Advance directives to protect embryos?

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The continuing debate about the use of human embryonic stem cell research

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here is a growing consensus among
scientists worldwide that embryonic
stem (HES) cell research will lead to
the development of therapies for com-
mon diseases or conditions that affect
millions of people, including neurologi-
cal disease or injury, diabetes, and
myocardial infarction. HES cells are also
valuable tools in understanding early human developmental processes, cell
division and differentiation mechan-
isms, drug discovery and toxicity test-
ing, and for developing models of
human diseases. At the same time many
individuals profess to be outraged by the
prospect of using human embryos for
research and therapeutic purposes and
some countries or states have declared
such research to be unethical and have
banned it. Many people also think it
would be immoral to benefit from what
they consider to be evil.

Obviously all those who think HES
cell research is immoral will wish to
ensure not only that no HES cell
therapies are developed but that they
will not openly or inadvertently benefit
from such therapies when they can
avoid it. I have accordingly designed
the following Advance Directive and
here offer it as a service to all those
offended by therapeutic and research
use of human embryos.

The design of this advance directive to
protect embryos highlights an important
point that is often overlooked, namely
that those who object to HES cell
research as unethical and block such
research are committed in consistency to
the rejection of any benefits or
therapies, which may flow from such
research. It is questionable whether
these people will fully accept this con-
sequence of opposition to HES cell
research, and whether this rejection of
HES cell research will be practically
possible. (Once stem cell therapies have
been developed and stem cell research is
conducted worldwide it will be very
difficult, if not impossible, for practicing
physicians to know whether a drug or
therapy was or was not developed
through HES cell research).

We, and especially policymakers,
should keep in mind that very often
there is a significant difference between
what people say that they believe—that
is their professed beliefs, and their actual
beliefs revealed by their actions. It does
not follow from the fact that people
claim that embryos should be protected
as if they are persons, that those same
individuals will follow through and do
everything necessary to ensure that in
fact this protection is implemented. In
most countries with restrictive legisla-
tion on the use of embryos, intrauterine
devices, and the “morning after” pill,
abortion without medical indication and
IVF are generally accepted practices. In
all these practices embryos are created
and sacrificed for purposes regarded as
important and beneficial. Likewise, it is
to be expected that if therapies were to
be proven for serious illnesses, using
HES cells, many people objecting to HES
cell research now will not refuse such
treatments when they or their loved
ones are suffering or dying from a
disease for which no other treatment is
available. The same can be expected at
the level of policy. Will societies that
continue to ban or severely restrict HES
cell research deny any such treatments
to their citizens? This is very unlikely. Of
course there will be some individuals
who will refuse treatments based on
embryo research or products derived
from embryos. Just as there are people
who, based on their deeply held beliefs,
refuse euthanasia while suffering terri-
ibly from a terminally illness, and
women who refuse to undergo abortion,
which would save their own life, to
protect the life of their foetus (like
Gianna Molla who, while she was
pregnant, was diagnosed with a large
cyst in her womb, which required
surgery and abortion of the fetus. She
refused abortion and the child was born
healthy, but Gianna died 7 days later.
She is now regarded as the martyr and
patroness of pro-life and anti-abortion
movements).

Here we come to a second reason for
designing this advance directive. In
a democracy it is not the opinion of the
majority alone that determines public
policy and regulations, nor should
minorities close all the options down
for their fellow citizens. The core
values in a democracy are freedom and
tolerance. As pointed out before, it is to
be expected that only a significant
minority will actually bring their pro-
fessed beliefs into practice. When such
beliefs are so at odds with self interest
and the public good, why would such a
minority have the right to block all the
options for their fellow citizens? There is
no agreement about what moral status
to accord to an embryo, and there never
will be. Looking for consensus or com-
plex compromises that satisfy neither
of the moral positions requires consider-
able effort and slows down important
life saving research. It is time to look for
better ways of dealing with the vested
interests and entrenched positions in
HES cell research, and we should do this
in accordance with democratic values,
that is, whilst maintaining a maximum
degree of choice for citizens.

Respect for minority views can be
shown by not imposing choices on them
which they consider ethically unaccept-
able. If people who accord very high
value to embryos refuse to benefit from
the results of HES cell research, they
should have the possibility to do so. But
tolerance should not go in one direction
only. Options open to some citizens
should not be constrained because of
deeply held, often religiously based
views of others. These minorities should
also tolerate the views and wishes of all
their fellow citizens who want to have
their lives and the lives of their loved
ones saved with treatments based on
HES cell research or products derived
from embryos. However, the problem
goes beyond the issue of minority versus
majority. Freedom of research is one of
the most important rights and moral
values in a democracy. It is not an
absolute value and can be restrained by
other important values such as the
freedom of research and respect for
research participants and patients.
However, in the context of HES cell
research, the application of the principle
depends greatly on the moral status of the
embryo. A justification primarily based on a
contested value is insufficient to restrict
freedom of research to such a consid-
erable extent.

The way forward in the stem cell
debate and, accordingly, stem cell pol-
cymaking is to recognise that most
people accord a relative moral status to
the human embryo and are prepared to
accept the creation and sacrifice of
embryos for purposes considered as very
important, such as life-saving therapies.
Most people accord high value to
embryos when these are included in a
parental project, that is, when people
create embryos to start a family, but in
most cases (in IVF treatments), this
value decreases when the family is com-
pleted and the embryos are “left-over”.

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Those who don’t share this viewpoint should, to the extent possible, have the choice not to benefit from HES cell therapies and they should have the freedom to defend their case—for example, by proving that there are equally effective alternatives that do not require the use of embryos. Stem cell therapies will surely be developed in the not too distant future. Focusing on a minority view on the moral status of embryos may crystallise both the issues and the sincerity of the participants in this crucial contemporary debate. We risk neglecting other issues that may be far more important to most citizens, including their safety and privacy, and their access to life-saving drugs and therapies. If we really do care about human lives, then we should not continue to be hostages of a particular viewpoint on the moral status of the embryo, but we should start to focus on these other issues. The proposed advance directive is meant to dramatise the consequences of consistently holding a particular moral view and to stimulate discussion about how the debate should proceed.

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