

# For love or money? The saga of Korean women who provided eggs for embryonic stem cell research

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Published online: 29 September 2009  
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**Abstract** In 2004 and 2005, Woo-Suk Hwang achieved international stardom with publications in *Science* reporting on successful research involving the creation of stem cells from cloned human embryos. The wonder and success all began to unravel, however, when serious ethical concerns were raised about the source of the eggs for this research. When the egg scandal had completely unfolded, it turned out that many of the women who provided eggs for stem cell research had not provided valid consents and that nearly 75% of the women egg providers had received cash or in-kind payments. Among those who did not receive direct benefits, some cited patriotism as their reason for participating in embryonic stem cell research, hence the question “for love or money?”—namely, patriotism versus payment. This paper summarizes the Hwang debacle with particular attention to the egg scandal and ends with some preliminary thoughts on patriotism as a motive for research participation.

**Keywords** Embryonic stem cells · Egg donation · Altruism · Patriotism

On April 29, 2009, South Korea’s<sup>1</sup> National Bioethics Committee ended a 3-year moratorium on human embryonic stem cell research when it conditionally approved a research application submitted by Hyung-Min Chung<sup>2</sup> at Seoul’s Cha Medical Center. This moratorium dates back to March 16, 2006 when Woo-Suk Hwang, the

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<sup>1</sup> South Korea, often referred to as Korea, is officially the Republic of Korea. All three terms are used interchangeably in this article.

<sup>2</sup> In Korean culture, the family name precedes given names. This article follows the Western style of naming where given names precede the family name.

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only scientist with a research a license to derive stem cells from cloned human embryos, lost his license because of scientific misconduct.

The National Bioethics Committee's conditional approval of the research stipulates the following: the research must be overseen by an independent Institutional Review Board to prevent fraud and ethics violations; the planned number of human eggs must be reduced by increasing the research use of lab animals (the original application was for 1,000 human eggs); the women who previously agreed to donate their eggs for research must renew their informed consent; and all references to cures must be removed from the title of research projects so as not to engender false hope [1–3].<sup>3</sup> Not surprisingly, all of these conditions trace back to the stem cell debacle involving Hwang, who is currently on trial for fraud (knowingly using fabricated data to apply for research funds), embezzlement (KRW2.8 billion (US\$3 million)), and violating Korea's bioethics law (failing to get proper consents and illegally purchasing eggs for research) [4].

In this article, I briefly summarize the Hwang debacle with particular attention to three facets of the egg scandal: the failure to properly inform egg providers about the nature of the research and the risk of harm (contrary to Article 5 of the *Bioethics and Biosafety Act*)<sup>4</sup>; the payment of egg providers (contrary to Article 13(3) of the *Bioethics and Biosafety Act* for any payments made after December 31, 2004); and the coercion or undue inducement of egg providers (contrary to Article 13(3) of the *Bioethics and Biosafety Act*).<sup>5</sup> While Mi-Kyung Kim [5] looks at these violations from a legal and policy perspective, first with reference to the *Bioethics and Biosafety Act* [6] and then with reference to the US National Academy of Sciences *Guidelines for Human Embryonic Stem Cell Research* [7], I look at these violations from an ethics perspective. Next, I offer some preliminary thoughts on patriotism as a motive for participation in research.

## The egg scandal

In February 2004, Hwang and colleagues announced to the world in *Science* that they had successfully cloned 30 human embryos and derived stem cells from one of these embryos [8]. Within a few months, however, the research was “clouded by nagging questions about the source of the key resource for the experiment: human egg cells” [9, p. 3]. Nevertheless, the research continued apace and in May 2005, a second landmark paper was published in *Science* announcing that 11 patient-specific

<sup>3</sup> At the time of writing, final approval is pending from the Ministry of Health, Welfare and Family Affairs. The *Bioethics and Biosafety Act* refers to the Ministry of Health and Welfare; there was a name change in 2008.

<sup>4</sup> Article 5 of the *Bioethics and Biosafety Act* refers to the right to self-determination and stipulates that: “Anyone who becomes a subject of research or experimentation in the area of life sciences and biotechnologies shall have the right to be fully informed of his or her involvement in the research and shall also have the right to consent, or refuse consent, after being fully informed of his or her involvement in the research.”

<sup>5</sup> Article 13(3) of the *Bioethics and Biosafety Act* prohibits payment for eggs in cash or in-kind: “No one shall induce or assist in providing or utilizing sperm or oocytes for the purpose of receiving financial reward, property, or any other personal benefit.”

embryonic stem cell lines had been derived from skin cells [10]. Meanwhile, ethical concerns about the source of the eggs used for the cloning research intensified. In addition to these concerns, there were concerns about fraudulent research.

In November 2005, Sung-Il Roh, a fertility expert at MizMedi Hospital in Seoul, admitted that he had purchased eggs and given them to Hwang. He “told *Nature* that he alone provided 313 mature eggs, from 21 donors, for the 2004 paper and 900 eggs, from 62 donors, for the 2005 paper” [11]. He also admitted to paying 20 or so women for their eggs. Hwang himself later admitted that he had used purchased eggs as well as eggs provided by junior members of his research team. Not long thereafter, Hwang was accused of having coerced female researchers into providing eggs for research.

As regards the total number of eggs used for research, both the Ministry of Health and Welfare and the Seoul Central District Prosecutors’ Office have concluded that Hwang used considerably more than the 242 eggs from 16 women reported in the 2004 *Science* article and the 185 eggs from 18 women reported in the 2005 *Science* article. The Ministry of Health and Welfare has reported that Hwang acquired 2,221 eggs from 119 women (during 138 stimulated cycles, as some women were cycled more than once), while the Prosecutors’ Office reported that 2,236 eggs were acquired from 122 women [12, p. 4]. In addition to these, there were the eggs retrieved from excised ovaries. It is believed that at least 57 whole ovaries and 56 partial ovaries from 72 patients were provided to Hwang for research use, from which 537 immature eggs were retrieved [12, p. 9].<sup>6</sup>

A number of ethical problems with the procurement of these eggs have been identified by the Seoul National University Investigation Committee, the National Bioethics Committee, and the Ministry of Health and Welfare. Some of these problems are discussed below.

### Adequate disclosure of information

Failure to disclose relevant information to prospective research participants has been widely identified as a key problem with the ways in which human eggs were acquired by Hwang for his embryonic stem cell research. Volunteer egg donors, paid egg providers, infertility patients who traded eggs for discounted in vitro fertilization (IVF) treatments, and women undergoing oophorectomy were not given adequate information about the nature of the research for which their eggs (ovaries) would be used and the potential harms associated with research participation.

For example, while many of the egg providers knew that their eggs would be used for research, some believed they would be used for infertility research, not stem cell research [12, p. 16]. As for the infertility patients who became egg providers, the National Bioethics Committee found that these women were not told that their eggs would be graded and that the better quality eggs could be used for research instead of treatment, thereby diminishing their chances of getting pregnant.

<sup>6</sup> Because the National Bioethics Committee was unable to ascertain the exact number of eggs extracted from excised ovaries for stem cell research (relevant information having been gleaned from an MA thesis prepared by one of Hwang’s students), this practice is reported separately from egg retrieval following hyperstimulation.

While only 48% of the eggs retrieved from infertility patients were sent to Hwang for research use, among them were 63% of the mature eggs [12, p. 20]. Hwang's lab was not skilled in *in vitro* maturation and for this reason, the more mature eggs frequently were provided to him for research [12, p. 20]. From a patient perspective, however, the better quality eggs should have been used for treatment with the lower quality eggs being available for research use. It stands to reason that if infertility patients had been told that their participation in research would decrease their chance of getting pregnant (as lower grade eggs would be used for their fertility treatment), they might not have agreed to become egg providers. Finally, many of the oophorectomy patients indicated that they did not know that their ovarian tissue would be used for stem cell research. A review of signed consent forms has revealed that some patients signed surgical consent forms with "possible excision and research donation" hand-written in the margins [12, p. 31]. Other patients were never informed of possible ovarian excision, while others knew of the possible excision but were never told that the ovaries would be used for research purposes.

Failure to disclose potential harms to prospective research participants—including pain, nausea and vomiting, accumulation of fluid in the abdomen, breathing difficulties, kidney and liver problems, hospital admission to manage symptoms of OHSS, future infertility and even death—has also been identified as a serious problem. For example, according to the National Bioethics Committee, the official consent form approved by the Institutional Review Board at Hanyang University Hospital was flawed insofar as it did not fully describe the harms associated with ovarian stimulation:

The early form of written consent included in the research protocol that went through the IRB of Hanyang Hospital only mentioned the short-term adverse side effects such as ovarian hyperstimulation syndrome (OHSS). But it failed to inform donors of several serious adverse side effects such as infertility, even though its incidence is very low [12, p. 25].

The finding of incomplete disclosure regarding potential harms is not insignificant given the (repeated) harms actually experienced by some of the egg providers—harms that were not reported to the Institutional Review Board as adverse events. According to the National Bioethics Committee:

Among 79 women who donated their oocytes through MizMedi Hospital 15 women attended the hospital or were hospitalized suffering from OHSS and among them two women were hospitalized for three times. As for MizMedi Hospital, the incidence of OHSS among oocyte donors was 17.7%.

Furthermore, without any screening procedure or medical consultation, MizMedi Hospital procured oocytes a second time from a woman who after involved in paid donation had already been hospitalized for OHSS. This woman had to be hospitalized again for OHSS....

Two voluntary donors, who underwent ovulation induction at Hanna Women's Clinic, stated that they had suffered ascites after oocyte donation [12, pp. 28–29].

Good data on the risks of OHSS for women undergoing superovulation for the purpose of donating eggs to research are seriously lacking, and what little data there is, is wildly inconsistent. Compare, for example, recent data from the United States and from the United Kingdom. In 2007, the US National Academy of Sciences' National Research Council reported:

Women taking fertility drugs in order to undergo in vitro fertilization (IVF) show that only a very small percentage—about 0.1 to 0.2 percent—experience what is classified as severe OHSS, and a much smaller percentage suffer truly dangerous complications. For example, about 1.4 of every 100,000 women undergoing an IVF cycle experience kidney failure.

The OHSS risks for egg donors are expected to be much lower than the OHSS risks calculated from women involved in IVF [13, p. 2].

In sharp contrast, data from Newcastle Fertility Centre at Life (also published in 2007) suggests that while OHSS is very unlikely when  $<20$  follicles are produced, the risks are significant and can be life threatening for women producing  $\geq 20$  follicles after superovulation. In this study, nearly all women with  $\geq 20$  follicles reported symptoms consistent with OHSS. 85.5% of the women were able to manage the symptoms as outpatients and 14.5% required hospital admission. The authors of this study “recommend that egg donors be given this information, so that they can make an informed decision about participation in research” [14, p. 187].

A third problem identified by the National Bioethics Committee was the failure of all institutions involved in egg procurement to use the official (though admittedly flawed) research consent form approved by the Institutional Review Board at Hanyang University Hospital. For example, MizMedi Hospital, where most of the egg providers worked through online egg-brokers, used its own consent form (which did not explain potential risks and side effects), as did the Hanna Women's Clinic [12, p. 24].

A final problem with the consent process was the failure to ask for consent from returning egg providers: “Paid donors who donated more than twice at MizMedi Hospital signed consent forms only once, and from the second time, they did not give consent” [12, p. 24].

Informed consent for research participation is an international norm. Among the elements of informed consent is adequate disclosure of material information. The failure to disclose information about the nature of the research and the potential harms associated with research participation calls into question the validity of any written consents that Hwang may have on file. In addition to this, there is the failure to use the IRB approved research consent form and the failure to obtain consent for each egg procurement.

### Payment for eggs

Another key element of informed consent is voluntariness, which can be undermined through coercive threats or coercive offers (which sometimes manifest as undue influence). In this instance, the general worry is that poor women will be

taken advantage of by powerful researchers who will make them financial offers they could not reasonably be expected to refuse. This is the problem of undue inducement, when excessive payment is offered to encourage women to assume risks that reasonable persons would not assume but for their limited options.

According to the National Bioethics Committee, of the 2,221 eggs identified by the Ministry of Health and Welfare, 1,336 were paid for [12, p. 7, p. 16]. The purchased eggs were produced by 63 women egg providers, who underwent a total of 75 stimulated cycles and egg retrievals. Most of these women used online egg-brokers and went to the MizMedi Hospital for the hyperstimulation and egg retrieval. Other egg providers did not receive cash payments, but instead received in-kind benefits from the Hanna Women's Clinic in the form of discounted fertility treatment (the value of which has been assessed at KRW1.8 million to KRW2.3 million per discounted cycle (approx. US\$1,500)) [12, p. 19]. 313 eggs were obtained from 22 fertility patients who underwent a total of 25 stimulated cycles and egg retrievals to provide eggs for research in exchange for discounted in vitro fertilization fees. Taken together, the total number of eggs purchased or traded was 1,649—nearly 75% of the total number of eggs used for research by Hwang and colleagues.

At the time that Hwang conducted his research and even today, there is no international agreement on the ethical acceptability of selling or trading eggs for research. The International Society for Stem Cell Research and the American Society for Reproductive Medicine insist that it would be unfair to ask women to accept the harms of ovarian stimulation and egg retrieval without financial compensation [15, 16]. They note that payment for eggs is a well-established practice in the context of fertility treatment and that since the labor involved and the potential harms are the same (regardless of whether the eggs retrieved are for treatment or research), the women egg providers should be treated similarly—both should be paid.

To date, few legislatures have endorsed this view. A notable exception is Estonia, which grants egg providers a positive right to remuneration [17]. As well, in June 2009 the Empire State Stem Cell Board within the New York Department of Health voted to allow researchers to compensate women up to US\$10,000 per egg retrieval. New York is the first and only state in the US to allow payment for eggs for stem cell research [18].

Other committees and countries prohibit cash or in-kind payments for gametes. This includes the US National Research Council of the National Academy of Sciences [7, pp. 84–87], and countries such as Canada, New Zealand, France, and Spain [19–22].<sup>7</sup> As others and I have argued, “The lure of financial gain may lead [women] to discount the risks to themselves and to make decisions they will later regret” [23, p. 28]. For example, women who need money “to avoid a crushing credit-card debt, to pay tuition or pay off student loans, to feed and clothe one's children and to be able to pay for medical treatment for oneself or a loved one” may

<sup>7</sup> Some of these countries permit reimbursement for expenses incurred while prohibiting payments for the gametes themselves. Beyond this, other countries permit payment for loss of earnings. Furthermore, in the UK, there is no limit on in-kind benefits that can be provided to egg providers in the form of discounted IVF fees [33].

become egg providers without properly weighing for themselves the short- and long-term consequences of their choice [24, p. 729]. Consider, for example, the women egg providers who experience serious side effects requiring hospitalization and who later have fertility problems. Or, consider the women infertility patients who, having traded their eggs for discounted IVF fail to become pregnant and wonder if the (better quality) eggs given to research might have allowed them to fulfill their dreams of becoming parents. A similar perspective is espoused by Thomas Berg, a member of the Empire State Stem Cell Board who dissented from the majority opinion: “With the economy the way it is, you don’t need to be a rocket scientist to know that when a woman is looking at receiving up to \$10,000 to sign up for a research project, that’s an undue inducement. I think it manipulates women. I think it creates a trafficking in human body parts” [25].

A second concern common to many who object to the payment of eggs for stem cell research is a deep-seated worry about the further commodification of women’s reproductive tissues and labor [7, pp. 84–87, 24]. This worry informs arguments to the effect that payments for eggs (for treatment and for research) should be limited to reimbursement for specified out-of-pocket expenses. On this view, not everything belongs in the market place.

Here it is important to remember that stem cell science is a global activity and there is good reason to be wary of stem cell tourism not only in the search for miracle cures, but also in the search for cheap research materials. In creating an international market for eggs, we risk undermining voluntariness as when a woman’s “unfortunate circumstances and compromised judgment are combined with substantial risks of serious harms” [26, p. 12]. We also risk legitimating the harmful exploitation of poor women, especially poor women living in poor countries [24].

In sum, the purchase of eggs for stem cell research raises the specter of coercion, undue inducement, commodification of reproductive labor and tissues, and harmful exploitation.

### Eggs from employees/students

Typically, there are significant power differentials between employers and employees, as well as teachers and learners. For this reason there are certain things that employers/teachers are not to ask of, or expect from, their employees/students. Beyond this, research ethics norms dictate that there should be no relationship (and sometimes no contact) between researchers and research participants so that researchers are not in a position to unduly influence or coerce research participation. Finally, when Hwang’s research was approved, it was stipulated that anyone who might benefit directly from the research should not be eligible to participate in the research.

The Ministry of Health and Welfare and the Prosecutors’ Office have determined that two female researchers—junior members of Hwang’s research team—provided a total of 31 eggs for his stem cell research [12, p. 8]. The first of these two egg providers is said to have been motivated by “a desire to help sick children, and her love of Korea” [27, p. 14] or, more precisely, by “patriotism and concern for those

with spinal cord injury” [28, p. 536]. Nonetheless, a number of factors call into question her voluntariness, not the least of which is the following email text that she sent to a colleague prior to making the donation:

Though it was I who started it, I’m scared. General anesthesia, self-cloning... Trust me and stand by me the same way as you have done till now, so I can understand myself and become strong. I shouldn’t have done it this way, not giving up until the end, not standing up to the professor. I will work harder to forgive myself. Only good things are waiting in the future—publishing paper with our names, and getting admission in a foreign university. I’m going there. From 000 [12, p. 44].

As well, another researcher from Hwang’s lab has reported that this donor “said she told Prof. Hwang Woo-Suk and Director Roh Sung-Il she would not go through with the procedure 1 day or 2 days before, and Professor Hwang got upset and said, ‘What could I do if you refuse it now?’ ” [12, pp. 44–45]. Hwang is known to have accompanied the graduate student to the hospital for the egg retrieval procedure, and in light of the above evidence there is reason to interpret this assistance as coercive rather than supportive. The Seoul National University Investigation Committee has recognized the donation as voluntary but has noted that it was “approved by Professor Hwang [who] accompanied the student to the hospital himself” [29]. This finding contradicts Hwang’s earlier claim that although “some students did offer to donate eggs...he ‘strongly refused’ ” [27, p. 14].

Furthermore, this graduate student is said to have “felt obliged to donate after making mistakes early in the experiment that wasted eggs and set the team back by months” [28, p. 536]. This claim (though denied by the graduate student [12, p. 44]) has led some to question the voluntariness of this donation suspecting that, at the very least, there was perceived pressure to donate. At least one bioethicist, however, is on record suggesting that this donation may not have involved coercion. Insoo Hyun explains, “To some degree, in Korean society, if you make a mistake you must make good on it somehow. It’s a grey area” [28, p. 536].

This controversial donation happened in March of 2003. In March or May of 2003 Hwang circulated consent forms for egg procurement to female researchers in his lab. Ten female members of Hwang’s research team have since admitted to signing these consent forms [12, p. 46]. Given the power differential between Hwang and his female employees/students, there is reason to think that these consents may not have been completely voluntary. One woman who signed the consent form reported having done so during a lab meeting in the presence of her superiors, including Hwang. According to the National Bioethics Committee:

[I]t could be regarded as a form of coercion constraining the freedom of researchers that Dr. Hwang distributed “consent forms for oocyte donation [sic]” and obtained signatures of the researchers who needed “special protection” without any sufficient or proper explanation about adverse side effects of extraction procedure. Thus his conduct is highly inappropriate [12, pp. 49–50].



The second employee to donate eggs for stem cell research reported, “As a mother of two children, I decided to donate oocytes when I met young children who were suffering from incurable diseases” [12, p. 47].

It is always difficult to know what really motivates someone to participate in research, and this case is particularly complex because of the overlapping unbalanced power relationships of employer–employee, teacher–student, and researcher–research participant that cloud the issue. Beyond undue deference and possibly fear, some or all of the following motives may explain the decision to provide eggs for stem cell research: altruism, patriotism, making amends, seeking personal advantage (e.g., authorship on a major science publication), and career advancement (e.g., a job in a research lab in North America).

### **Patriotism and research**

In the West, it is widely accepted that altruism—unselfish concern for others—is an appropriate reason for healthy volunteers to participate in research, but what about patriotism—love and devotion to one’s country—as a reason for research participation?

A 2009 UK study on attitudes and intentions of prospective egg donors confirms that altruism strongly influences the decision to donate to research: “Most of our potential donors reported they would donate to find a cure for illnesses, improve fertility treatment, and do something that makes a difference” [30, p. 7]. In all likelihood, this finding can be extrapolated to potential eggs donors in other countries. But what about an additional motive, namely to help promote domestic science and technology?

Researchers from developing countries have identified patriotism as a motive for their career choices. For example, José Francisco David-Ferreira (a pioneer in the use of electron microscopy in cell biology and experimental embryology) reports:

When I was young, my generation was still influenced by the idealism and romantic patriotism of our fathers. To be useful to our country and community was a strong motivation. Science was a good cause in a poorly developed country like Portugal. To be a professor, a scientist or a physician were adequate professions to pursue that goal [31].

Not everyone can serve his or her country through a career in science, however. For those who lack the interest, skills and training to be researchers, might they not make important and legitimate contributions to the scientific achievements of their country and community by volunteering to participate in research?

From the beginning, Hwang’s stem cell research “became closely identified with the national interest and cultural values of the country” [32, p. 304]. This linkage of personal and national interests was made possible in no small part by Hwang, who promoted his work as a national priority. His personal scientific reputation and status thus became inextricably linked with the nation’s reputation and status: “Professor Hwang’s achievements were not only a step forward in conquering

disease, they were a contribution towards South Korea's efforts to establish its status in the world" [32, p. 292].

This perspective explains why local media reports on Hwang's success celebrated the "Korean" nature of the breakthrough and reveled in explaining how national cultural values and practices facilitated the achievement that had attracted such international acclaim...They noted the popular commitment to technological innovation and praised the notion of "a national enterprise" which "is essentially foreign to people in the West where more attention is paid to individual pursuits" [32, p. 296].

Not surprisingly, given the early enthusiasm for the Korean way of doing things, when the controversy around the sourcing of eggs for research began to unfold, criticism from the West was promptly characterized as a failure to understand and respect Korean style "family-like lab-culture." Indeed, some Koreans warned against a certain kind of ethical imperialism. It is from this perspective that Kim writes:

In the strict hierarchy of a scientific laboratory in a Confucian society like South Korea, junior members might often feel great pressure to please their superiors. In Confucianism, teachings of filial piety and respect for and obedience to elders, bosses, and teachers are central [5].

Korea is a country strongly influenced by Confucianism and Confucian values. Within Confucianism as a living normative framework, the metaphor of filial relations—central to Confucian ethics—implicates duties and responsibilities from son to father, subject to ruler, younger sibling to older sibling, etc. But these duties and responsibilities are not uni-directional. Meng-tzu (Mencius), second only to Kung Fu-tzu (Confucius) in importance for Confucianism, is well known for criticizing those in authority who show little or no regard for those under their care or jurisdiction (see *Meng-tzu* 1A7, 2A6, 4B28). And, at one point Meng-tzu goes as far as to permit rebellion in the face of intractable disregard for those under one's care or authority (see *Meng-tzu* 1B8). In Confucianism, someone in authority must act appropriately relative to his or her social station—this is the essence of Confucian teaching on the so-called rectification of names (see, for example, *Analects* 12:11). To fail to do so is to fail in that role, and, moreover, to fail morally. All of this to say that Confucian values can neither explain nor excuse abuses of authority.

To return to the question of patriotism as legitimate motivation for participation in research, a key question is whether nationalism is good for science. No doubt, some will answer this question in the affirmative and point to technological advances achieved in the West during the Cold War. Others, myself among them, will call into question the desire to seed competition between nations and promote nationalist fervor among citizens, when in many instances it is multinational corporations and not nation states that are in direct competition. On this view, national competition is at best a distraction, and one that is not likely to promote the interests of future patients.

## Conclusion

Korea is at the dawn of a new era in stem cell science with the recent conditional approval of a license for embryonic stem cell research for Hyung-Min Chung at Seoul's Cha Medical Center. It is to be expected that the new research program will not repeat the ethical mistakes made by Hwang and colleagues in sourcing human eggs for research. Instead, women egg providers: (i) will be properly informed of the nature of the proposed research and of the potential harms associated with hyperstimulation and egg retrieval; (ii) will not be paid for their donations; and (iii) will not be subject to other forms of undue inducement resulting from interpersonal relations with members of the research team. Without money, undue deference, or fear as possible motivating factors, it remains to be seen whether altruism alone will be sufficient motivation for Korean women to participate in embryonic stem cell research by donating their eggs. In the alternative, will there be overt appeals to patriotism with a view to collectively redressing Korea's tarnished reputation in stem cell science?

**Acknowledgments** Research for this article was funded in part by a salary award from the Canada Research Chair program. Thanks are owed to Tom Wallwork for research assistance, to Andrew Fenton for his assistance with the section on Confucianism, and to members of the Novel Tech Ethics research team ([www.noveltechethics.ca](http://www.noveltechethics.ca)) for helpful comments on an earlier draft of this article.

**Conflict of interest statement** Françoise Baylis is a member of the Board of Directors of Assisted Human Reproduction Canada. The views expressed herein are her own.

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