



From altruism to monetisation: Australian women's ideas about money, ethics and research eggs



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ABSTRACT

We report the results of a qualitative study carried out in metropolitan Australia between 2009 and 2011 that canvassed the issue of payment for research oocyte donation with participants drawn from three potential donor groups; fertility patients, reproductive donors and young, non-patient women. Research oocytes are controversial tissues because women around the world have proved largely unwilling to donate them altruistically. In the ensuing international debate about procurement, the issue of money and its appropriate and inappropriate uses in tissue donation has taken centre stage. While there is now an abundance of expert commentary on this matter, there are almost no studies that probe this issue with potential donor populations. Our study asked the three groups of women about their understandings of altruistic, reimbursed, subsidised, compensated and paid donation for both reproductive and research eggs. We identify a resistance to the introduction of money into the sphere of reproductive donation, which the majority of respondents felt should remain an area of personalised gift relations. In the area of research donation we find a strong relationship between degrees of *liquidity* (the extent to which money is constrained or unconstrained) and a sense of ethical appropriateness. We also describe a culturally specific sense of fairness and equity among participants, associated with the relatively high public subsidisation of fertility treatment in Australia, which they used to benchmark their sense of appropriate and inappropriate uses of money. While the participant responses reflect the regulatory environment in Australia, particularly the absence of a US style market in reproductive oocytes, they also make an important contribution to the global debate.

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Introduction

Since the mid-twentieth century in the advanced industrial nations, two methods have been used to procure human tissues for research. The first is altruistic donation through formal consent. The second is the harvesting of so-called 'abandoned' or 'waste' tissue, left behind in the clinic after surgical procedures, diagnostic tests or biopsy, in which the patient is assumed to lack interest. While regulatory reform and increasing concern over patient's rights have made the category of abandoned tissue more residual, for the most part the principle of *altruistic* donation for public benefit remains intact, despite assorted controversies over the patenting or commercialisation of human tissues *after* donation (Waldby & Mitchell, 2006).

In this paper we will examine a kind of research tissue that has proved inaccessible to these two procurement systems: human oocytes. Since the development of mammalian cloning and human embryonic stem cell lines in the late 1990s, human oocytes have become objects of intense scientific interest. Oocytes are essential elements in a type of stem cell research termed somatic cell nuclear transfer (SCNT), which, in theory at least, could be used to produce patient specific tissues suitable for transplant. In SCNT, a nucleus from a patient's body cell, such as a skin cell, is introduced into an unfertilized oocyte from which the original genetic material has been removed. The oocyte is then used to produce a blastocyst (an early embryo) whose stem cells could be used to create tissue that would be compatible with that of the patient. Human SCNT research remains highly experimental. The first human embryos were generated through somatic cell nuclear transfer in 2013 (Tachibana, Amato, et al., 2013) and considerable research will be required before clinical applications are feasible. This research requires large numbers of fresh, unfertilised oocytes, as techniques are developed and refined. However, clinics that have attempted to

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secure strictly altruistic donation report either complete failure or very small numbers (Baylis & McLeod, 2007).

The reasons for this are complex, but the succinct explanation is that oocytes do not readily constitute a *surplus* tissue for women. Historically the system of altruistic donation, such as blood donation, depends on the donor being able to readily part with the material, in both a biological and a social sense. They are both healthy enough to do without the tissue, and the method of donation itself is tolerably simple and without significant risk. In practice the determination of what counts as a surplus is often very involved, and intimately tied into broader social systems of equity and inequity (Waldby & Mitchell, 2006). Surpluses can be elicited as an effect of power relationships, particularly those associated with poverty. Hence we see the phenomenon of live kidney vending, where the precarity of the seller forces them into exchange for money, to the detriment of their health (Cohen, 2001).

Even in more equitable circumstances, the determination of a tissue surplus is not necessarily transparent. For example, recent research into the ways couples in fertility treatment designated their embryos as available for research donation, found that it depended on a multitude of factors including; the clinic freezing policies, its facilities for blastocyst culturing, grading procedures, and the woman's age and risk for pregnancy complications (Scott, Williams, et al., 2012). Nevertheless, this formulation has largely been successful in securing altruistic donations of embryos to stem cell research (Parry, 2006).

However, the biological and social qualities of oocytes do not readily lend themselves to altruistic donation. Both IVF embryos and oocytes are onerous to produce, involving several weeks of hormonal treatment, clinic visits and surgical collection. Nevertheless, oocytes occupy a more critical position in the IVF trajectory. Their numbers and degree of fertility set the initial conditions for any chance at subsequent success in the creation of a child, and fertility patients express a strong preference to retain and fertilise them all, rather than divert them to research. Moreover, while a proportion of embryos are routinely frozen during a treatment cycle, and can be donated *after* treatment is completed, oocytes are used fresh and all at once. Hence, they do not lend themselves readily to deliberation, because they are not preserved over time (Waldby & Carroll, 2012).

A small number of empirical studies investigate altruistic oocyte donation, mostly for reproductive purposes, and they confirm both a low willingness to donate and something of a preference for reproductive over research donation. So, Byrd and colleagues surveyed 113 reproductive egg donors in the UK, and found that their overwhelming motivation to donate was a desire to help childless couples, with little interest in research donation (Byrd, Sidebotham, et al., 2002). Murray and Golombok in their UK study found that three-quarters of potential reproductive oocyte donors in IVF clinics changed their mind about donating after receiving information about the procedures (Murray & Golombok, 2000). An Australian survey of 2269 IVF patients found that only two percent had donated oocytes for research. The most common reason for not donating (48%) was a reduction in the number of eggs available for the respondents themselves to conceive (Access Australia, 2008). So we can see that women already in fertility treatment have proved unwilling to designate oocytes as surplus tissues and divert them from their own reproductive path.

Money and ethics debates

In short, the gift relation (Titmuss, 1997 [1970]), which underpins the statutory regulation of tissue transfer in West European, Canadian, Australian and many other jurisdictions, has failed spectacularly in the case of research oocytes. This failure has

thrown open the assumptions underpinning such regulation to unprecedented revision and debate. In particular, debate centres on the role of *money* in the regulation of supply. It is this feature of the debates which are perhaps most compelling for sociological and bioethical analysts, precisely because of the complex status of money in the history of post-war research ethics. Since the adoption of the Nuremberg Code, money has been allocated a highly circumscribed place among the standardised elements of bioethical reason. In the 1960's in particular, both sociologists and moral philosophers, most notably Titmuss (1997 [1970]), and Jonas (1969) argued forcefully that citizens should participate altruistically in research because they had a moral obligation to contribute to the public good. The approach to compensation was subsequently liberalised by Institutional Review Boards in the USA during the 1970s, partly to increase the number of participants for clinical trials and partly in response to the construction of this issue as simply a matter of informed consent (Lemmens & Elliot, 2001). However, compensation again became a matter of debate after 1980 following the death of Bernadette Gilchrist. Gilchrist was a National Institutes of Health nurse who was found to have concealed her history of bulimia from trial clinicians in order to receive payment made to trial participants (Kolata, 1980). Since then, money has been central to debates about 'undue inducement', and posed as a potential threat to the principles of autonomy, justice and consent (Emanuel, 2004; Halpern, Karlawish, et al., 2004).

It is notable that Georg Simmel, in his magisterial analysis *The Philosophy of Money*, also recognises this coercive and singular power. In his account, money facilitates *exchange*, changes in ownership and the transfer of a surplus from one party to another. It does this precisely in its role as incentive, forcing the less willing party into trade once the price point is sufficiently high. Money *disentangles* objects from their owners by providing equivalence, while also facilitating impersonal circulation (Callon, 1998). As Simmel (1990, 1900: 293) puts it, 'exchange itself is embodied in money'. Buyers and sellers strike price, complete their transaction and are quits. It is for this reason that money transactions are posed as the opposite of the gift relation, substituting an antagonistic commodity market for the ethically and socially preferable gift for the public good (Titmuss, 1997 [1970]; Waldby & Mitchell, 2006). Money transactions around tissues are further constrained by various Tissue Acts and Directives. For example, EU member states are signatories to the *Oviedo Convention* and the *EU Tissue and Cells Directive*, as well as various national statutes that prohibit the exchange of body parts for money (Council of Europe, 1997).

Hence, money may only be admitted into bioethical regulation in certain constrained forms that are understood to avoid the exercise of undue inducement and the formation of markets associated with frank monetisation. We refer here to the operation of money as pure liquidity, infinitely and instantly substitutable for other objects and infinitely mobile; the unconstrained conversion of assets into cash for example, or the striking of price purely as an effect of supply and demand, rather than the storing of value in more embedded forms. Liquidity is an expression of money's rapidity of flow, exchange and circulation (Bryan & Rafferty, 2013). Instead of this free, anonymous circulation of monetary value, money may be used in bioethical practice as *reimbursement*, the recovery of direct costs incurred in the act of donation (for example, travel costs) and the somewhat more vexed *compensation*. As a bioethical principle, compensation is intended to recognise less tangible costs to research participants, elements like inconvenience and risk, and to return the participant to a position of social and economic equilibrium through equivalent payment or in-kind services.

In the case of research oocyte procurement, however, the role of money, as compensation, as subsidy and as frank payment, has

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