

行政院國家科學委員會專題研究計畫 成果報告

產前基因篩檢,科學母職與「完美的嬰兒」:探究基因科技對
社會關係的衝擊(II)

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「產前基因篩檢、科學母職，與『完美的嬰兒』」：

探究基因科技對社會關係的衝擊」

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一、中英文摘要

科技不只是意圖篩檢出「不完美」的嬰兒，也可能促發增加不完美嬰兒的比例。早產兒基金會對於台灣實施人工協助生殖科技植入過多胚胎、增加台灣早產兒比例的現象，提出批判與介入，就是一個重要的例子。藉由探討新生殖科技有助於我們瞭解科技與社會的多重關係，同時也能增進我們瞭解民間團體如何介入科技評估。如果從台灣的病患權益運動發展來看，過去以資源分配（例如爭取納入健保給付）認同政治（例如去除特定疾病的污名）為主，近幾年出現類似早產兒基金會以挑戰科學知識生產的運動內容，特別值得深究。這種新興病患權益運動的方式與策略，對於理解常民專家如何產生，科技民主化如何進行，以及 21 世紀一個「科技社會」新結構的特色，提供了重要的分析線索。本計畫發現，科學社群內部對於議題的爭議界定，專業之間的分裂，以及社運成員高文化資本的特色，是常民運動者能夠成功達成訴求的關鍵。

關鍵詞：人工協助生殖科技、病患權益運動、科學爭議

Abstract

More screening resources or technological advancement do not necessarily lead to the reduction of “disabled babies.” Some babies at high risk for disability are borne because of advanced medical technologies. In this preliminary report, I intend to present how the Premature Baby Foundation of Taiwan (PBFT) has challenged some practice of ART doctors in Taiwan for their implantation of 3 to 5 embryos, which leads to the high rate of multiples, as well as the increasing number of disabled premature babies. The process the PBFT negotiated with the Taiwanese Society for Reproductive Medicine (TSRM), reflected a new facet of patients’ rights movements in Taiwan since 2000. How do these groups collect and present different forms of credibility? If scientific knowledge lies in its esoteric forms as well as the control of the evaluation of their work, to what extent can these lay people challenge it? In what circumstances can such challenge lead to effective responses? Exploring such case can help us explore the role of patients’ organization in the interaction between technology and society.

Keywords: assisted reproductive technology, patients’ rights movement, scientific controversy

二、結果與討論

In an “ART (assisted reproductive technologies) counseling in practice” conference held by the Taiwanese Society for Reproductive Medicine (TSRM) in June, 2002, Executive Director Esther Lai of the Premature Baby Foundation of Taiwan (PBFT) co-chaired the conference with Dr. Kuo-Guang Li, the president of TSRM, for a section called “Minimizing the risk of multiple pregnancy.” In a seminar in which only medical doctors gave lectures, Ms. Lai’s chairing position seemed quite unusual. Lay activists gave advice to doctors doing advanced medical technology and the advice was taken seriously? This shows that the Premature Baby Foundation has made the first success step to advise ob-gyns in Taiwan not to create more disabled premature children. What a breakthrough.

While we have entered an age of controlling the quality of fetus through various medical technology, some “imperfect babies” are born *because of* medical technology as well (Landsman 1998). In-vitro fertilization (IVF) counts one. In 1998, among 2305 live births through IVF in Taiwan, 7.4% weighed lower than 1500 grams, and 35.8% were between 1500 and 2500 grams, also classified as premature babies.¹ Most of these under-weight babies were twins or multiplets. The proportion of IVF babies who are twins, triplets or other multiplets has increased from 30% in 1992 to 55% in 1996, two times that of the US.² Since ob-gyns in Taiwan usually implant 3 to 5 embryos, such practice leads to this high rate of multiplets. Both women and babies may suffer from multiple pregnancy: Mothers face greater risk of premature labor and pre-eclampsia, abruption, and premature infants face various morbidity (Bronson 1997).

Heated discussions were raised by leading medical journals like *The New England Journal of Medicine* and *The Lancet* regarding limiting the number of embryos implanted (e.g.; Templeton and Morris 1998; Ozturk and Templeton 2002). *Human Reproduction*, one of the leading journals on IVF, even had two sequential debates in 1997 and 1998, involving medical scientists from UK, US and Belgium. Some article leading to debates had provocative titles like “Who’s afraid of single embryo transfer?” (Coetsier and Dhont 1998). The UK used to limit three embryos implantation per cycle, and the British Fertility Society further recommended in 1998 that “it should be the usual practice to transfer a maximum of two embryos in each treatment cycle” (Murdoch 1998: 2669). As early as in 1991, Germany strictly regulated that fertility workers can only fertilize less than three eggs recovered after follicular aspiration (Beier and Beckman 1991). The American Society of Reproductive Medicine offered a more lenient guideline in 1999, for example, that if the maternal age is over 40, no more than five embryos could be transferred.³

Transferring three to five embryos is the most common practice according to the doctors

¹ <http://www.doh.gov.tw/newdoh/90-org/org-4/900524-1.htm>

² *China Times*, April 16, 2000.

³ <http://www.asrm.org/Media/Practice/practice.html> (Guidelines on Number of Embryos Transferred by American Society for Reproductive Medicine)

we visited. A mother in Pingtung gave birth to quintuplets after IVF in September 2000, and the IVF clinic even held a media press for this event, showing they do not see multiple implantation as controversial.⁴ Interestingly, responding to this unusual event, the doctor from a medical center criticized the lack of fetus reduction during pregnancy, rather than the multiple embryo implantation itself.⁵ President Li of the Taiwanese Society for Reproductive Medicine did report the high number of embryo transfer in Taiwan in 2000, but he recommended to follow the more lenient US guideline, rather than the regulations in force in the UK or Germany.⁶

How did the Secretary General Lai of the Premature Baby Foundation come to sit with President Li of TSRM? The Premature Baby Foundation has worked for improving the quality of care for the past ten years. They have successfully lobbied to put the care of premature babies under the coverage of the National Health Insurance. In the past, most of their resources were devoted to the care and service of those families with premature babies. Only after the basic health care is guaranteed does the foundation start thinking about “prevention.” Besides warning women on their lifestyle for prevention of premature birth, the foundation also gradually noted that advanced medical technology also “creates” more premature babies. For example, one mother of three pre-mature newborn babies wrote about her complaint about the over-implantation of IVF. Her writing was published in the PBFT newsletter. This deeply touched Ms. Lai. She visited several families who raise multiple premature babies due to the multiple embryos transfer during IVF treatment. After some simple investigation, Ms. Lai began to respond to the media report on the birth of multiplets, overtly criticizing some practice of ART doctors in Taiwan.⁷ Since President Li of TSRM is from Mackay Memorial Hospital, where PRBF was founded and is currently located, Ms. Lai has more opportunity to ask face to face: “What are you planning to do to solve this problem?”

The conflicts between pediatricians and obstetricians facilitate such protests. Half of the executive directors of PBFT are pediatricians, and only a few are ob-gyns. While it is ART technicians and doctors that implant too many embryos, it is pediatricians who have to take care of premature babies. If ART workers initiate such undesirable results, it seems that they are not responsible for managing the consequences. Pediatricians and obstetricians have not had any overt disagreement in public regarding this issue. However, the pediatricians’ complaints gave support to Ms. Lai that she could enroll behind her argument that obstetricians of ART should reduce the multiple pregnancy. Ms. Lai as a social worker has increased her credibility through the backing the credibility of others with academic degrees in science. The story did not end with Ms. Lai’s sitting next to President Li for the

⁴ *United Daily*, p. 10, September 19, 2000.

⁵ *United Daily*, p. 10, September 19, 2000.

⁶ *China Times*, April 16, 2000.

⁷ See *China Times*, Jan. 31, 2002.

seminar. TSRM is working on a guideline on the number of embryo transfer, showing further efforts on self-regulation and improvement.

To summarize, it seems that this case has already involved professional conflicts, and it supports Epstein's (1995) argument that when scientific controversy exists, that is the best chance for lay activists to intervene. The interests of lay people will be easier heard by scientists when they also need to seek legitimacy for their argument. PBFT also has longer history of working with doctors and scientists; PBFT is mainly founded by the doctors and then start its self-criticism. Full-time workers in PBFT hold at least college degree. Some workers have master degree. Overall, PBFT legitimates their case through enrolling various supports from the science community, their access to esoteric knowledge, and their own authoritative role as the representatives of patients.

三、計畫成果自評

本計畫第二年持續前一年的切入角度，我們發現從成長團體或是病患團體來著手進行研究，不只是能夠得到較豐富的資料，也能進一步從法人團體探索科技與民主的關係。這裡呈現的社會團體挑戰科學知識部分，先發表於 2002 年台灣社會學年會，並於 2003 年 10 月在東亞 STS 會議中，宣讀修改後的論文。未來計畫將此文投稿英文期刊。

Chia-Ling Wu. 2002. "Confronting Scientific Knowledge: The Transformation of Patients' Groups in Taiwan in 2000s." Paper Presented for the annual meeting of Taiwanese Sociological Society, Tung-Hai University, Taichung, December 14-15, 2002.

過去一年也針對腦性麻痺團體參與相關社會政策部分，有較多的著墨。也是想從民間團體的角度，來瞭解對於科技相關政策的介入。這是未來論文寫作的方向，而有關於這類以女性為主的民間組織的行動力，部分發表於「凝聚台灣生命力」的研討會。

藍佩嘉、吳嘉苓，2003，「變遷中的性別與家庭，弱勢與移民的女性照顧者」，發表於「凝聚台灣生命力」研討會，10月25日台大應力學館。

四、參考文獻

Beier, H. M. and J. O. Beckman. 1991. German Embryo Protection Act (Oct. 24, 1990).

Human Reproduction 6: 605-606.

Bronson, Richard. 1997. "How Should the Number of Embryos Transferred to the Uterus

Following In-Vitro Fertilization be Determined to Avoid the Risk of Multiple

Gestation?" *Human Reproduction* 12(8):1605-1618.

Coetsier, T and M. Dhont. 1998. "Avoiding Multiple Pregnancies in In-Vitro Fertilization:

- Who's Afraid of Single Embryo Transfer?" *Human Reproduction* 13(10): 2663-2664.
- Epstein, Steven. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.
- Landsman, Gail H. 1998. "Reconstructing Motherhood In the Age of the 'Perfect' Babies: Mothers of Infants and Toddlers with Disabilities." *Signs*24(1):69-100.
- Murdoch, Alison P. 1998. "How Many Embryos Should be Transferred?" *Human Reproduction* 13(10): 2666-2670.
- Ozturk, Ozkan, and Allan Templeton. 2002. "In-Vitro Fertilisation and Risk of Multiple Pregnancy." *Lancet* 359:232.
- Templeton, Allan, and Joan K. Morris. 1998. "Reducing the Risk of Multiple Births by Transfer of Two Embryos After In Vitro Fertilization." *The New England Journal of Medicine* 339(9):573-577.
- Wu, Chia-Ling. 2000. "Patients' Rights Movement in Taiwan: A Preliminary Analysis." Pp. 384-432 in *The Social Welfare Movement in Taiwan*, eds. Michael Hsiao and Kuo-Ming Lin. Taipei: Chu Liu. (in Chinese)