Regional Collaborative Workshop 3-b: South Korea

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1. Summary

Title: Present and future of stem cell research: Korea and beyond

Date: 17, December, 2009

Venue: Seoul National University, Seoul

Participants: Students and local citizens (13)

Format: Scientific lecture and group discussion

Organiser: Seyoung Hwang

2. Aims

The Korea workshop was organised as a public engagement event in order to explore what public concerns and interest exist, and can be developed, in relation to various scientific and ethical issues around human embryonic stem cell research. Participants were encouraged to learn about various scientific issues around different areas of stem cell research, and to address and share their views, concerns, and interest on a wide range of social and ethical issues. The workshop was intended to address questions around public concerns about new science and technology and governance, as follows:

- to stimulate informed discussion amongst ordinary citizens,
- to explore the wider range of views, concerns and interest that are not necessarily well identified in the other public discourses, and;
- to try out and examine a new communication approach that can be further useful to inform policy and expert discussion.

The workshop yielded various forms of data for examining the question of what it means to be 'informed citizen' by investigating ways in which information and knowledge are made available to the public, how members of public make use of them in the way that their views and concerns are better expressed and what are their strategies and difficulties in doing so.

3. Public debate and local context

In 2005, the sudden fall of Hwang Woo-suk, the pioneer of human embryonic stem cell research, put the nation into turmoil. The public was hugely disappointed by the truth that there were no world-first human embryonic stem cells derived by somatic cell nuclear transfer (SCNT) Hwang's team claimed in the journal *Science*, so called therapeutic cloning. In 2006, the South Korean government identified stem cell research as one of new biotechnologies that will enable Korea's world-leading bioeconomy, premised upon an ambitious vision to reach the world top 3 countries in this area¹ (MOST et al. 2006). In May 2009, under stricter regulation, the Cha Stem Cell Institute became a first research group in Korea who will conduct SCNT research after three years' suspension. Earlier in 2008, the license application for the same kind of research by The Suam Biotech Research Foundation where Hwang Woo-suk is currently the head was rejected by the government following the National Bioethics Committee (NBC)'s decision. The reasons were given that Hwang's case was still on trial and the gravity of the ethical misconduct. In October 2009, Hwang was convicted of embezzling research funds, illegally buying human eggs, and of other serious charges related to his fraudulent research.

In the meanwhile, the media poll shows that more than 80% of public expressed support for Hwang's human embryo research (SBS TV, 2008, July, 19). Is the public support simply an expression of sympathy for their disgraced hero Hwang Woo-suk? Or is this the evidence that the public myth over the therapeutic application of human embryonic stem cells persists? Perhaps the public interest in ethical issues was never greater than that in the existence of the world first patient-specific human embryonic stem cells. By contrast, for scientists, to evade ethical issues has increasingly become a risky business due to the stricter implementation of regulation. Whereas the policy and scientists have learnt lessons from the Hwang scandal, the communication between policy and experts, and lay public seems not to be very effective. What is

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¹ Ministry of Science and Technology, Ministry of Commerce, Industry, and Energy, and the Ministry of Health and Welfare (2006). Bio-Vision 2016: The 2nd Framework Plan for Biotechnology Promotion. Seoul.

being missed is the attention to public confidence and the questions about what relevant their concerns are and how they can participate in the debate.

The conception of the debate on ethical issues around human embryonic stem cell research for the workshop then emerged out of this cultural context, by focusing on the role of *science communication* in ways that engage participants in both understanding and critical inquiring about scientific information and other social frames for decision-making, and the means through which they become available to the public. Therefore the workshop was designed to stimulate debate in the way that participants are encouraged to learn about various *frames and interests* that constitute the discourses of bioethics, and to critically reflect on *the means of communication* through which public concerns, understandings and trust about science and bioethics and their institutions are constructed.

4. Design

1) Format

Focus on science communication:

- Scientific lecture: how does scientist-participants communication form the basis of the role of scientific information in the decision-making process?
- Group discussion: how participants consider various sources of information (distributed materials are media articles and summary of regulation; the Internet search also available)

2) Selection of two hESC issues

- Topic 1: Should scientists be permitted to use human embryos for stem cell research?
- Topic 2: Should Hwang Woo-suk be permitted to conduct SCNT research?

3) Timetable

| 13.30 – 14.00 | Welcome and introduction | By organiser |
|---------------|------------------------------------|--------------|
| | Title: present and future of hESC: | |
| | Korea and beyond | |

| 14.00 – 15.00 | Lecture | By scientist |
|---------------|---------------------------|------------------------------|
| 15.00 – 15.20 | Coffee break | |
| 15.20 – 16.40 | Group discussion | Observers (organiser, |
| | | assistant); |
| | | Note-taker, chair, presenter |
| | | elected in each group |
| 16.40 – 17.40 | Presentation & discussion | |
| 18.00 - | Dinner | |

4) Participant recruitment

The recruitment of participants started from the end of October 2009. At first, workshop advertisement posters were distributed around SNU campus and posted in SNU website. At the same time, advertisement through lectures was sought as more direct means to invitation. Through personal contact, three course instructors agreed to introduce the work during their session and invite students' attendance. All three courses – Environmental Lecture Series for Community Citizens, two Environmental Education (one for social studies students, the other for science students) deal with socially scientific issues in their course sessions, therefore the instructors found the workshop can be beneficial to students' hands-on learning. Nonetheless, recruiting did not go smooth, mainly due to the timing: the date of workshop was within just week after final exams when students were already leaving for long winter vocation. 14 persons signed for and eventually 13 persons turned up. 11 were SNU students and 2 were local senior citizens. During the course, the logistics of the workshop was optimised to suit the small scale event.

5) Data collection

Participants were informed that all sessions during the workshop were planned to be recorded. Various forms of data were collected as follows:

- Recordings of all sessions (introduction, lecture, group discussion)
- Survey on participants' perceptions about hESCs
- Pictures taken during the workshop

5. Summary of group discussions

<u>Topic 1: Ethical issues of human embryonic stem cell research</u>

Core issue: definition of life

Approach

- Discussion focused on the question of when life begins and whether embryo research entails destruction of life.
- Whilst the need to reach social consensus was shared, questions were raised regarding the limit of ethical judgments.
- Various frames such as science, religion and law were considered in making personal decisions which resulted in varied conceptions of life and decisionmaking itself.

Conclusion

- Given the different definitions of life, social consensus is necessary.
- Nonetheless, it remains questionable whether humans have the right to define what life is.

<u>Topic 2: Should Hwang's team be permitted to resume SCNT research?</u>

Core issue: ethical regulation of scientific research

Approach

- Pre-debate voting showed 'yes' by 5:2.
- Reflective thoughts on the Hwang scandal facilitated the discussion of scientists' responsibility in the society.
- As discussion progressed, reasons for both views were considered in balance.
- Some came to realisation that the focus was not any longer on Hwang, but on how to ensure ethical scientific practice generally.

Conclusion

- The public should be given more access to scientific information and balanced views on the progress of scientific research, so as to make rational judgements.
- Regulations should be strictly abided by scientists.

6. Analysis of

1) Scientist-participants interaction

Summary of lecture

| Contents of scientific lecture | Relevance to ethical issues | | |
|-----------------------------------|------------------------------------|--|--|
| 1. Scientific concepts and issues | | | |
| Fertilisation and developmental | Definition of life | | |
| process | Inducement of over-ovulation | | |
| Pluripotency and difference | Varied ethical baggage according | | |
| between SCNT and cloning | to different methods | | |
| Culture and differentiation | Similarity between cancer cell and | | |
| | stem cell | | |
| | Risks involved in hESCs in using | | |
| | for therapy | | |
| Distinction between embryonic, | The case of fetus-derived neural | | |
| somatic, iPS cells, and their | stem cells for therapy | | |
| medical potential and limit | Hwang's 2004 Science paper | | |
| Application of stem cell research | Uncertainty issues in clinical | | |
| The concept of cell therapy and | application | | |
| research trend | | | |
| Animal stem cell research | Safety issues | | |
| Xenotransplantation | | | |
| 2. Policy and regulation | | | |
| Safety and efficacy issues | Myth about 'stem cell therapy' | | |
| 3. Ethical issues | | | |

- Academic freedom vs. social accountability
- Distinction between scientific achievement and medical potential
- Research ethics

Contribution to more 'realistic' understanding about bioscience

[excerpt]

concept.

Participant: This article says, after Dr. Hwang scandal the stem cell research in our country has been restricted, and regulation has become too strict compared to other developed nations, therefore our country has lost competitiveness.

Scientist: If I may correct you, our research was not so much advanced even when he's doing very well [as opposed to people's view at that time]. The SCNT was one of few areas whereby Korea was competitive. But you need to have a big picture, which is the fact is that we are not a leader in this research area, generally speaking. As I listen to you today, I feel that we need to know more about facts, I mean, about frames. It's not just about some information, but about the effects of the media, for example.

2) Participants' consideration of scientific information

Group 1: Can primitive streak be a criterion for defining when life begins and therefore for permitting embryo research?

Discussion followed in this sequence:

Step 1: The group shared their understandings about embryo, fertilisation, and implantation, through the guidance of the bioscience student

Step 2: They expressed their own views about the definition of life, either relying on scientific knowledge or not. For example, one student expressed her catholic faith as the ground for her view on life and hESCR. Another student agreed with the 'pre-implantation' view, but stressed strict regulation in using embryos for research. Step 3: One student asked of the scientist why primitive streak is the important

Step 4: The group shared their tentative views: Christian students remained uncompromising for the scientific criteria, whereas others stressed the necessity of making consensus, and perceived science as a reasonable criterion, if not absolute.

Group 2: Debate on 'fresh eggs'

Discussion followed in this sequence:

Step 1: One student found in the newspaper article the claim that legal blocking of the use of 'fresh eggs' may hinder the success of SCNT experiments.

Step 2: Scientist joined the discussion and explained about efficacy rate differentiated by the use of different eggs (frozen, fresh). At the same time, he stressed ethical issues around egg donation.

Step 3: Moderator asked who made such claim. Students realised the newspaper article was written in the context of the SCNT research that was recently set off by a team at CHA Stem Cell Institute. Some found the nuance of the article might give the (wrong) sense that regulation impedes innovative scientific research.

Step 4: Further discussion continued on the possible risks of egg extraction to women. Some found 'fresh eggs' argument is unethical in the sense that women's health and right might be in jeopardy.

3) Participants' reflection on their decision-making

Whilst science communication formed the major part of lecture and discussion, participants were encouraged to reflect on the limit of scientific knowledge in the decision-making process, and to consider other social elements involved. Main points that participants addressed regarding the criteria and quality of decision-making are as follows:

Firstly, in spite of the varied acceptance of scientific information in their decision-making, participants seemed to share the idea that science cannot offer right answers to all ethical issues. For example, both science and other social frames (law and policy) were considered to be partially useful and partially limited.

Secondly, they realised the role of communication between experts and lay people is crucial, apart from the role of institutions such as science and regulation. Especially concerning the Hwang affair, they realised that transparent communication (e.g. media) must be ensured, so as to prevent public anxiety or misunderstanding.

Finally, participants' understanding about the role of scientific knowledge in the decision-making was more than the simple choice between accept or reject, instead reflexive in the sense that they tried to perceive the contingency and uncertainty issues in the nature of science.

Appendix

<u>Abstract</u> of the research paper that contains full analysis of the workshop, entitled *The role of scientific knowledge in the cultural contextual model for bioethics education: the case of human embryonic stem cell research workshop*, submitted to The Korean Society for Biology Education Journal (under review, April 2010).

This article develops a cultural contextual model for bioethics education by considering the role of scientific knowledge in the decision-making process. The meanings of cultural contextual learning are conceptualised from the perspectives on the role of science in the society and on the nature of science in science education. The case of human embryonic stem cell research workshop for the public is introduced and analysed in ways that address the scientist's and learners' views and their use of scientific knowledge when they engaged in the decision-making process in two controversial human embryonic stem cell debate cases. The analysis finds out the meaning of learning in two aspects: 1) learners' critical and elaborated views on the role of scientific knowledge, 2) their understandings about criteria and quality in decision-making in bioethical issues.