
Racially conditional donation: The example of umbilical cord blood

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While direction of donated tissue to family members has long been accepted, direction to members of specific racial groups has been opposed, on the basis that it is discriminatory and contrary to the ethos the institution of organ donation seeks to promote. It has, however, recently been proposed that racially conditional donation may provide a useful – and ethically acceptable – way to address the social inequalities and injustices experienced by certain cultural groups. This article examines the ethical, legal and cultural arguments for and against racially conditional donation, concluding that the practice is more likely to undermine the values of equity and justice than to promote them and that it may also lead to other unfavourable personal and social outcomes.

INTRODUCTION

Allogeneic haematopoietic stem cell transplantation is a potentially curative therapy for many malignant and non-malignant conditions, including leukaemias, lymphomas, bone marrow failure syndromes, haemoglobinopathies, immunodeficiencies and inborn errors of metabolism. Stem cells for transplantation can be sourced from donor bone marrow, peripheral blood or umbilical cord blood. However, this procedure is only an option for a patient in need of a transplant if a donor with a suitable immunological match (referred to as a “human leukocyte antigen match”) can be found. There is wide variation in human leukocyte antigen “types” in the community and the chance of finding a matched donor is highest within one’s own family. Unfortunately, only 25-30% of patients have a suitably matched family donor, meaning that the majority of patients must rely upon the identification of suitably matched unrelated donors from international bone marrow donor registries and publicly accessible umbilical cord blood banks. But despite the fact that there are now almost 14 million adult volunteers registered on these registries worldwide and an estimated 600,000 umbilical cord blood units available through a global network of cord blood banks,¹ it remains the case that for some patients a suitably matched donor will not be found.

While human leukocyte antigen variation between individuals (when defined at the molecular level) means that identifying a suitably matched donor is always a challenge, this is even more problematic for patients from indigenous and ethnic minority communities. This is primarily because ethnic minorities are usually poorly represented in donor registries and public umbilical cord blood

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¹ Gluckman E, Ruggeri A, Volt F, Cunha R, Boudjedir K and Rocha V, “Milestones in Umbilical Cord Blood Transplantation” (2011) 154 *British Journal of Haematology* 441; Bone Marrow Donors Worldwide (BMDW) website, <http://www.bmdw.org> viewed 28 October 2011.

banks, limiting the chances of finding a donor with a matching genotype. In fact, as most volunteers on the United States, European and Australian Bone Marrow Donor Registries and public umbilical cord blood banks are of North Caucasian descent, there is a powerful ethnic bias in these registries and banks that makes transplantation a much less likely therapeutic option for patients from non-Caucasian and indigenous backgrounds. (In general terms, patients of North Caucasian ethnicity have a likelihood of finding a suitably matched donor of approximately 60-80% whereas those from indigenous, Asian or Indian populations have a likelihood of finding a donor of less than 30%.)² This inequity is of particular concern in the United States, Australia and Canada, which have significant indigenous populations as well as many citizens who have immigrated from Asia, the Middle East and South America or are of mixed ethnic backgrounds. What makes this inequity even more disturbing is that it has persisted, despite the establishment of umbilical cord blood banks which it was hoped would help increase the number of stem cell donors from indigenous and non-Caucasian populations, and despite efforts by cord blood banks to increase donations from these populations through establishment of banks and collection centres in areas of high ethnic diversity and through education campaigns aimed at those populations under-represented in public umbilical cord blood banks.

DIRECTED AND CONDITIONAL DONATION OF HUMAN TISSUE

In response to the problem of the limited availability of tissue for haematopoietic stem cell transplantation for under-represented racial groups, it has been proposed that donation of regenerative, non-regenerative and post-mortem tissue by members of these groups might be increased by adopting a system allowing “directed” and “conditional” donation.³ Directed donation covers various types of donation, including *familial-directed donation*, where there is a direct donation of tissue from the donor to a relative or friend, and *non-familial directed donation*, where individuals directly donate to other persons with whom they have no previous relationships, normally because they have heard of the plights of those persons through the print or television media or the internet,⁴ or have been approached by “tissue-sharing” groups, such as LifeSharers, soliciting donations.⁵

Familial-directed donation of solid organs is common in the United States, United Kingdom and Australia, particularly for living donations. The donation of bone marrow is also commonly familial-directed. With respect to cord blood, in Western countries there has been a proliferation of private cord banks, with parents often encouraged to store their children’s umbilical cord blood in private banks for possible later personal or family use. It has been argued that familial-directed donation is ethically acceptable because it is consistent with obligations imposed and mandated by family relationships.⁶

Non-familial directed donation is less common and is considered by some to be ethically more problematic. This is primarily because it may be used to circumvent attempts by authorities to ensure transparent and objective criteria for selection of recipients, leading to “queue-jumping” by those who claim to have the most tragic stories.⁷ Nonetheless, non-familial directed donation is legal and is practised in most common law jurisdictions.

Both familial and non-familial directed donation can be compared with “conditional donation”. The latter can be of two kinds:

- *conditional directed donation*, where either a familial or non-familial directed donation is made on certain conditions, such as that the recipient must also promise to donate her or his organs to

² Samuel GN, Kerridge IH, Vowels M, Trickett A, Chapman J and Dobbins T, “Ethnicity, Equity and Public Benefit: A Critical Evaluation of Public Umbilical Cord Blood Banking in Australia” (2007) 40 *Bone Marrow Transplantation* 729.

³ Arnason WA, “Directed Donation: The Relevance of Race” (1991) 21 *Hastings Center Report* 13.

⁴ Truog R, “The Ethics of Organ Donation by Living Donors” (2005) 353(5) *NEJM* 444 at 445.

⁵ See the discussion of LifeSharers in Murphy TF and Veatch RM, “Members First: The Ethics of Donating Organs and Tissues to Groups” (2006) 15 *Cambridge Journal of Healthcare Ethics* 50.

⁶ Kluge E-HW, “Designated Organ Donation: Private Choice in Social Context” (1989) 19 *Hastings Center Report* 10 at 12.

⁷ Murphy and Veatch, n 5; Truog, n 4 at 445.

a particular individual or identified member of a group (such as occurs in LifeSharers) or promise that someone he or she knows will donate organs to an identified member of a group (as in paired kidney exchanges); and

- *conditional non-directed donation*, where the donor makes a donation, not to an identified individual or identified member of a group but rather to a class of possible recipients who are defined by the donor's preferences. Although in principle these preferences may be based upon any criteria, in practice they tend to be religious, sexual, cultural or racial. This article is concerned primarily with conditional non-directed donation where the donor has adopted race as the criterion upon which to find a recipient. This type of condition is referred to here as a *racially conditional donation*.

Both conditional directed and conditional non-directed donations raise significant ethical issues. There is undoubted widespread support for types of conditional directed donations, such as paired kidney exchanges, because of their perceived ability to increase the number of available organs while at the same time minimising risks of coercion and commodification. On the other hand, there are types of conditional non-directed donation which are widely condemned, both from legal and ethical perspectives, because they involve decisions which many regard as discriminatory. Two examples illustrate this problem: that of Thomas Simons, a Ku Klux Klan member who died in the United States in 1994 during a failed robbery and whose family would only agree to donate his organs to white people;⁸ and that of a donor family in the United Kingdom in 1998 which sought to consent to organ donation restricted to "non-ethnic" recipients.⁹ In both cases the organs were accepted on these terms but went to the recipients who would have received them anyway, even without the conditions attached. However, the public outcry that resulted led to the adoption of policies in both the United States and the United Kingdom expressly forbidding conditional non-directed organ donation.¹⁰

In spite of these misgivings about conditional non-directed donation, it continues to be practised, at least occasionally. In fact, the New South Wales Government recently made it legal for donors to impose conditions on who might receive donated sperm and ova. The *Assisted Reproductive Technology Act 2007* (NSW) allows gamete donors to control who can have access to their gametes and embryos for either reproduction or research. According to this Act, donors are permitted to discriminate against potential recipients on any basis, including race, ethnicity and sexual preference. It appears that this change was motivated by two goals: on the one hand, to protect donors' procreative freedom to choose who will parent their biological children, and on the other, to increase the number of donors, which had been falling, possibly owing to the legal removal of donor anonymity.

ARGUMENTS FOR AND AGAINST RACIALLY CONDITIONAL DONATION OF UMBILICAL CORD BLOOD

The arguments concerning the acceptability or otherwise of racially conditioned donation of tissues fall into two broad categories, and refer either to the interests or rights of individuals, or to social and cultural factors.

It is argued by proponents of racially conditioned donation that allowing donors to choose this type of donation is a way of respecting their right to control their own tissue. From this perspective, it is claimed that while common law prevents people from "owning" their tissue in a legal sense, regulatory regimes should still recognise and respect the moral choices of tissue donors, as is the case with the recent New South Wales legislation mentioned above. If it is considered both morally and legally acceptable for a donor to exercise racist values during directed donation it would – according to this view – be irrational to prevent her or him from making such choices in non-directed donations.

A related argument refers to the widely accepted right of individuals to decide who receives gifts they may wish to make. It is generally accepted that tissue donation is a kind of gift from one

⁸ The case has been widely discussed. See Murphy and Veatch, n 5 at 50.

⁹ See United Kingdom, Department of Health, *An Investigation into Conditional Donation: Report of the Panel* (2000); Wilkinson TM, "Racist Organ Donors and Saving Lives" (2007) 21(2) *Bioethics* 63.

¹⁰ United Network for Organ Sharing website, <http://www.unos.org> viewed 28 October 2011.

individual to another. From both legal and ethical points of view, individuals are entitled to be as capricious as they like regarding the disposition of their property. Indeed, it is a familiar reality that gifts are bestowed with conditions all the time and there is no evidence of disquiet about this from either a legal or cultural perspective. It may be noted that, from a strictly legal perspective, although in principle the respect could be limited by public policy and the rules regarding certainty of vesting, it is clear (in the United Kingdom and Australia at least) that racial conditions placed on gifts will almost invariably be upheld.¹¹

A further key argument in favour of racially conditional donation is that it is likely to generate socially beneficent outcomes by increasing the donor pool from unrepresented groups, thus helping to redress the current racial biases in umbilical cord blood banking. According to this view, a policy that establishes a clear principle of respect for the free choice of donors is likely to make potential donors feel more confident and supportive of the principle of donation in general, as a result of which they will be more inclined to donate. Many unrepresented groups have had bad experiences relating to medical management and control of their tissues: eg, Aboriginal Australians have a long history of fighting for the return of ancestral remains held as exhibits in Australian and British museums. Increased control by donors over their donated tissue, it is argued, would help to redress these injustices and reduce fear and misunderstanding about why health authorities wish to take and store umbilical cord blood.

As an immediate and obvious consequence of this, it is claimed, racially conditional donation may contribute, at least in part, to overcoming the existing racial biases in umbilical cord blood banking. This would be a desirable outcome, because it would redress inequities in the existing system, but what is more, it would be achieved – according to this view – without causing any harm to other members of society. From this perspective, it is clearly better to have umbilical cord blood donated, and thus potentially save lives, than not to have umbilical cord blood donated at all. Furthermore, because the umbilical cord blood would rarely be of use to people outside the ethnic group of the donor owing to close correspondence between human leukocyte antigen-matching and race, any increases in availability of umbilical cord blood would automatically go to members of the same ethnic group, and this would mean that any conditions that appeared to discriminate against – rather than in favour of – a particular group would be of minimal effect. In other words, the benefits would be achieved without any harmful outcomes for other individuals or groups, ensuring its ethical acceptability. It may be noted that a similar argument has been made in relation to the supply of organs more generally, where it is claimed that racial conditions on donation should be respected if these may benefit at least one person without causing harm to others.¹²

The arguments regarding personal autonomy and the likely social benefits associated with racially conditional donation are compelling and widely accepted. Against them, the opponents of the practice have advanced four main arguments.

The first argument against racially conditional donation is that there is no empirical evidence that such donation would, in fact, increase donation rates or the availability of tissue to disadvantaged groups. Opponents argue that the view that donation rates are low among under-represented groups because of the absence of positive discrimination in favour of them is simplistic, and that it is more likely that a variety of factors are operating, such as lack of awareness, religious beliefs, fear and mistrust of the Western health care system and fear of premature declaration of death. Indeed, they argue that there is abundant evidence in support of their contention that all these factors are important

¹¹ Cf, however, Leslie Cannold who, in reviewing the New South Wales assisted reproductive technology law, stated that “donations of any kind should be given in the spirit of generosity, rather than with discriminatory strings attached”: ABC News, *Restrictive Donor Bill “Sets Dangerous Precedent”* (29 November 2007), <http://www.abc.com.au/news/2007-11-29/restrictive-donor-bill-sets-dangerous-precedent/971894> viewed 28 October 2011

¹² Wilkinson, n 9.

contributors to low donation rates.¹³ In addition, studies in the United States show that hospital staff are less likely to approach African Americans about donation and that various other hospital practices may also contribute to lower rates of donation.¹⁴ Accordingly, on the basis of the available empirical evidence, there appears to be little correspondence between the absence of racially directed donation and poor donation rates among under-represented groups. As a result, addressing this factor on its own would be very unlikely to lead to an increase in donation rates. Furthermore, the view that under-represented groups will invariably choose to discriminate against other races, cultures or religions reflects a lack of appreciation of the heterogeneity and complexity of their beliefs and social relationships, which – it is supposed – need to be rectified by enhanced understanding and empirical knowledge. From the point of view of this argument, therefore, before adopting a system of racially conditional donation it would be necessary to learn about how such donation would be viewed by minority communities according to their own values and customary laws.

The second argument against racially conditional donation follows directly from the first. Not only is it claimed that the evidence does not support the likelihood of beneficent social outcomes: it is argued that, in fact, it is much more likely that the practice would generate perverse social and cultural effects that could not be controlled. Despite apparent good intentions, it is not possible to define racially conditional preferences in a manner that absolutely precludes their malign extension to disadvantaged minorities, including those they are designed to help. This is supported overwhelmingly by historical experience regarding the effects of practices limited to or directed towards particular racial groups, whether related to health care, education or access to social amenities in Australia, the United States or elsewhere. Indeed, it is possible that the mere acceptance of the principle that decision-making based on racial or cultural characteristics is acceptable under any circumstances will, in itself, provoke significant pain among groups and individuals still struggling with the legacy of past examples of racism. Accordingly – it is argued – the historical lesson is that extreme caution should be exercised in relation to racially based social rules of any kind, and the onus must be on those advocating such acceptance to provide convincing evidence that harm would not ensue.

The third argument against racially conditioned donation refers to its possible effects on donors or potential donors who do not belong to disadvantaged groups – specifically, that the adoption of such a practice would be self-defeating, in that it may subvert the entire rationale for the umbilical cord blood banking process and thereby undermine both social support for it and its viability. According to this view, although affirmative action to address social inequalities is widely accepted, it is objectionable from an ethical point of view to base decisions about health care or the distribution of the society's resources on biological characteristics. Where the latter relate to racial differences, there is even more sensitivity, in view of the invidious history of racial discrimination in Western countries.

Fourthly, the opponents of racially conditional umbilical cord blood donation argue that the practice opposes a fundamental premise of the organ and tissue donation system as a whole, that particular social groups should not be excluded from its benefits. If it were to be permitted, indigenous individuals would be able to restrict the use of their child's umbilical cord blood solely to patients of indigenous descent while at the same time themselves enjoying the possibility of access to all umbilical cord blood units in public banks, no matter what the source. Under such conditions it is possible that a situation may arise in which a non-indigenous patient may be denied a perfectly-matched, stored umbilical cord blood sample which could save her or his life. This potential situation sets racially directed umbilical cord blood donation apart from directed organ donation, and directed charitable donation more generally, since in these cases the donated tissue is not usually stored, deliberately withheld from others and potentially wasted.

¹³ Boulware E et al, "Understanding Disparities in Donor Behaviour: Race and Gender Differences in Willingness to Donate Blood and Cadaveric Organs" (2002) 40(2) *Medical Care* 85; Rozon-Solomon M and Burrows L, "'Tis Better to Receive than to Give': The Relative Failure of African American Community to Provide Organs for Transplantation" (1999) 66 *Mount Sinai Journal of Medicine* 273.

¹⁴ Guadagnoli E et al, "The Influence of Race on Approaching Families for Organ Donation and Their Decision to Donate" (1999) 89(2) *American Journal of Public Health* 244.

The fifth and final argument advanced by the opponents of racially conditional donation refers to the nature of gift giving and seeks to refute the claims of the supporters of the practice that it is the unquestionable prerogative of anyone giving a gift to attach to it whatever conditions he or she wishes. Here it is argued that tissue donation is a special kind of gift, one which is “social” rather than “private”, and is subject to moral conditions that may not apply in the broader field of gift giving. Several characteristics of tissue donation are invoked to show that it is distinguishable from the form of gift giving that might be regarded as private, for which it may be appropriate to accept unlimited control. A private gift may be a personal expression of one individual towards another which does not affect other people or relationships. The act of giving it may be conceived and executed independently of social customs and traditions, and it may be free of wider social consequences. The gift of human tissue, however, is deeply and irrevocably social. It arises out of a broad social concern for and commitment to the welfare of other members of the society. It depends on extensive and elaborate systems of social support which involve a significant allocation of the society’s resources and require the active participation of many other members of the community. It contributes to the establishment and maintenance of social solidarity, thereby helping to stabilise social relationships and support harmonious relationships between different cultural groups. And it draws on and validates a range of social traditions, thus establishing the historical continuity of social institutions. In all cases, it is subject to regulation by public authorities which are charged to act in a manner supportive of widely held values, beliefs and customs in the society. As Kluge states (in the context of organ donation):

[T]he donation must take place in a heavily institutionalized context consisting not only of the medical transplant team but of a whole array of support services without which the transplant would not be possible ... Therefore organ donation is not only a personal action but also a social act.¹⁵

Tissue donation is not, of course, the only kind of gift that is deeply social. However, a consequence of its embeddedness in the cultural structures is that it supports a wide range of social values and traditions. From the point of view of this argument, therefore, the institution of tissue donation represents an inherent social good which should be protected in its own right: once again, at the least, extreme care must be exercised before it is associated with potentially discriminatory or divisive practices.

WHICH SET OF ARGUMENTS SHOULD PREVAIL?

Having presented what appear to be the main arguments in favour of and against racially directed umbilical cord blood donation, it is the authors’ view that, on balance, the latter outweigh the former. The basic argument of the proponents of the practice – that it is a fundamental premise of our society and culture that the rights of individuals to control what happens to their bodies should be respected – is undoubtedly a powerful one. However, autonomy and freedom have never been, and can never be, unconditional. They are always subject to the interests of, and effects on, other members of society. In the present circumstances it seems that the potential for adverse effects on all the parties involved is so great that it would be ethically unsafe to support it at this time.

The arguments in favour of racially directed umbilical cord blood donation are significantly weakened by the lack of empirical substantiation of benefit; indeed, on the basis of evidence that suggests the contrary, the practice may well generate socially undesirable outcomes. The need to increase indigenous and ethnic representation in the organ and tissue donation sector generally is incontestable and it is possible that reparative affirmative action may in some way be justified to achieve this end. However, the arguments appear strong that conditional donation is more likely to undermine than to enhance the interests of indigenous people. Further, the principles of equity and universal accessibility are at least as fundamental as those of individual autonomy and freedom, and are undermined by the distribution of publicly derived social goods on racial grounds and support for discriminatory practices in other settings.

The urgent need to redress the under-representation of indigenous and ethnic populations in umbilical cord blood registers is not sufficient to justify the practice of racially conditional donation, at

¹⁵ Kluge, n 6 at 11.

least in the absence of evidence supporting benefits and disproving risks. Attempts to achieve this are much more likely to be successful if they take the form of strategies and interventions that oppose the social attitudes that generated the inequalities in the first place. The establishment of remedial policies and practices must therefore be based on reliable empirical research into the factors limiting indigenous and ethnic donation rates.

Further, the case seems to be a compelling one that racially conditional donation has the capacity to undermine key structures of altruism and reciprocity which lie at the heart of social life. Because the risks are so high, it would seem that the onus should be on the proponents of the proposed practice to show that it will not fatally compromise the beneficent social institution of donation as a gift. The fact that organ or tissue donation is irrevocably a public act which depends on extensive structures of social support, including physical and human resources and legitimating moral and legal discourses, renders it inherently vulnerable to corruption by misguided, if well-meaning, policies. To attempt to regulate it according to the principles that apply to private individuals acting in isolation from their communities – that is, by granting full private control in which no third party has superior rights or is able to exercise authority – undermines its social basis and depletes a major source of moral value creation.

It is often argued in favour of racially conditional donation that, because its aims and purposes are to improve the health of unrepresented minorities, it should be viewed as a form of positive discrimination to overcome past wrongs rather than as itself racist. For the reasons given above, this argument does not appear to be sustainable. It may be added, incidentally, that this argument applies also to familial-directed donation. The view that the latter practice is ethically permissible because it is justified by the donors' familial obligations may also be seen as supporting racist, or at least culturally discriminatory, attitudes; this is because it assumes a Western concept of family which excludes complex systems of obligation and duty structures such as occur in many indigenous communities. If those arguing in favour of familial-directed donation were to be consistent, they would have to accept that under-represented communities might very well express a preference based on race or ethnicity precisely because they feel the same familial duties and obligations that are accepted for familial-directed donation.

But even though analysis of the arguments for and against racially conditional donation suggests that there is insufficient reason to justify such policy, it is worth considering, for a moment, why this issue is so difficult. It is suggested that it is because the word "race" belongs to two contending discursive systems: a "cultural" one, which is tainted by a long history of brutality, discrimination and oppression, and a "scientific" one, which concerns itself with the classification of biology. While there is little question that culture penetrates the assumptions underlying, and concepts constituting, science and medicine, our recent cultural memory reminds us that deeper cultural intrusions into science, and loose transitions from one discourse to the others (particularly with regard to race) contaminate the disinterested and rigorous nature of science and may lead to ethical transgressions, such as those witnessed during the Holocaust and at Tuskegee. Science, it is argued, should transcend cultural, religious and political interests, and allowing race to become a feature of scientific and medical discourse may simply give scientific justification for malign social and political actions. Our contemporary social values, interpreted in light of cultural history, create the imperative to keep the cultural and scientific/medical discourses of race separate. The necessity for this separation, and the difficulty in doing so, is illustrated by the following examples.

1. It is acceptable, socially, legally, culturally and emotionally, for someone to bequeath money (itself a cultural value) to black people (that is, a specific cultural group) but unacceptable for the same person to require that the blood that they donate goes only to a black person.
2. It is acceptable for the government to allocate substantial resources to encouraging organ donation and transplantation among Aboriginal Australians but unacceptable for them simply to designate a proportion of available donor organs for the specific use of indigenous populations.
3. It is acceptable for someone to bequeath money to black people but unacceptable for someone to bequeath money on the condition that it goes only to a white person.
4. It is acceptable for black and white children to be bussed to different schools to overcome segregation but not for them to be bussed to increase segregation.

The first and second examples refer to the need to keep cultural and scientific discursive systems apart while the third and fourth refer to the specific and contemporary contrary valorisations of the positions of black and white people. The question of racially conditioned donation is difficult because, on the one hand, it supports “progressive” (or at least acceptable) social practices directed at redressing historical wrongs, while on the other it offends against the universalist myth of science that to a large extent made these practices possible.

Racially conditional donation is not an appropriate response to inequity, therefore, not only because the empirical evidence and conceptual arguments that would support it are lacking, but because it is inconsistent with current social values and ignores Australia’s recent cultural history.