In published commentary on the guidelines, NIH officials said there was “broad public support” for funding research using stem cells from donated embryos, but that “a similar consensus has not emerged” on the ethics of creating stem cells through procedures like cloning, in part because they require women to provide eggs at some risk to their health.<sup>59</sup> In this respect, we can see an effort to provide accessible reasons for the decision and, possibly,

to economize moral disagreement by allowing only limited expansion of the funding rules.

But another aspect of the guidelines failed to conform to deliberative ideals. In a telephone press briefing on the final guidelines, Acting NIH Director Dr. Raynard Kington said the agency had received thousands of comments opposing government funding of any research using stem cell lines created through embryo destruction. The official commentary on the guidelines neither mentions those comments nor explains why they did not prevail. In the telephone briefing, Dr. Kington said that agency officials deemed the comments “nonresponsive” to their request for comments on the guidelines they had proposed earlier in the year.<sup>60</sup> A robust deliberative approach would have acknowledged the high number of opposing comments and devoted at least a few sentences to explaining why the agency’s position differed from that taken in the comments.<sup>61</sup>

## Conclusion

Stem cell research could generate knowledge that would allow certain individuals to live longer and better lives. It would be a happy event if in the future stem cell research produced relief for at least some individuals with illnesses or injuries not curable at present. Yet there are no guarantees that this happy future will materialize. Although we may support and admire the scientists devoted to developing a better understanding of human health and disease, we should also be aware that no one can ensure that effective treatments will emerge.

The therapeutic benefits of stem cell research are possible, but uncertain. And many other areas of biomedical science fit this description. Stem cell research is not the only field in which exciting discoveries are occurring and future patients may benefit from investments in these areas, too. This is not a reason to deny support to stem cell research, but it is a reason to consider it in a larger context. Advocates weaken their case when they portray stem cell research as if it were the only promising research around.<sup>62</sup> More government support for stem cell research could help patients in the future, but so could support for research in other biomedical fields.

Participants in the stem cell debate should also recognize deficiencies in the health system denying patients the benefits of past research. Advocacy for stem cell research should include advocacy for a better health system. Without improvements in this system, any therapeutic benefits developed through stem cell research will be unjustly limited to patients fortunate enough to have access to the best health care.<sup>63</sup>



Moreover, the stem cell controversy should press us to reexamine existing research and health care priorities. Should officials devote more funds to research aimed at translating laboratory discoveries into actual clinical benefits?<sup>64</sup> Should they channel more funds to studies that could have a significant public health impact? And what level of investment should the U.S. make in programs aimed at developing and delivering affordable care to disadvantaged people in this nation and around the world? These are ethical questions with immense significance, but they are often overlooked amid the excitement over specific research discoveries like those involving stem cell research.

Last, ethical considerations sometimes justify setting limits on scientific innovation. For example, there is nearly universal agreement that people should not be forced to participate in research, even though a coercive research policy could generate extremely valuable knowledge. Some people believe there should also be severe limits on research involving early human embryos, while others disagree. These are not disputes that science can settle. They are instead value conflicts to be expected in a pluralistic society like ours. In struggling with these conflicts, we should maintain respect for those holding differing views, and we should look for policies that are consistent with as many of those views as possible.

Advocates often portray stem cell research as presenting a choice between ending human life and saving human life.<sup>65</sup> But the choices are much more complicated than that. Many ethical considerations are relevant to policy choices about stem cell research, but they often go unmentioned. Instead, the sound bite approach to stem cell research has produced a shrill and divisive policy climate. Fewer sound bites and an expanded ethical conversation could produce more defensible policy decisions about stem cell research.

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