

Informed Consent and Fresh Egg Donation for Stem Cell Research

Incorporating Embodied Knowledge Into Ethical Decision-Making

Katherine Carroll · Catherine Waldby

Received: 29 March 2011 / Accepted: 7 December 2011 / Published online: 23 December 2011
© Springer Science+Business Media B.V. 2011

Abstract This article develops a model of informed consent for fresh oocyte donation for stem cell research, during in vitro fertilisation (IVF), by building on the importance of patients' embodied experience. Informed consent typically focuses on the disclosure of material information. Yet this approach does not incorporate the embodied knowledge that patients acquire through lived experience. Drawing on interview data from 35 patients and health professionals in an IVF clinic in Australia, our study demonstrates the uncertainty of IVF treatment, and the tendency for patients to overestimate their chances of success prior to the experience of treatment. Once in active treatment, however, patients identify their oocytes as both precious and precarious. We argue that it is necessary to formally include embodied experience as a source of knowledge in informed consent procedures, both for gratuitous donation and for egg-sharing regimes. We recommend that at least one full cycle of IVF be completed before approaching women to divert eggs away from their own fertility treatment.

Keywords Informed consent · Fertilization in vitro · Oocyte donation · Stem cell research · Egg sharing · Embodied knowledge

In 2006 both the United Kingdom and Australia¹ took steps to facilitate the donation of human oocytes (eggs) for embryonic stem cell research, with a particular focus on the somatic cell nuclear transfer (SCNT) technique. Somatic cell nuclear transfer is a procedure that aims to produce patient-compatible transplantable tissue, overcoming the risks of organ rejection and the need for immunosuppressants. A more immediate and feasible aim of SCNT is to create disease-model embryos for research. However to develop SCNT embryos, which form the source of the tissue, scientists require large numbers of fresh, fertile oocytes, preferably donated by young women less than 35 years of age. Moreover, in cases where donors are also fertility patients, such oocytes must be diverted away from fertility treatment prior to the establishment of their fertility; that is, prior to attempted fertilisation with sperm. In practical terms this means that female fertility patients cannot elect to donate

K. Carroll (✉)
Centre for Health Communication,
University of Technology, Sydney,
Sydney, Australia
e-mail: katherine.carroll@uts.edu.au

C. Waldby
Department of Sociology and Social Policy,
The University of Sydney,
Sydney, Australia

¹ Australia established the *Prohibition of Human Cloning and the Regulation of Human Embryo Research Amendment Act 2006*, which opened the way for Australian scientists to legally utilise women's oocytes for SCNT. In the same year in the United Kingdom, the Human Fertilisation and Embryology Authority (HFEA) enabled egg-sharing arrangements to be extended for research oocyte donors.

solely non-fertile oocytes and that these oocytes will be as likely to be donated to science as viable ones.

In the United Kingdom, the Newcastle Fertility Clinic and the North-East England Stem Cell Institute are licensed to allow “egg-sharing” to encourage research donation through increasing the reimbursement available to donors. While undergoing treatment, female in vitro fertilization (IVF) patients can choose to donate oocytes to research in exchange for discounted fertility treatment (Roberts and Throsby 2008; Waldby 2008). This mode of reimbursing donors through discounted IVF fees is controversial as it departs from the position of altruistic gifting. Altruistic gifting has been considered the desirable bioethical norm since World War II in Western Europe and most developed Commonwealth countries—a means of fostering citizenship and mutual social obligation and pre-empting the marketisation of tissues (Waldby and Mitchell 2006). While critics of egg-sharing argue that it constitutes a form of commodification and undue inducement to less wealthy women (Dickenson and Idiakez 2008), the regulator (the Human Fertilisation and Embryology Authority) regards it as a form of compensation, a recompense for the material and emotional costs of gifting tissues that is acceptable within European guidelines for tissue donation (e.g., the European Union Tissues and Cells Directive).

In Australia, where this research is based, oocyte donors may be compensated for reasonable expenses, but egg-sharing systems are not in operation. An Australian laboratory, Sydney IVF, holds SCNT licenses, with permission to obtain up to 2,400 oocytes for this purpose (Embryo Research Licensing Committee of the NHMRC 2008). Two feature articles in the August 10, 2006, edition of *Nature* detail the ethical implications of oocyte donation (Check 2006). The editorial commentary leading the edition reveals a debate surrounding whether or not IVF patients are the most appropriate oocyte donors because they are already exposed to the risks of ovarian stimulation, as distinct from procurement from healthy volunteers (Nature 2006). Certainly, ovarian stimulation and oocyte harvesting are onerous processes, involving daily injections of hormones for several weeks to first shut down ovulation and then stimulate the ovaries to produce high numbers of oocytes (Thompson 2007). This is quickly followed by day-surgery for oocyte harvesting. Thus, women who act as oocyte donors will go

through an invasive, time-consuming,² and highly uncomfortable process. They are also at risk of ovarian hyperstimulation syndrome (OHSS), which occurs in between 1 percent and 5 percent of cases and can have dramatic consequences, such as hospitalisation and—in rare cases—death (Ballantyne and de Lacey 2008). Furthermore, the long-term consequences of ovarian stimulation have not as yet been adequately researched (Schneider 2008).

In Australia the regulatory framework for research oocyte donation is as yet unformed by social scientific inquiry detailing the experiences of women who have undertaken oocyte harvesting or the experiences of health professionals and scientists who work with them in the IVF setting. This absence is also evident at the international level, where ethical concerns about stem cell research tend to focus on the moral status of the embryo, at the expense of concerns about oocyte donors (Dickenson 2006), or clinicians who may have to work between the procurement of oocytes for treatment and research (Widdows 2009, 134). To date the only research investigating the perspective of potential research oocyte donors in Australia is a survey conducted by Access Australia—an association for fertility patients (Access Australia 2008). This survey revealed extremely low oocyte donation rates (2 percent) and a broad lack of preparedness among the 2,269 fertility patients surveyed to donate oocytes to research; however, the survey did not employ the required qualitative methodology to enable a deeper examination of the perceptions that lay behind the decision-making of potential donors. This needs to be redressed, as Australia is one of many countries that conduct stem cell research and is a key player in the international research context (Brown and Webster 2004, 72–73), where demand for research oocytes far outstrips supply (Ballantyne and de Lacey 2008; Roberts and Throsby 2008).

Ethics, Informed Consent, and Embodied Knowledge

With the developments in science and technology, ethical inquiry into necessary changes to the institutional establishment of values and morals is critical. Ethics attempts to analyse and reconcile conflicts

² One American study estimated the labour invested in donating eggs is around 56 h (Widdows 2009).

among the many values and rules for action. Informed consent is characterised as the solution to some problems associated with patients' participation in medical research or clinical trials (Corrigan 2003). A "fully informed" consent is that which is freely given, with full understanding, and without coercion (Corrigan 2003; Little 2009). The ethical ideals at the heart of informed consent include the disclosure of material information and ensuring comprehension or understanding, such as the subject's ability to weigh up outcomes and probabilities in the information provided (Little et al. 2008; Little 2009; Rid and Dinhofer 2009). However, it is through the concept of relational autonomy with regard to informed consent that it becomes increasingly clear that patients understand and make decisions about the associated written information as socially connected and culturally embedded family members or community citizens (Ehrich et al. 2007).

Relational autonomy characterises the social and interactional self as defined and redefined through relationships and interaction with other selves and institutions that the agent themselves did not create (Friedman 2000; Ehrich et al. 2007). It also highlights that our reflective capacities are "partly constituted by communal traditions and norms" (Friedman 2000, 41) and thus broadens discussions on informed consent from a position of decontextualised ethics to one which embeds patients in their social contexts and interpersonal relations throughout their decision-making (Corrigan 2003). Important to our present discussion on embodied knowledge and its role in informed consent, we connect how experiential knowledge generated from within the body is intimately connected with the subject's interaction with the social world and her position in a social context.

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 oocyte donation. 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). In harmony with this approach is that of Virginia Held, who argues for a moral inquiry that incorporates *actual* rather than *hypothetical* experience when choosing whether to act or to accept or reject moral positions (Held 1993). Held states that this will avoid the situation of a disembodied moral reasoning of "a view from nowhere" (Held 1993, 57–58). She goes on to explain that there is often a gap between the theory and

actual embodied experience of lived reality and, therefore, that moral theory needs to be tested in actual experience and then "be found satisfactory in the actual situations people find themselves in" (Held 1993, 23). In incorporating actual embodied experiences into moral deliberations, judgements will include feelings and particular circumstances, rather than assume a disembodied impartiality (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, which is personal, private, and known from within (Belenky et al. 1986). 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.

In settings outside the IVF context, research participants do not always clearly delineate between lay and expert knowledge and may frequently use a multitude of knowledge sources in decision-making (Belenky et al. 1986; Corrigan 2003; Wadsworth Hervey 2007; Markens et al. 2010). This multiplicity can be regarded as a strength; for example, gynaecological educators, as agents of medical instruction, have legitimately integrated their own embodied, experiential knowledge of the pelvic examination with the construction of the body-as-object as part of the formal training in gynaecological assessments by medical students (Underman 2011). Like other feminist researchers who position women's obstetric and gynaecological embodied experiences in relation to biomedical and techno-scientific epistemologies (e.g., Markens et al. 2010; Underman 2011), we do not wish to further dichotomise these different ways of knowing by pitting them against one another. Instead we seek to reveal the place of embodied knowledge *within* the rational and formalised 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).

This research takes a sociological approach to informed consent by drawing attention to different types of knowledge used to inform decision-making and by critically examining the rationalist epistemology that, for the most part, governs the consent process. 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 a relatively linear, smooth account

of the treatment trajectory (Franklin and Kaufman 2009; Rid and Dinhofer 2009). Although crucial to proper decision-making, this format risks sidelining the contribution of “tacit knowledge based on personal experiences” (Corrigan 2003, 777), “prior experiences and personal biography” (Corrigan 2003, 776), and the role of emotion and intuition (Little et al. 2008; Braude and Kimmelman 2010; Halpern 2010). It is this experiential, affective dimension of decision-making that we designate as embodied knowledge, including as it does the consequences of particular lived histories, desires, and fluctuations in health and illness.

We refer to two empirical studies that exemplify these theoretical concerns. The first is an investigation of patient consent to autologous stem cell transplantation for recurrent lymphoma (Little et al. 2008), an onerous and prolonged treatment. It revealed three important findings for the basic requirement of material disclosure in informed consent (Little et al. 2008, 627). First, “that personal experience of the ordeal of transplantation increases awareness of the limitations of conventional medical information” (Little et al. 2008, 627); second, that “it is not ... possible to convey the experience of any extreme treatment, however conscientiously the clinical staff may try” (Little et al. 2008, 627); and, third, that “material disclosure of the details of the transplant experience does not achieve the purpose of preparing patients ... for what it is actually like to go through the ordeal” (Little et al. 2008, 627). Similarly Haimes and Taylor’s (2009) in-depth interview study of 44 IVF patients’ experiences of being asked to donate fresh embryos to stem cell research reveals that asking patients to donate does not create harm, yet patients did not properly comprehend the significance of donating viable embryos until they had completed the first IVF cycle. These studies demonstrate that although a patient may be materially informed through the use of standard informed consent procedures, a patient can only be more fully informed in an embodied sense through the endurance of a particular treatment trajectory.

In many cases, of course, patients do not repeatedly endure a procedure, so the possibility of developing the kind of fully embodied informed consent described above does not frequently arise. However, in the specific case of oocyte donation during IVF, it is not unusual for patients to embark upon repeated fertility treatment cycles. In what follows, we consider how the specific features of IVF treatment lend themselves to an

embodied knowledge approach to consent and a more just and equitable form of decision-making. This has implications for other kinds of tissue donation and research participation, particularly where these involve repeat procedures.

Methods

This research is part of a study funded as a Linkage Project through the Australian Research Council, entitled “Human Oocytes for Stem Cell Research: Donation and Regulation in Australia.” Together with the industry linkage partner (a fertility clinic in Australia), the study seeks to identify the values, needs, and perspectives of potential oocyte donors, develop ethically robust regulation of oocyte donation for SCNT in Australia, and improve the social equity of oocyte donors in Australia. The primary methodology of this study involved in-depth semi-structured interviews based on a schedule of open-ended questions (Kvale 1996, 129). The interviews were conducted by the first author with two participant cohorts. Cohort one included 25 former patients of the fertility clinic, and cohort two included 10 current staff members of the clinic. Participants were recruited with assistance from the fertility clinic. The hospital-based ethics committee granted ethics approval for this research.

Cohort one included 20 female IVF patients and five reproductive oocyte donors, all of whom have experienced oocyte collection. The IVF patients had also experienced at least one full cycle of IVF treatment. Cohort one was identified using the fertility clinic’s patient database³ during two recruitment periods, one in 2009 and one in 2010. If patients received IVF treatment between January 2008 and February 2010 or acted as an oocyte donor for an IVF patient, they were sent a “consent for contact” package that included a letter of invitation to participate in the research, a research information statement, and a consent form.⁴ The interviews with cohort

³ The researchers did not access the database. Instead two senior and experienced clinicians accessed the patient database and provided the contact address details of potential participants. This yielded 585 potential participants.

⁴ Participant names were first screened by the fertility clinic’s senior nurse and counsellor to ensure that participants were not in need of an English translation service (26), living in a country location (42) that made it difficult to attend a face-to-face interview, or subject to a highly traumatic IVF experience (2). Participant response rate was 7 percent.

one were predominately conducted in the homes of participant, and lasted between 60 and 90 min. Of the 20 IVF patients, eight had not conceived a child and only one of those had reported discontinuation with IVF. Of the five reproductive oocyte donors, two had donated an oocyte that resulted in a pregnancy for the recipient couple.

The interview schedule for cohort one had four main segments. It began with an open question asking participants to share their experience of IVF treatments or oocyte donation.⁵ It then moved to an exploration of preparedness to donate embryos or oocytes to another couple for the purposes of conceiving a baby or to scientific research. This was followed by participants responding to a variety of international incentive models for oocyte procurement. These were named “compensation,” “payment,” and “egg sharing.” We will now briefly outline these.

Compensation

The “compensation” models presented to participants were the current U.K. and Australian models whereby non-patient donors in the United Kingdom received compensation of up to £250 of direct expenses incurred (Waldby 2008, 19) and Australian donors received the “reimbursement of reasonable out-of-pocket expenses associated with the procedures ... [but not] the compensation of time” (National Health and Medical Research Council 2007, 68).

Payment

The payment models presented to participants were based on the market model of the United States reproductive oocyte donation market, in which some young and fertile women can earn between \$10,000 (U.S.) and \$40,000 (U.S.) for their donation. The second payment model presented was the recent ruling in New York State, where research oocyte donors can receive up to \$10,000 (U.S.) “for the expense, time, burden and discomfort associated with the donation process” (Empire State Stem Cell Board 2009, 1).

⁵ Participants were recruited from a clinic that does not undertake oocyte harvesting for research purposes. Participants in both cohorts were asked to respond to hypothetical scenarios rather than report directly on experiences of research oocyte donation.

Egg-Sharing

The egg-sharing model presented to participants is that currently used by the Newcastle Fertility Clinic in the United Kingdom (Murdoch 2008), the details of which have already been discussed in this paper. The interview schedule concluded by asking participants to think about broad ethical regulation or policy implications for donating oocytes for stem cell research in Australia.

Cohort two included 10 health professionals (six nurses, one counsellor, and three scientists) who work in the fertility clinic. This cohort 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 and clinicians were welcome to approach the researcher or their clinical team leader if they were interested in participating.⁶ The interviews with cohort two were conducted in the IVF clinic and lasted between 30 and 60 min. The interview schedule for cohort two was similar to that of cohort one, except that questions relating to issues of working within fertility treatment and with oocyte donors replaced the questions on experiences of IVF treatment.

All interviews were transcribed verbatim by a professional transcriber and checked by the researcher. Data analysis was conducted by the same researcher and followed a grounded and emergent thematic coding method (Boyatzis 1998) using NVivo software. For the purposes of this paper, the empirical focus is on egg donation within the general context of participants’ experiences of receiving or providing IVF treatment. We also draw on participant responses that are particular to the egg-sharing model used in the United Kingdom. The dominant themes emerging from this data structure the following section of this paper. All names used are pseudonyms.

Desire, the Technological Fix, and the Promise of Cure

We begin the empirical section of this paper by framing it with the broad experiences of our participants as consumers of fertility treatment. The deliberate seeking

⁶ Recruitment did not involve an individual approach by the researcher to potential participants. Only upon the expression of written interest did the researcher contact participants (during normal work hours).

of treatment for suboptimal fertility or infertility forms the context that informed participants' decisions about egg donation during fertility treatment. Illness (as opposed to disease) is defined as the subjective experience of a malfunctioning body and the seeking of treatment to rectify it (Lupton 1994, 93). Illness can also be reshaped as a disease through a medicalised or scientific diagnosis that subsequently enables it to be treated (Lupton 1994). For many infertile couples, the diagnosis of suboptimal fertility or infertility opens the door to IVF treatment that, in turn, offers a solution. This scenario is typical of what Arthur Frank calls "the plot of the restitution" (1995, 77), an illness narrative that has as its basic storyline, "yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (Frank 1995, 77). In applying Frank's work on illness narratives to IVF treatment, it becomes clear that IVF redefines infertility as a temporary state, fixable through the actions and control of medical regimes. IVF clinics and drug companies certainly project this simplified narrative (Lupton 1994, 157; Franklin 1997): "[T]he focus on success rather than failure is ubiquitous in IVF discourses" (Roberts and Throsby 2008, 162). This is despite fairly low success-rates: There is only a 20–30 percent chance of pregnancy per IVF cycle for a woman in her 30s, odds that decline sharply with each year of age (Gunby et al. 2010).

Although our interviewees were presented with such statistical information at the outset of their treatment, it is evident that they interpreted this apparently neutral information in decidedly non-neutral ways; they inflected information through the optic of their own desires—the hope that undertaking IVF would give them a child. Many commenced IVF or reproductive donation programs thinking that pregnancy would be achieved in the first treatment cycle. They typically overestimated the capacity of the technology to compensate for their (or their partner's) declining biological fertility and were surprised to find that they could find themselves on the wrong side of the fertility odds. The following extracts demonstrate this.

We obviously didn't think it was going to take us thousands and thousands of dollars! You think you're going to get one, first go (Rebecca, IVF patient, married with two children).

I think the first time ... you're really kind of ... blinded to what IVF can be (Mira, IVF patient, married with one child).

I rationally knew that it didn't always work and that there could be issues, but emotionally I thought, "Oh this is going to work!" So I guess that was the disconnect there, in a way ... so maybe I wasn't being as realistic as I could be (Jenny, egg donor, married with two children).

I really—I looked at the statistics and everything, so I didn't go in blind, but I thought, "Oh, I'll be one of the, whatever it was, 20-something percent: No, I'll be one of those." And the people it doesn't work for, well they must have other ... serious issues. ... But that's not necessarily the case: There's lots of people that go through without success and it's not necessarily explained (Mandy, IVF patient, married and childless).

The portrayed simplicity of the IVF journey is pervasive, enhanced by patients' desperation for pregnancy (Katz Rothman 1989; Franklin 1997). Mandy's account is typical of the reluctance of even well-informed patients to let go of the hope of immediate or eventual success (Franklin 1997, 108). When the body has lost its control, such as during illness, one may approach medicine to control the situation (Frank 1995, 30). For example, "arriving at an IVF clinic ... symbolizes a positive step forward, even a relief" (Roberts and Throsby 2008, 161–162) and the technical promise of IVF appears to improve choice (Katz Rothman 1989). Yet the experiences of women undergoing IVF demonstrate that there is still a lack of control over fertility. Patients leave the bleak state of infertility and enter a state of potential fertility, contingent on many factors, a state that, as we will show, has marked implications for informed consent for oocyte donation.

Uncertain Egg Fertility and Diminishing Viable Reproductive Material

The amount of viable reproductive material available for treatment diminishes as an IVF treatment cycle progresses. To present a fairly typical scenario: Women may start out with 25 oocyte follicles, while 20 oocytes may be collected, 10 may fertilise in vitro and become embryos. Only five embryos may develop sufficiently for implantation in utero, and then the best one or two embryos are selected by scientists to be

transferred back to the woman. Two patient accounts below exemplify this diminishing availability of viable reproductive material, while the second account demonstrates that even if an embryo has been successfully cultivated and transferred in utero, there are still many obstacles to a full-term pregnancy and healthy birth:

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).

Then the second [IVF cycle] was something like nine [eggs] out, six fertilised, and four grew to blastocyst stage. One in—miscarriage; one in—miscarriage; two in the freezer (Caroline, IVF patient, married and childless).

The accounts of IVF clearly demonstrate the collective contingencies of the body, in vitro tissue growth, and pregnancy outcomes during treatment. We argue that such contingencies need to be taken into account when considering egg-donation during fertility treatment. Oocyte donation is particularly consequential because it diverts reproductive material at the beginning of the *ex vivo* process and, because the fertility of any given oocyte is unknown prior to actual fertilization, the patient cannot calculate the effects of such diversion on down-stream treatment processes.

Experience Mediates Donation Decisions

Our interview data indicates that it is only after women directly experience this dwindling of apparent reproductive potential, from many follicles to fewer *ex vivo* oocytes to even fewer fertilised embryos (or none at all) to full-term pregnancy (or miscarriage), that they really begin to understand the poor odds of IVF success and the ways their oocytes set the parameters for the rest of the process. This deficit spiral of reproductive material was neither expected nor comprehended by IVF patients at the outset of treatment. The following extracts reveal how the subsequent experience of IVF treatment and its unpredictable outcomes mediate pre-treatment expectations and beliefs about the powers of IVF.

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. It's 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, IVF patient, married and childless).

I just thought, "IVF? Oh, that's serious. Oh well, like that'll definitely work because there's nothing wrong with us and so it'll work first time!" ... But then when that IVF didn't work, that was a huge shock, because I had just thought, "Well there's no chance of that not working; it's probably more than we need, so it'd have to work." And it didn't. That was the biggest shock (Mandy, IVF patient, married and childless).

Reproductive oocyte donors and fertility clinic staff also recognise the importance of patients' direct experience of IVF's contingency, in order to fully comprehend the process and make informed donation decisions:

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 [IVF] 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). 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).

You have to have a little bit of experience to really understand it (Rena, social worker).

Importantly, as our data indicate, this realisation of contingency and risk is generally accomplished, not through the interpretation of statistical evidence, but through direct experience of an IVF cycle.

Precious Eggs: The Pregnancy Prerogative

The overwhelming majority of women interviewed after their IVF treatment stated that they needed to

retain all of their own oocytes for fertility treatment. After their IVF treatment experience, they no longer subscribed to the restitution narrative of infertility. They feared that any oocytes donated to stem cell research *might* include “the one” oocyte that would become a baby. As oocytes had to be donated prior to the establishment of their fertility, they concluded that their oocytes were far too precious to give away.

For me, no! Look, maybe ... having gone through the process, maybe the first time, and not being fully aware of, as I say, how precious they are... it might have been a consideration then. Certainly not now! (Dominique, IVF patient, married and childless).

I’m not going to put my body and emotion and time through that just to give it away. They’re too precious, when you’re going through IVF, to do that (Caroline, IVF patient, married and childless).

Their embodied experience of IVF contingency became either a more persuasive source of evidence than the statistical information they had read or acted as supporting evidence that made the statistical evidence of IVF pregnancy rates more accessible or real. Fresh embryo donation suffers the same complication as oocyte donation. It is impossible to fully know which tissue would result in successful reproduction in advance of its donation, therefore quality tissue that has a potential reproductive future risks being cast off on a separate journey to the world of research (Haimes et al. 2008; Haimes 2009).

Our interviewees were not confronted with the kinds of difficult choices presented to women trying to decide to enter an egg-sharing arrangement. Egg-sharing patients enter a perilous situation in which they will “lose” in their exchange (Roberts and Throsby 2008). In other words, by trading oocytes for research in return for treatment, it is highly likely that women will not achieve their primary goal: pregnancy. Roberts and Throsby argue that,

[w]hile the procurement of ... failed-to-fertilise eggs takes place after they have been deemed unusable for treatment, the extraction of eggs prior to their reproductive (non)value to the

woman herself being established ... raises the question as to why anyone undergoing fertility treatment would donate eggs potentially useful for their own treatment (2008, 167).

We asked our interviewees their perceptions of egg-sharing.

I have nothing against egg sharing, except you’d be pretty mad if ... you’d donated eggs and discovered somewhere along the way that your embryos didn’t produce anything, and you’d given away the ones that did (Philippa, IVF patient, married with one child).

I’m going though this whole process to have a baby and if that’s [egg-sharing] going to halve my chances ... for research, then no (Dominique, IVF patient, married and childless).

In fact, of the 20 IVF patients we interviewed, only two stated that they would consider egg-sharing. The experience of going through IVF mediates IVF patients’ perception of the likely success of treatment and the importance of every oocyte to that success. This embodied and personal experience is important information to be considered when deciding whether one would donate oocytes as part of their IVF treatment for SCNT research. Given this, IVF patients’ embodied knowledge needs to be at the core of informed consent for oocyte donation during fertility treatment.

Bringing Embodied Knowledge Into Informed Consent

Embodied knowledge involves a complex interplay between rationality and abstract understanding and more experiential, affective insights gained from phenomenal location within a social and material world (Weiss 1999). In the case of female IVF patients and donors who adapt to, act within, and interpret the constantly changing demands and contingencies of oocyte harvesting and IVF treatment, experience is a key knowledge resource that could be utilised when formally consenting to oocyte donation during fertility treatment. For most IVF patients and oocyte donors in our study, only the

direct experience of oocyte donation or undergoing a cycle of IVF led to an informed appreciation of the statistical odds of falling pregnant. Informed consent requires that participants have the capacity not only to understand information, but also to integrate it into decision-making regarding oneself (Iltis 2006). Patients asked to give consent to a procedure frequently fail to understand risk estimates and probabilities as they apply to their own situation (Iltis 2006, 184–185). In fact, “only with the benefit of hindsight ... when they [participants] know whether or not a risk materialized and ... how it affected them are most people able to assess whether it was ‘worth it’ to assume a risk” (Iltis 2006, 185–186).

We can see this gradual process of sense-making with regard to risk in the responses of our study participants. It was only after they had experienced the complex contingency of a treatment trajectory that they fully comprehended what the statistical odds meant *for them*. To put it another way, it was only the direct experience of their body’s limits, and the limits of the technology to compensate for their declining fertility, that fully communicated the qualitative, affective significance of statistical, quantitative information. The contingency of IVF treatment is exacerbated if fresh oocytes are donated, because the numbers of oocytes set the parameters for downstream chances at successful pregnancy, although they do this in highly unpredictable ways. The uneven and untestable distribution of fertility among any given batch of oocytes means that, in the eyes of IVF patients, any oocyte diverted to research donation could be “the one” oocyte that would produce a viable embryo for pregnancy.

In terms of informed consent, respecting the contingency of the IVF process, the embryo, and the body is key. In her embodied approach to ethics, Wadsworth Hervey focuses on the ways a person learns with his/her body (2007, 94). Using Arthur Frank’s work, she states: “[T]he ethical position is accepting one’s body as contingent upon and responsive to infinite variables” (Wadsworth Hervey 2007, 96). She distinguishes this ethical position from one that “strives for predictability through control” (Wadsworth Hervey 2007, 96). Arguably, the tendency to rely on linear, non-contingent accounts of treatment in the informed consent process inscribes an idea of the body that is inappropriately predictable. By comparison, this research has demonstrated how their experiences of

IVF enable women to accrue knowledge of the body’s contingency that they can utilise when deliberating over oocyte donation for stem cell research. This result challenges the notion of informed consent that relies solely upon material information derived from scientific rationality.

Conclusion

In the case of oocyte donation decisions during fertility treatment, an approach to informed consent that facilitates attending to one’s embodied experience would give formal recognition to the embodied knowledge and collective agency that many women across the world have developed from their experiences of IVF. When faced with the ethical challenge of choosing whether or not to provide oocytes for SCNT during fertility treatment, it makes sense that women first attend to their embodied experiences of IVF. In practice, this means that they should not be approached to donate research oocytes until they have experienced at least one cycle of IVF. This recommendation would not depart from the practical reality of IVF, in which most couples will undergo more than one cycle to achieve a live birth (Gunby et al. 2010). Australia operates within a system of partial public funding of IVF cycles through Medicare. However, the national differences in the financial accessibility of fertility services would need to be taken into account if our recommendation were to be implemented for fresh oocyte donation during fertility treatment. Nevertheless, the recommendation arising from our research is in harmony with findings from research conducted by Haines and Taylor (2009) in the United Kingdom on fresh *embryo* donation for stem cell research. They advise that these patients should not be asked to donate fresh embryos during their first cycle, both because it is characterised by many patients as stressful and confusing and because of the ways the meaning of the embryo changes as treatment progresses. Haines and Taylor argue that these experiences need to be considered before donation decisions are made, so that couples are more aware of donation consequences for themselves. Both our approach and that of Haines and Taylor involve the embodied ethics of accepting one’s body as contingent and responsive to the complex variables of IVF.

Recommendation

When faced with the ethical challenge of choosing whether or not to provide oocytes for SCNT during fertility treatment, women should not be approached to donate research oocytes until they have experienced at least one cycle of IVF.

Acknowledgements This research was funded by an Australian Research Council Linkage Grant (LP0882054). The authors would like to thank the participants for their involvement in the study and anonymous reviewers for their insightful feedback.

References

- Access Australia. 2008. The utilisation and meaning of human embryos and eggs: A survey of Access Australia members: A report of the access survey commissioned by the NHMRC. Access Australia.
- Ballantyne, A., and S. de Lacey. 2008. Wanted—egg donors for research. A research ethics approach to donor recruitment and compensation. *The International Journal of Feminist Approaches to Bioethics* 1(2): 145–164.
- Belenky, M.F., B.M. Clinchy, N.R. Goldberger, and J.M. Tarule. 1986. *Women's ways of knowing: The development of self, voice, and mind*. New York: Basic Books.
- Boyatzis, R. 1998. *Transforming qualitative information: Thematic analysis and code development*. London: SAGE publications.
- Braude, H., and J. Kimmelman. 2010. The ethics of managing affective and emotional states to improve informed consent: Autonomy, comprehension, and voluntariness. *Bioethics*. doi:10.1111/j.1467-8519.2010.01838.x.
- Brown, N., and A. Webster. 2004. *New medical technologies and society: Reordering life*. Cambridge: Polity.
- Check, E. 2006. Ethicists and biologists ponder the price of eggs. *Nature* 442(10): 606–607.
- Corrigan, O. 2003. Empty ethics: The problem of informed consent. *Sociology of Health and Illness* 25(3): 768–792.
- Dickenson, D. 2006. The lady vanishes: What's missing from the stem cell debate. *Journal of Bioethical Inquiry* 3(1–2): 43–54.
- Dickenson, D., and I. Idiakez. 2008. Ova donation for stem cell research: An international perspective. *The International Journal of Feminist Approaches to Bioethics* 1(2): 125–143.
- Ehrich, K., C. Williams, B. Farsides, J. Sandall, and R. Scott. 2007. Choosing embryos: Ethical complexity and relational autonomy in staff accounts of PGD. *Sociology of Health and Illness* 29(7): 1091–1106.
- Embryo Research Licensing Committee of the NHMRC. 2008. Licence Number 309714. National Health and Medical Research Council.
- Empire State Stem Cell Board. 2009. Statement of the Empire State Stem Cell Board on the compensation of oocyte donors. http://stemcell.ny.gov/oocyte_donation.html. New York Stem Cell Science.
- Frank, A. 1995. *The wounded storyteller: Body, illness, and ethics*. Chicago: The University of Chicago Press.
- Franklin, S. 1997. *Embodied progress*. London: Routledge.
- Franklin, S., and S. Kaufman. 2009. Ethical and consent issues in the reproductive setting: The case of egg, sperm, and embryo donation. In *Tissue and cell donation: An essential guide*, ed. R. Warwick, D. Fehily, S. Brubaker, and T. Eastland, 222–242. Oxford: Wiley-Blackwell.
- Friedman, M. 2000. Autonomy, social disruption, and women. In *Relational autonomy: Feminist perspectives on autonomy, agency, and the social self*, ed. C. MacKenzie and N. Stoljar, 35–51. Oxford and New York: Oxford University Press.
- Gunby, J., F. Bissonnette, C. Librach, and L. Cowan. 2010. Assisted reproductive technologies (ART) in Canada: 2006 results from the Canadian ART Register. *Fertility and Sterility* 93(7): 2189–2201.
- Haimes, E. 2009. Fresh embryo donation for human embryonic stem cell (hESC) research: The experiences and values of IVF couples asked to be embryo donors. *Human Reproduction* 24(9): 2142–2150.
- Haimes, E., R. Porz, J. Scully, and C. Rehmann-Sutter. 2008. “So, what is an embryo?” A comparative study of the views of those asked to donate embryos for hESC research in the UK and Switzerland. *New Genetics and Society* 27(2): 113–126.
- Haimes, E., and K. Taylor. 2009. The contributions of empirical evidence to socio-ethical debates on fresh embryo donation for human embryonic stem cell research. *Bioethics* 25(6): 334–341. doi:10.1111/j.1467-8519.2009.01792.x.
- Halpern, J. 2010. When concretized emotion-belief complexes derail decision-making capacity. *Bioethics*. doi:10.1111/j.1467-8519.2010.01817.x.
- Held, V. 1993. *Feminist morality: Transforming culture, society, and politics*. Chicago: The University of Chicago Press.
- Ilits, A. 2006. Lay concepts in informed consent to biomedical research: The capacity to understand and appreciate risk. *Bioethics* 20(4): 180–190.
- Jaggar, A. 1993. Taking consent seriously: Feminist practical ethics and actual moral dialogue. In *Applied ethics: A reader*, ed. E. Winkler and J. Coombs, 69–86. Cambridge: Blackwell.
- Katz Rothman, B. 1989. *Recreating motherhood: Ideology and technology in a patriarchal society*. New York: W.W. Norton and Company.
- Kvale, S. 1996. *InterViews: An introduction to qualitative research interviewing*. California: Sage.
- Little, M. 2009. The role of regret in informed consent. *Journal of Bioethical Inquiry* 6(1): 49–59.
- Little, M., C. Jordens, C. McGrath, K. Montgomery, W. Lipworth, and I. Kerridge. 2008. Informed consent and medical ordeal: A qualitative study. *Internal Medicine Journal* 38(8): 624–628.
- Lupton, D. 1994. *Medicine as culture: Illness, disease and the body in Western societies*. London: Sage.
- Markens, S., C. Browner, and H. Preloran. 2010. Interrogating the dynamics between power, knowledge and pregnant bodies in amniocentesis decision-making. *Sociology of Health and Illness* 32(1): 37–56.

- Murdoch, A. 2008. *Information leaflet for egg sharing for research*. Newcastle upon Tyne: Newcastle upon Tyne Hospital.
- National Health and Medical Research Council (NHMRC). 2007. *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research*. Canberra: Australian Government.
- Nature. 2006. Safeguards for donors. *Nature* 442(7103): 601.
- Rid, A., and L. Dinhofer. 2009. Consent. In *Tissue and cell donation: An essential guide*, ed. R. Warwick, D. Fehily, S. Brubaker, and T. Eastland, 67–97. Oxford: Wiley-Blackwell.
- Roberts, C., and K. Throsby. 2008. Paid to share: IVF patients, eggs, and stem cell research. *Social Science and Medicine* 66(1): 159–169.
- Schneider, J. 2008. Fatal colon cancer in a young egg donor: A physician mother's call for follow-up and research on the long-term risks of ovarian stimulation. *Fertility and Sterility* 90(5): 2016.e1–2016.e5.
- Thompson, C. 2007. Why we should, in fact, pay for egg donation. *Regenerative Medicine* 2(2): 203–209.
- Underman, K. 2011. "It's the knowledge that puts you in control": The embodied labour of gynecological educators. *Gender and Society* 25(4): 431–450.
- Wadsworth Hervey, L. 2007. Embodied ethical decision making. *American Journal of Dance Therapy* 29(2): 91–108.
- Waldby, C. 2008. Oöcyte markets: Women's reproductive work in embryonic stem cell research. *New Genetics and Society* 27(1): 19–31.
- Waldby, C., and R. Mitchell. 2006. *Tissue economies: Blood, organs, and cell lines in late capitalism*. Durham: Duke University Press.
- Weiss, G. 1999. *Body images: Embodiment as intercorporeality*. London and New York: Routledge.
- Widdows, H. 2009. Border disputes across bodies: Exploitation in trafficking for prostitution and egg sale for stem cell research. *International Journal of Feminist Approaches to Bioethics* 2(1): 5–24.