Embodied Knowledge: Bringing a new epistemology to the informed consent of oöcyte donation.

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Abstract
Australia has legalized somatic cell nuclear transfer (SCNT), a type of stem cell research, in the hope of finding cures for chronic diseases. SCNT requires large numbers of fresh, fertile eggs to be donated by women. In vitro fertilisation (IVF) patients have their eggs harvested for fertility treatment. In the United Kingdom these patients are targeted as egg donors for SCNT in an ‘egg sharing’ program where 50% of harvested eggs are donated to SCNT in exchange for discounted IVF. This paper explores the notion of informed consent for egg sharing by drawing on 35 semi-structured in-depth interviews with staff, ex-IVF patients and egg donors from an Australian IVF clinic. Participants detailed their experiences of providing or receiving IVF treatment and their opinions about egg sharing. This research finds that the difficulty of achieving pregnancy through IVF treatment is not fully comprehended by most patients until they have experienced at least one IVF cycle. Therefore, to work towards ‘fully’ informed consent for egg sharing, we must go beyond the provision of rational, scientific information and include the opportunity for women to draw upon their own embodied IVF experience, for example, by stipulating that IVF patients undergo one full treatment cycle before being offered egg sharing.

Keywords: informed consent, embodied knowledge, stem cell research, egg sharing, in vitro fertilisation

Introduction

The establishment of the Prohibition of Human Cloning and the Regulation of Human Embryo Research Amendment Act 2006 has opened the way for Australian scientists
to legally utilize women’s oocytes (eggs) for the experimental somatic cell nuclear transfer (SCNT) technique, which is part of the larger field of regenerative stem cell medicine. Through SCNT stem cell scientists hope to develop a technique to produce new patient-specific tissues that are compatible with individuals, therefore bypassing the need for whole-organ transplants and averting side effects such as organ rejection. Stem cell scientists hope that diseases such as diabetes, Parkinson’s disease and spinal cord injuries could be cured through SCNT. However SCNT requires large numbers of fresh, fertile oocytes, preferably donated by young women less than 35 years of age. This in an onerous process involving daily injections of hormones for several weeks to stimulate the ovaries to produce high numbers of oocytes, followed by day-surgery for oocyte harvesting. Payment and compensation is said to encourage oocyte donation from non-IVF patients (Widdows 2009) though in Australia oocyte donors are arguably more likely to come from IVF populations as, unlike the USA, Spain and Romania, Australia does not allow payment for oocytes (O’Riordan and Haran 2009) or for the compensatory models of oocyte donation found in the UK and India.

Australia currently lacks an ethical regulatory framework for oocyte donation for stem cell research which takes into account the views and experiences of women who have experienced oocyte harvesting, and of health professionals and scientists who work closely with the process of oocyte procurement in the IVF setting (Waldby et al. 2009). Although some research has been conducted in the UK regarding oocyte donation for stem cell research during IVF treatment cycles (Blyth 2004; Roberts and Throsby 2008; O’Riordan and Haran 2009), no research has investigated the Australian perspective. This is important to investigate as Australia does not provide any payment or monetary incentive to women who may wish to donate oocytes, yet Australia is one of many countries that conduct stem cell research in the international context where demand for research oocytes far outstrips supply. In recent years there has been a strong public debate in Australia regarding SCNT. Australia has witnessed the Parliamentary Lockhart Review in 2002 and the Amendment to the aforementioned Human Embryo Research Act in 2006 which reviewed Commonwealth legislation regarding human embryo research and then legalized SCNT techniques. Leading Australian academics have also published in journals and the media about whether non-patient women should be paid to donate oocytes
This paper adds to the debate by contributing the voices of women who have experienced IVF and oöcyte extraction first hand, alongside those of health professionals who are directly involved in delivering IVF treatment. Embodied knowledge is garnered from the experience, meaning-making, information and impulses from within the body (Wadsworth Hervey 2007). This process occurs as a result of the body’s interaction with, and interpretation of the environment (Johnson 1989). In the case of female IVF patients and donors who adapt to, act within and interpret the constantly changing demands of the treatment experience, this experience can be considered as a key resource in consenting to future decisions about donation. Thus in this research, female patient’s voices in addition to the clinical staff of the fertility clinic will be used to review the notion of informed consent with regard to oöcyte procurement during IVF treatment for SCNT. This paper argues that current standards of informed consent are insufficient for egg sharing, particular because providing ‘adequate’ and ‘clearly written’ information for informed consent is often equated with the full provision of information. Little research has examined the influence of past embodied experiences of similar or identical medical treatments as an influence on decision-making or as a source of information for informed consent. In the case of IVF this is important as more than one cycle will often be required in order to achieve pregnancy. The repetitive nature of IVF, although arduous, enables the possibility of ‘learning from experience’ before agreeing to egg sharing in future cycles.

**Ethics and Informed Consent**

Ethics is an evolving study of values and morals which change to keep apace with progress made in science and technology. Ethical ideals sit at the heart of informed consent, where a ‘fully informed’ consent is that which is freely given, with full understanding and without coercion (Corrigan 2003). Informed consent is held up by many in the medico-scientific community as the ethical antidote to problems associated with patients participation in medical research or clinical trials (Corrigan...
However problems have been identified with aspects of informed consent for oöcyte donation, such as the lack of information provided to patients or trial participants (George 2008); the impossibility of knowing potential side-effects in the future as a consequence of participation (Dickenson and Idiakez 2008; Schneider 2008); being unable to withdraw once a treatment cycles has commenced due to a patient’s inability to pay full costs (Roberts and Throsby 2008); and the complexities of patient relationships with medical practitioners, particularly in relation to seeking treatment for medical conditions as part of research participation (Corrigan 2003; George 2008).

Through concepts such as ‘relational autonomy’ (Ehrich et al. 2007), sociological attention has broadened discussions on informed consent, moving it from a position of decontextualised ‘empty ethics’ to one which embeds patients in their social contexts and interpersonal relations throughout their decision-making (Corrigan 2003). This reveals how patients come to make decisions and understand the written information through their position as a socially connected and culturally embedded family member or community citizen (Ehrich et al. 2007). Despite this important contribution, the type of information provided to achieve ‘full information’ in informed consent remains a rational, disembodied, and scientifically determined epistemology, a knowledge that is most often provided in written form. Specifically, patients are asked to review and consider a consent form containing accessibly-written scientific discourse detailing information on potential side effects, the percentage-chance of various risks, and an account of an idealized, smooth and relatively linear progression through the study. This mode of delivering information risks ignoring how research participants ‘deploy tacit knowledge based on personal experiences’ (Corrigan 2003: 777) and ‘the extent to which an individual’s understanding of the consent information is sometimes based on prior experiences and personal biography’ (Corrigan 2003: 776). Despite concern among bioethicists and research advocacy groups that ethical guidelines ensure that research participants are fully informed and have ‘sufficient understanding of their involvement in the trial prior to consent’ (Corrigan 2003: 777) informed consent is unlikely to suggest drawing on previous experiences of participation in similar medical trials or treatments is important for decision-making.
Method

This paper is based on 35 in-depth semi-structured interviews with two main cohorts involved in IVF. Cohort One includes 20 ex-IVF patients (8 of whom had not achieved a live birth as yet from IVF) and 5 reproductive oöcyte donors who have experienced oöcyte harvesting. Cohort Two includes 10 health professionals and scientists who work in an Australian IVF Clinic and therefore have experience in patient care and the careful management and classification of reproductive tissues. The clinic does not undertake oöcyte harvesting for research purposes, therefore the participants needed to imagine scenarios rather than report directly on experiences of research oöcyte donation. Cohort One was invited to participate in the research via the IVF clinic database between 2008 and 2010. Cohort Two was recruited through research information sessions conducted at the IVF clinic where the researchers presented the aims, methodology and importance of the study to the health professionals and scientists. The interviews with Cohort One were predominately conducted in the homes of participants, and lasted between 60 and 90 minutes. The interviews with Cohort Two were conducted in the IVF clinic and lasted between 30 and 60 minutes. Interview transcripts were coded using emergent thematic coding (Boyatzis 1998) and thematic coding of participant responses to each case-study. All names used are pseudonyms.

The interview schedule included open questions related to the experience of IVF treatments and willingness to donate oöcytes in addition to brief case-studies of incentive models for SCNT oöcyte donation from around the world. For the purposes of this paper, the empirical focus is on the data provided by the responses of Cohorts One and Two to the egg sharing model used in the UK (detailed below) and their general experiences of receiving IVF or providing IVF treatment.

Egg Sharing for SCNT: the UK situation

Egg sharing for reproductive purposes has existed in the UK for more than 15 years (Blyth 2004). However egg sharing for SCNT is currently underway in the Newcastle Fertility Clinic, UK. The patient Information Leaflet for Egg Sharing Research
provided by the Newcastle Fertility Clinic states that egg sharing offers ‘a scheme for those couples who wish to reduce the cost of their IVF treatment by donating some of their eggs for research’ (Murdoch 2008: 1-2). Women between the ages of 21 and 35 years of age who are in need of IVF treatment are welcome to be egg sharers. As part of the consent process, women are required to have an appointment with a counselor which assures the clinic that women have a full understanding of the egg sharing procedure, and consent forms need to be signed by both the woman and her doctor.

The Information Leaflet states, ‘in general all eggs are shared equally [between the woman for her IVF treatment and for SCNT] in number and in quality\[vi\]’ (Murdoch 2008: 3). By participating in the egg-sharing program, costs of IVF are reduced by fifteen-hundred pounds (AUD$2600), currently subsidized by the UK Medical Research Council (Roberts and Throsby 2008). With regard to the effect on pregnancy rates, the Information Leaflet (Murdoch 2008: 3) advises women:

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\text{there is a close relationship between the number of eggs we collect and the pregnancy rate. Obviously, if you give half your eggs away this may reduce your chance of success. If we collect a lot of eggs (approx 20) and you have a good fertilization, your chance of success may not be significantly reduced. If we collect less eggs, ... your chance of pregnancy will probably be reduced if you share them.}
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The wording in this document, particularly the italicized words ‘if’, ‘chance’, and ‘probably’ are highly significant in light of how the women interviewed perceived IVF, particularly women who had never had IVF before.

**Egg Sharing is OK, but not for me!**

When the egg sharing program for SCNT was detailed to Cohort One there was a strong overarching sentiment that egg sharing increases choice for women and couples who could not otherwise afford IVF treatment. However this was countered by two dominant themes. The first, expressed by a minority of respondents, was that egg sharing is not really a choice if you egg share solely for financial respite\[v\]. The conundrum in Cohort One was that egg sharing was being perceived as increasing
choice for women while simultaneously forcing a choice on those who are unable to afford IVF. This is portrayed in the following interview extract:

’it’s good in … one way, because she agrees to do that … and then because of the financial matter she has to agree, even if she doesn’t like it, she had to agree to do it.’ (Nadia, Married with one son from IVF)

Second, and overwhelmingly, most women in Cohort One stated that women in IVF need every chance at conception. Women felt that the eggs one would share could be the one egg that would become a baby. Therefore women concluded that their eggs were too precious to donate. In sum, egg sharing was thought to be a viable option for obtaining eggs for SCNT, but an option of last resort or an option solely for women other than themselves.

**Pregnancy Prerogative**

Cohort One and Cohort Two explain that women undertake IVF primarily to get pregnant. Despite the statistics that show about a 30% chance of pregnancy per cycle for a woman in her early thirties, women often come to IVF thinking that it will work first cycle. Many are surprised to find that IVF is not an easy journey. Women watch as egg numbers at the beginning of treatment are transformed into a dwindling supply of viable reproductive tissue that may be suitable for treatment:

’Six eggs. I think we got … four embryos. One was transferred and three were frozen. So, the fresh cycle didn’t work. Tried a frozen one, didn’t work. Went to try the third frozen and … that one didn’t survive the unfreezing, so then we had one left and that didn’t work, so we had not embryos left’. (Eva, married with one child from IVF)

What is most important in relation to informed consent for egg sharing is that the dwindling numbers of what initially seems to be a robust amount of reproductive material and the low success rate is not fully comprehended by IVF patients until a complete cycle of treatment has been experienced:
‘I think your first cycle, you’re kind of excited, and I remember saying to someone, ‘this isn’t as hard as what everyone supposedly reckons it is. I’ve heard IVF is really hard. Its not that hard’... and if that doesn’t work you get to the second time and you’re all excited and gee’d up and that doesn’t work and then, you know... (Caroline, married and childless)

‘Before I went through IVF, everything I had read indicated the way I had twenty two eggs, that was great, and you wouldn’t need them all and so maybe, before going through, I might have thought, ‘oh well, I don’t need all those...and I’m sure they could be used for something valuable’ ... (Mandy, married and childless)

The centrality of experiencing IVF in order to comprehend the value of eggs is similarly found among reproductive donors, who undergo egg harvesting to provide eggs to women who are unable to conceive a pregnancy:

‘I’m not anti-[egg sharing], but I think it’d be hard for a lot of women to decide to do, especially when they haven’t done it before’. (Donna, Egg Donor)

‘There are some good discussion sites ... where people can post information and their experiences as well .... but it’s very hard ... to be prepared ... It’s so experiential’. (Jenny, Egg Donor)

The importance of experiencing egg collection and lack of success in IVF treatments in order to fully comprehend IVF are also recognized by staff in the IVF clinic:

‘And once they’ve done the treatment, once they know what’s ahead of them ... that it may not work ... they know then ‘Oh, doing it a second time may not work as well.’ ... it sort of shocks them as they come along’. (Chandie, Registered Nurse)

‘I think there’s a big difference: you have to have a little bit of experience to really understand it’. (Rena, Social Worker)
These extracts from interviews with IVF patients, oocyte donors, and fertility clinic staff collectively reveal that the experience of going through IVF actually mediates IVF patients’ perception of the likely success of treatment and the importance of every egg to that success. This embodied and personal experience is important information to be considered when deciding whether one would donate eggs through egg sharing programs as part of IVF treatment.

**Bringing Embodied Knowledge into Informed Consent for Egg Sharing**

The notion of a free and informed consent arises from a contractualist moral theoretical tradition that relies upon information, rationality and an absence of coercion (Jaggar 1993). Yet we often bypass a very important asset – the body - as a resource for ‘sensing, deliberating or knowing’ (Wadsworth Hervey 2007: 100), for learning, and for meaning-making in ethical decision making. This is due to our reliance on disembodied moral reasoning and ethical guidelines (Wadsworth Hervey 2007) that predominate in informed consent.

Knowledge is diverse and includes ‘the affective knowledge found in our body’ (Hamington 2004: 44). Furthermore research participants do not clearly delineate between knowledge and frequently use a multitude of knowledge sources in decision-making (Belenky et al. 1986; Corrigan 2003; Wadsworth Hervey 2007; Markens et al. 2010). Women’s experiences of IVF treatment challenge the notion of a fully informed consent that relies solely upon information derived from scientific rationality. A number of feminists, ethicists and philosophers encourage an embodied approach to ethics that could be further applied to reconfiguring the informed consent process for egg sharing. For instance, Wadsworth Hervey focuses on ‘attending to the signals or impulses [of the body] … and recognizing the need to consider their source and their meaning…’ (Wadsworth Hervey 2007: 102), while Virginia Held argues for moral inquiry that incorporates actual rather than hypothetical experience to avoid the disembodied moral reasoning of ‘a view from nowhere’ (Held 1993). Similarly, feminist philosopher Alison Jaggar suggests that moral knowledge is inseparable from practical wisdom (Jaggar 1993: 69), which could be aligned with what Belenky et al. call a ‘subjective knowledge’; a truth derived from experience and which is personal,
private and known from within (Belenky et al. 1986). Thus embodied experience and subjective knowledge shifts the locus of knowledge from outside to within (Belenky et al. 1986: 54) and trust is placed in knowledge generated by first-hand experience.

The learning garnered from women’s embodies experience of a full IVF cycle needs to be considered alongside the information derived from scientific-rationality on the consent form. The provision of embodied experiences upon which potential egg sharers could draw may be accomplished through policy stipulating that it is advisable for IVF patients to undergo one full treatment cycle before being approached for egg sharing. Such heterogeneous knowledge could assist women in making more informed egg sharing decisions.

This paper has demonstrated how the experiences of IVF enable women to accrue an embodied knowledge which, when deliberating over egg sharing programs for SCNT, can act to protect their primary interest of achieving a pregnancy. Like other feminist researchers that position women’s embodied experiences in relation to biomedical and techno-scientific epistemologies (e.g. Markens et al. 2010) I do not wish to further dichotomise these epistemologies. Instead I seek to reveal the place of embodied knowledge within the rational and formalized process of informed consent as ‘although our bodies are always present, we do not always attend to and with them’ (Csordas 1993 cited by Wadsworth Hervey 2007: 101). In the broader context of uncertainty with IVF outcomes, many of the women in this research had the courage to refer to their own embodied experience of diminishing viable oöcyte and embryo numbers and use this to justify their hypothetical egg sharing choices. This demonstrates the importance of embodied knowledge in making decisions about egg sharing and the place of it in formal informed consent procedures. In conclusion, it is important to recognize diverse epistemologies that could inform, and also be represented in improved consent for egg sharing regimes.
References


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\(^1\) With the exception of the five egg donors in Cohort One who donated eggs to other women so that they may fall pregnant.

\(^2\) Participant names were first screened by a nurse and counselor to ensure that participants were not in need of English translation service or subject to a highly traumatic IVF experience.

\(^3\) Human Research Ethics Committee granted ethics: HREC2009/2/3.5(2919) AU RED HREC09/WMEAD/5

\(^4\) If less than six eggs are retrieved from a woman, this is considered a poor result by the clinic and all eggs are provided to the woman at no extra cost.

\(^5\) This is consistent with findings from Blyth (2004).