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"Good mothering" or "good citizenship"? Conflicting values in choosing whether to donate or store umbilical cord blood

Porter, E., Kerridge, I., Jordens, C. (2012)

Abstract

Umbilical cord blood banking is one of many biomedical innovations that confront pregnant women with new choices about what they should do to secure their own and their child's best interests. Many mothers can now choose to donate their baby's umbilical cord blood (UCB) to a public cord blood bank, or pay to store it in a private cord blood bank. Donation to a public bank is widely regarded as an altruistic act of civic responsibility. Paying to store UCB may be regarded as a "unique opportunity" to provide "insurance" for the child's future. This paper reports findings from a survey of Australian women that investigated the decision to either donate or store UCB. We conclude that mothers are faced with competing discourses that force them to choose between being a "good mother" or fulfilling their role as a "good citizen". We discuss this finding with reference to the concept of value pluralism.

Keywords

Mothers, Umbilical cord, Tissue banks, Social values, Capitalism, Australia

Introduction

Mothering is widely regarded as a woman's most important task and is central to constructions of femininity (Gillespie 2000). Women are generally expected to ensure safe gestation and birthing and provide lifelong care for their children, and in many societies they are expected to fulfil this nurturing role to the exclusion of all other roles. The idea that women have a duty to be a "good mother" pervades many cultures and societies and the norms of good mothering shape decision-making about reproduction and health care. Many new social practices have been framed in terms of the extent to which they maintain or fail to maintain the values and norms of "good mothering". This is reflected in debates surrounding, for example, caesarean section (Bryant et al. 2007), breastfeeding versus bottle feeding, childhood obesity and food choices for children (Chapman and Ogden 2009; Rørtveit, Åström, and Severinsson 2009), and whether mothers should stay at home to raise children or return to work (Kahu and Morgan 2007; Johnston and Swanson 2006).

The most critical characteristic of being a good mother is the degree to which a mother acts to ensure the health and well being of her children. Kukla (2008) has noted that society measures motherhood

...by a set of signal moments we interpret as emblematic tests, and summations of women's mothering abilities. Mothers often internalize these measures and evaluate their own mothering in terms of them. These "defining moments" tend to come very early in the mothering narrative—indeed; several of them come during pregnancy or even before conception. (p. 69)

Women who satisfy the tests of mothering are celebrated for their commitment and success, while those who fail to meet these expectations are condemned. Mothering is thus regarded not simply as fulfilment of possibility, but as the willing acceptance of a responsible role that is enacted through a plethora of choices. Whilst it is surely a good thing that mothering is regarded as a choice for women rather than as their "biological destiny" (de Beauvoir 1976), the contemporary re-framing of the mothering role in terms of choices (rather than, say, rights) has repositioned women as consumers (Hausman 2008), exposed women to possible criticism for making the *wrong* choices (Solinger 1998) and thereby increased anxiety around childbirth options and antenatal care. Reproduction, gestation and childcare increasingly embody choices among goods and services which offer the promise of a healthy and happy baby and developing child: "reproduction has increasingly come to be constructed as a matter of consumption" (Taylor 2000),392). The pregnant body, therefore, has become a site for commercial opportunism and "good mothering" is increasingly seen as something enacted through purchasing decisions.

As women achieve equal rights as full citizens, they are expected not only to be good mothers but good citizens as well. Citizenship is defined, in broad terms, as what individuals are entitled to, and as what is expected of them, as a function of their membership of a particular community (Kymlicka and Norman 1994). Good citizenship is most clearly enacted through altruism—that is, through choices and actions that serve the wider public good. In the health and welfare sector, such choices and actions typically take the form of volunteering, participating in research and donating goods such as blood, tissue or organs to public "banks" for therapeutic or research purposes (Titmuss 1970; Valentine 2005; Waldby 2006; Wildman and Hollingsworth 2009). More recently, Waldby (2006) has argued that donating to public tissue banks qualifies one as a "good citizen" because it is a way of contributing to the collective good (Waldby 2006),58).

While the expectations associated with mothering and citizenship often coincide, there are situations in which they diverge. One such situation arises where parents must decide whether to bank or store their child's umbilical cord blood.

Until recently, umbilical cord blood (UCB) was routinely discarded as medical waste. During the 1980s, however, researchers discovered that it could be used as a source of stem cells for bone marrow transplantation. Since then, it has been shown that outcomes of transplants using cord blood in both children and adults are roughly equivalent to outcomes from transplants that use stem cells sourced from bone marrow or peripheral blood (Gluckman et al. 2011). Accordingly, a global network of umbilical cord blood banks has gradually been established in order to provide a ready source of stem cells for people in need of an allogeneic stem cell transplant.¹ UCB banks thus provide access to an important medical resource, and they have attracted large numbers of donations across the world: there are currently an estimated 600,000 UCB units stored in cord blood banks worldwide and over 20,000 units have already been distributed to transplant centres around the world for the treatment of both children and adults with haematological diseases (Gluckman et al. 2011).

¹ In an allogeneic transplant, a person receives tissue from someone else (i.e. a donor).

In recent years, a large number of commercial umbilical cord blood banks have appeared on the scene offering to store a child's cord blood for future autologous use.² Given current indications for autologous stem cell transplantation, a child is highly unlikely to need or benefit from a transplant of their own stem cells; s/he is much more likely to need cells provided by a donor (Armson 2005). The rationale for private cord banking is based largely on the potential future benefits of stem cell research and, in particular, regenerative medicine: the cord blood is stored in the hope that it may one day provide a safe source of cells that can be used to treat degenerative diseases such as diabetes, Parkinson's disease and dementia. Private storage of cord blood is thus marketed, in accordance with neoliberal principles, as a form of speculative "bio-insurance": the cord blood "account" offers the client personal bio security and personal risk management (Waldby 2006), 64). In effect, the prospective mother is asked to consider a future where their unborn is "at risk" and invest in the potential for transplantation and regenerative medicine in order to reduce that future risk. Thus, even before the child is born, mothers are invited to speculate over the price they would be prepared to pay to secure better health for their child in the future.

Critics of private cord blood banks argue that they threaten altruistic donation of umbilical cord blood to public cord blood banks (Beal and Aken 1992; Bordet, Kharaboyan, and Lebrun 2007; Kurtzberg, Lyerly, and Sugarman 2005; O'Brien, Tiedemann, and Vowels 2006; Samuel, Kerridge, and O'Brien 2008). This view is supported by the fact that there are an estimated 800,000 cords stored in private banks, which far exceeds that number of cords available for public access (Gluckman et al. 2011; Manegold et al. 2011). To date, however, there has been a paucity of empirical research into prospective mothers' motives for and decisions about opting either to donate or store UCB. On the basis of empirical research presented here, we will argue that the choice to bank or donate a child's cord blood creates a genuine moral dilemma for expectant mothers: Will they bank their baby's cord blood and fulfil their role as a "good mother" or will they donate to a public cord blood bank and fulfil their role as a "good citizen"? Competing discourses on cord blood banking and donation have in effect created a new "defining moment" in motherhood (Kukla 2008) one which is best understood in terms of value pluralism.

Methods

This paper is part of a study of ethical and legal issues surrounding the donation and storage of umbilical cord blood. It draws on responses to surveys of a representative sample of expectant mothers in the state of New South Wales, Australia, who have either donated their child's cord blood to a public cord blood bank or opted to store it in a commercial cord blood bank.

With assistance from the Sydney Cord Blood Bank (a public cord blood bank) and Australian Stem Cell Health Care (ASCHC) which operates two commercial cord blood banks (CellSense and BioCell), survey packs were mailed to women who had donated or stored cord blood in 2008 and 2009. Survey packs included a participant information sheet, a contact letter, and a pre-paid, addressed envelope for return of the survey. A total of 2014 surveys were posted, 1012 to registered cord blood donors and 1002 to clients of ASCHC. Donors completed and returned 412 surveys (41% response rate) and private banking clients completed and returned 392 surveys (39% response rate).

Among the survey questions, survey respondents were invited to explain in their own words why they made the choice either to donate or store their baby's cord blood. Of the 412 donors, 126 (31%) offered detailed comments. Of the 392 clients of Biocell or CellSense, 128 (33%) provided detailed comments. This paper is based on a qualitative analysis of these comments. (A full, quantitative analysis of the survey results will be reported elsewhere.)

² In an autologous transplant, a person receives their own tissue.

Respondents' comments were entered into code-and-retrieve software for qualitative analysis. The first author (MP) developed a coding framework using key terms in the survey such as 'donation', 'cord blood', 'private banking', 'decision making' and coded the data accordingly. Using an inductive analysis, "good citizenship" and "good mothering" were identified as frequently recurring themes, and a review of relevant literature suggested that these themes represented contested values. The authorship team worked towards an interpretive consensus of the participants' responses in the drafting of this manuscript.

Results

"Help anyone who needs it": UCB donation an act of good citizenship

Respondents who had chosen to donate their child's UCB to the Sydney Cord Blood Bank almost universally cited the importance of communitarian values and the desire to "save a child's life" as the main motivations for their choice:

"I decided to donate. I'm glad I did. The thought it may one day be able to save a child's life was very important to me". (Donor: 40-year-old, two children, university educated)

Other donors referred to their child's cord blood as a "priceless gift" and suggested that the act of donating was its own reward:

"My decision to donate our child's cord blood was based on my desire to do something good for someone else. It didn't cost me anything (apart from the time). It didn't hurt me or my child and the reward is that I know we have given a truly priceless gift to someone else – and so easily". (Donor: 33-year-old, two children, university educated)

Many respondents said that umbilical cord blood, like similar valuable medical resources, should be accessible to anyone who needs it:

"I donate blood on a regular basis. I donated cord blood for the same reason - to hopefully help someone else who needs it and if I or my family need blood hope that other people have donated so it's there if we need it." (Donor: 35-year-old, two children, university educated)

"Just in case my own child needs it": Private UCB storage as an act of good mothering

Whereas donors to the Sydney Cord Blood Bank emphasised the immediate and proven benefits of cord blood, clients of private cord blood banks were all apparently motivated by the possibility that their child might in future need their own UCB and benefit from its yet-to-be-discovered therapeutic potential. The obligation to protect one's child was evidently strongly felt, as indicated by clear expressions of anticipated regret at missing this opportunity:

"Our decision was not based on what is available (medical help) at the moment but what might be available in future. It is an insurance policy to the same extent, and you also do not want to blame yourself one day when research has moved on, and something actually happens to your child – to be told – if you only stored the cells!" (Private banking client: 37-year-old, one child, university educated)

"My main reason was for the possible unforeseen reasons. If my son needed it I would rather have it. I'd rather have it and not need it than need it and not have it" (Private banking client: 33-year-old, one child, high school education to year 10)

“My husband and I cannot believe that everyone doesn't take advantage of this service. We would never forgive ourselves if something happened to our son and we didn't have the stem cells to fix him.” (Private banking client: 39-year-old, one child, diploma education)

“It seems such a waste”: Collective anxiety over unused or discarded UCB

When participants were unable to donate their child's cord blood they often expressed concern about it being wasted – that they were simply “throwing it away”. Where donation to a public bank was not possible for logistical reasons, the reluctance to “waste” cord blood sometimes motivated the choice to store it in a private facility:

“I was certain I wanted to donate our cord blood to the public cord blood bank but this was not an available option at the hospital where I had my daughter. My only option was private cord blood bank which my obstetrician did not think was necessary. The money was not our concern in making the decision, but rather than waste this cord blood, we chose a private cord blood bank”. (Private banking client: 37-year-old, one child, university educated)

Whichever option they pursued, it was clear that many respondents had a strong belief in medical progress in general and the value of cord blood as a medical resource in particular:

“Of all my friends who have had children only one has donated cord blood to the public bank. No one else has heard of it. It is a shame that so much cord blood is wasted... You need some testimonials on them and some Australian photographs —not stock photos, real people. Let people who have been helped by stem cell research have their say. (Private banking client: 41-year-old, one child, senior high school education)

In summary, the survey respondents' explanations for why they decided to donate or store their child's UCB reflect social norms about what it is to be a “good mother” or a “good citizen”. They also reflect a belief that UCB is a valuable medical resource and so it *should* therefore be collected and utilised whether this be for public benefit or personal use.

Discussion

We asked a representative sample of pregnant Australian women about their motives for donating their child's umbilical cord blood (UCB) to a public cord blood bank, or paying to have it stored in a private cord blood bank. Of the 804 women who responded to the survey, 254 (32%) provided an explanation in their own words. Our analysis of these explanations found that women are faced with the decision to fulfil the role of “good citizen” by donating cord blood to public UCB banks for public access, or fulfil the role of “good mother” by banking it privately for the use by their child should s/he experience illness later in life. The importance of this decision is made even greater because of the belief that cord blood is a valuable resource and should not be wasted. Furthermore, the complexity of this decision is exacerbated by substantial practical and financial barriers and by misperceptions about the likelihood that (in particular) stored UCB will be used and will provide a medical benefit.

Cord blood, value pluralism and decisional regret

The choice to donate or store cord blood presents a major challenge for prospective parents, consumers, health professionals and policy makers because it entails choosing between two important competing values related to motherhood and citizenship. The participants in our study all recognised the potential for transplantation to provide enormous benefit for those suffering serious illness. They also recognised that transplant units rely on altruistic donation of cord blood to publicly

accessible umbilical cord blood banks. Cord blood banks (like blood banks more generally) were thus regarded as an important community resource, and as a marker of a functional community and a civil society. At the same time, however, mothers were compelled to consider the actual and possible future needs of their child, and consider whether their capacity to meet these needs would be compromised if they donated their cord blood for use by (anonymous) others. As the participants in our study made clear, uncertainty about the future and anxiety about ensuring that their child's best interests were secured often made decisions about cord blood donation and storage difficult, and these factors frequently motivated decisions to store privately as a form of "bio-insurance". And like life insurance or income insurance, the need for cord blood that compelled private storage was neither real nor immediate; but it was possible, if unproven and remote. Furthermore, unlike other forms of insurance, where a contract offers monetary reimbursement in the event of misadventure, private banks can provide nothing more than a "speculative investment" (Waldby, 2006, 64) and hope in possibilities yet to be realised in biotechnology and biomedical research. But as our data reveals, when couched in terms of the values and responsibilities of "good mothering", even this speculative investment is difficult to resist.

The situation that mothers confront when having to decide between donating or privately banking their child's cord blood is best explained by the idea of *value pluralism* (and *foundational value pluralism* in particular). According to value pluralism, the moral world is not reducible to one single value, one notion of "goodness", or one principle of action. This is a view common to the work of (among others) Berlin, Williams, Jarvis-Thomson, Taylor, and Stöcker (Berlin 1969; Stöcker 1992; Williams 1985; Taylor 1982; Thomson 1997). If there are many different moral values, furthermore, and if they are held to be equally fundamental or important, they may, at different times and in different circumstances, be incompatible or incommensurable.

What makes value pluralism so compelling, both in general terms and in relation to choices about cord blood, is that captures the complexity of the moral world and explains both the difficulty that people have in making rational moral choices, and their reactions to those choices (Gill and Nichols 2008). For if people have to choose between several different options, as is the case here, and if each option has different advantages and disadvantages and privileges different moral values, it is entirely reasonable that it is difficult to choose between them. Moreover, regret is inevitable because choosing one option over another entails that something of value is lost. (Stöcker 1992; Williams 1985)

While value pluralism appears to capture something of the complexity and richness of the moral world, it fails to explain *how* people choose between different, equally fundamental values. While our data do not allow us to interrogate exactly how the women who decided to donate or store their baby's cord blood weighed up the competing values of motherhood and citizenship, it is clear that the mere existence of competing values does not make choice impossible.

Those who argue in favour of value pluralism respond to this challenge to rational decision-making in two ways. The first is to suggest that there are a number of strategies that enable rational choices to be made between competing values of equal worth. These include *phronesis* (practical wisdom) (Nagel 1979); appeals to basic preferences and the capacity to act (agency) (Raz 1999); and reference to 'higher order' values or synthesising categories, such as 'goodness' or 'the good life'. The second response is to accept that there are some situations in which conflicts between values are irresolvable, or in which concepts are "essentially contested" (Gallie 1955), and that it is a mistake to expect that people can make completely rational decisions in such circumstances. Berlin (1969) and, Williams (1985) and others argue that while many apparent moral conflicts may be resolvable, the moral world is complex and challenging and there may be times where disagreement is inevitable and where it is neither possible nor desirable to search for simple solutions (Berlin 1969;

Williams 1985). Importantly, however, the fact that moral disagreement may be unavoidable does not mean that moral reflection is pointless, or that foundational values are somehow misplaced. Rather, the fact that different actions or decisions may not equally promote different values should remind us of the necessity for reflective consideration of the complex issues that surround our decisions (DePaul 2001). This, we suggest, is the case in decision-making about cord blood. For while it may not be possible to completely resolve the tension between the values of motherhood and citizenship, there is much to be gained by reflecting on which decision may benefit both one's own child and the community to which one belongs and depends on. Such reflection may lead one to consider the likelihood that a child will require their own cord blood to treat an adult-onset disorder, the threat to public cord blood banks posed by private banking, the genuine potential of regenerative medicine, and alternative models of cord blood banking that may enable both private storage and public donation.

Umbilical cord blood: from waste product to a commodity with "biovalue"

Over the past decade, developments in science and biotechnology have seen a growth in the utilisation and commercialisation of biological "waste" (Annas 1999; O'Brien, Tiedemann, and Vowels 2006; Waldby 2006), including pathology specimens, tumour tissue, bone, menstrual blood, and cord blood. Umbilical cord blood, in particular, is now seen as a valuable biomaterial, both because it provides a source of haematopoietic stem cells that can be used to treat various malignant and non-malignant conditions that affect both children and adults, and because it may provide the substrate for cellular therapies and regenerative medicine. Public education and promotional material generated by both commercial and public cord blood banks have instilled in the public consciousness the idea that cord blood is a useful and therefore valuable commodity and this has completely changed the way in which cord blood is viewed. Given this, it is unsurprising that irrespective of whether the mothers in our study preferred to donate or store their baby's cord blood, all were convinced of its value and were therefore concerned about "wasting" it. Our participants said that cord blood should not be "wasted" (i.e. "thrown in the bin") but should either be collected and used to meet a defined clinical need or stored for a future time when bioscience confirms its regenerative or therapeutic potential. This discourse of biovalue (Waldby 2006) and the concomitant anxiety over "wasting" it are, therefore, clearly dependent both upon developments in science and on the public discourse surrounding science. It is thus vulnerable to rhetoric that exaggerates utility (and thereby anxiety), and to promotional messages that are designed to increase consumption of biotechnology.

Conclusion

Stakeholders and medical professionals who are keen to harvest cord blood for therapeutic or commercial purposes have helped to generate public anxiety about the potential waste of a biomaterial that could otherwise be used (as they understand it) to "help others", "save a life" or "protect a loved one against future risks". The choice that expectant mothers now face if they wish to avoid "wasting" their child's cord blood - that is, to donate or store it rests on an uncomfortable choice between an act of civic responsibility borne of a desire to help others (Titmuss 1970) and an act that promises to ensure (and insure) the health and well-being of a loved child. While this dilemma must ultimately be resolved at the level of individual choice, policy makers and healthcare providers can assist parents to reflect on the information and values that inform these choices by ensuring that information about cord blood banking and donation is accurate, that the benefits of each option are not overstated, and by encouraging open and critical discussion of the issues. It would not serve the interests of neither expectant mothers nor the wider community to turn cord blood banking into a new front in the "birth wars" (MacColl 2009).

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