VIEWPOINT

Patients' Voices: The Powerful Sound in the Stem Cell Debate

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Millions of patients may benefit from the applications of stem cell research, although there is disagreement about whether public funds should be used to develop the science. Patients have been key to winning political support. Acting as advocates, they have contended that public investment will speed the research and bring accountability to biomedical technology. A political dispute about the new research, which holds the potential for cures to devastating diseases and to foster healthy aging, shows the need to respect public sensibilities and to court public approval, as well as the importance of involving patients in debates where the methods of biomedical discoveries and ethical beliefs collide.

The achievement of isolating and growing cultures of self-renewing human pluripotent stem cells has set off waves of optimism among both researchers and the lay public (*1*). The promise is tangible for effective new approaches to incurable diseases and underlying biological processes (*2*). As shown in Table 1, over 100 million Americans suffer from illnesses that might be alleviated by cell transplantation technologies that use pluripotent stem cells. Yet some representatives in Congress and some of the lay public, as well as religious groups such as the National Conference of Catholic Bishops, oppose putting public funds behind the technology. They say that stem cell research belongs under a federal ban that currently prohibits federal funding of embryo research (*3*).

Patients for Research

In 1999, a coalition of three dozen national nonprofit patient organizations, the Patients' Coalition for Urgent Research (CURe), emerged to argue for public funding of human embryonic stem cell research under guidelines of the National Institutes of Health (NIH). This would achieve two goals: (i) participation by the broadest number of scientists under established peer-review mechanisms, thus rewarding the most promising research and speeding progress, and (ii) public accountability and guidelines developed through processes that allow for public comment on an area of science that has raised ethical concerns (*4*).

Why a patients' coalition? As taxpayers, patients and their family members are entitled to expect their government to make the most of a substantial public investment in biomedical research through the NIH and other agencies. And as the bearers of the ultimate burden when medicine cannot relieve their suffering, patients are the most compelling witnesses to the value of research that quite literally can save their lives.

In general, the patients and their advocates who are active for CURe display tempered optimism when it comes to appraising the chances of anyone's health benefiting soon from applications of stem cell research. Furthermore, broad views on the ethics and appropriateness of the technology have been expressed by those in CURe. For example, they believe in the principles of informed consent and free choice. Stem cell research must not lead to an underground black market in "spare" embryos for research. In addition, women and men, as individuals or as couples, should not be paid to produce embryos for research purposes.

The stories of patients and family members have fostered bipartisanship on Capitol Hill and have effectively complemented other activities such as the stance voiced by leading theologians from four major faiths—Roman Catholicism, Protestantism, Judaism, and Islam—who, noting the calls of their religions for compassion for the sick, wrote a joint letter to Congress urging federal involvement (*5*).

The Broader Stakes

The promise of human pluripotent stem cell research increases the likelihood that vastly more people will experience healthy and productive aging. Age-related disease costs billions of dollars and burdens millions physically and financially (*6*). The additional costs in medical and long-term care that are incurred annually in the United States because its Medicare recipients lose their functional independence are calculated at $26 billion (*7*).

Table 1. Persons in the United States affected by diseases that may be helped by human pluripotent stem cell research. Data are from the Patients' Coalition for Urgent Research, Washington, DC.

Condition	Number of persons affected
Cardiovascular diseases	58 million
Autoimmune diseases	30 million
Diabetes	16 million
Osteoporosis	10 million
Cancer	8.2 million
Alzheimer's disease	4 million
Parkinson's disease	1.5 million
Burns (severe)	0.3 million
Spinal cord injuries	0.25 million
Birth defects	150,000 (per year)
Total	128.4 million

One can imagine the cost 20 years from now in the United States alone, when the population over age 65 is expected to double and the number of Americans over age 85 is projected to quadruple (*7*). Unless bioscience engenders and receives broad popular support, in the future, nations like the United States, which have a rapidly increasing aging population, will more than likely struggle with a much greater health care burden. This is why it is so important to respect public sensibilities and to court public approval fervently, even though it is also likely that the next discoveries will, too, collide with the ethical and religious beliefs of some.

In the stem cell debate, patients have stepped forward to help draw the line between science in service to the community and science for lesser motives. Sadly, some of their most compelling stories will be silenced before long by the progression of their diseases. It surely behooves us to remember their contributions and to engage their successors, who will continue to put a human face on the promise of biomedical research.

References and Notes

1. J. A. Thomson *et al.*, *Science* **282**, 1145 (1998); M. J. Shamblott, *Proc. Natl. Acad. Sci. U.S.A.* **95**, 13726 (1998).
2. *Stem Cell Research and Applications: Monitoring the Frontiers of Biomedical Research* (American Association for the Advancement of Science and Institute for Civil Society, Washington, DC, November 1999).
3. Rep. J. Dickey (R-Ark), "No such thing as spare embryos," *Roll Call* (3 June 1999), p. 4; R. M. Doerflinger, testimony on behalf of the Committee for Pro-Life Activities of the National Conference of Catholic Bishops before the Senate Appropriations Subcommittee on Labor, Health and Education hearing on legal status of embryonic stem cell research (Senate Hearing 105-939), 26 January 1999 (available at frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=105_senate_hearings&docid=f:54769.wais).
4. Goals adopted by Patients' CURe, Washington, DC, 20 May 1999.
5. "Theologians from four major faiths express support for Federal funding of stem cell research," press release from Patients' CURe, Washington, DC (14 October 1999).
6. *A Call for Action: How the 106th Congress Can Achieve Health and Independence for Older Americans Through Research* (Alliance for Aging Research, Washington, DC, 1999).
7. *Independence for Older Americans: An Investment for Our Nation's Future. A Report by the Alliance for Aging Research* (Alliance for Aging Research, Washington, DC, 1999).

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