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Strengths and pitfalls of Canadian gamete and embryo donor registries: searching for beneficent solutions




Vincent Couture ^a, Marie-Andrée Dubois ^a, Régen Drouin ^a,
Jean-Marie Moutquin ^{b,c}, Chantal Bouffard ^{a,*}

^a Division of Genetics, Department of Pediatrics, Faculty of Medicine and Health Sciences, Université de Sherbrooke, 3001 12th Avenue North, Sherbrooke, Qc, Canada J1H 5N4; ^b Department of Obstetrics-Gynecology, Faculty of Medicine and Health Sciences, Université de Sherbrooke, 3001 12th Avenue North, Sherbrooke, Qc, Canada J1H 5N4; ^c National Institute of Excellence in Health and Social Services, 2021, Avenue Union, Room 10.082, Montréal, Qc, Canada H3A 2S9

* Corresponding author. E-mail address: Chantal.Bouffard@icloud.com (C Bouffard).



Vincent Couture, MA, is a PhD student in the Program of Clinical Sciences, Faculty of Medicine and Health Sciences, Université de Sherbrooke. His research interests focus on cross-border reproductive care, gamete transaction and rerogenetics. He works for the transdisciplinary research programme on the social, ethical, medical and legal aspects of rerogenetics (Fonds de recherche du Québec—Santé, Health and Society Program) with Professors Chantal Bouffard, Régen Drouin and Jean-Marie Moutquin at the Division of Genetics of the Faculty of Medicine and Health Sciences, Université de Sherbrooke. He holds studentships from the Fonds québécois de la recherche sur la société et la culture and the Quebec Training Network in Perinatal Research.

Abstract For the gamete and embryo donation community, it is well recognized that the implementation of a gamete and embryo donor registry (GEDR) represents a good initiative to ensure the best possible health conditions for donor-conceived individuals. Be they national, institutional or independent, GEDR can play a major role in the transmission of health-related genetic and medical information. However, from a bioethical analysis standpoint, GEDR raise many questions regarding the extent of their beneficent nature. Based on the recent Canadian GEDR aborted attempt, this article will focus on bioethical issues and paradoxes that can impact the wellbeing of donor-conceived individuals, half-siblings, donors and parents. On one hand, the implementation of a GEDR can be ethically justified as a beneficent action towards lessening harm associated with the transmission of hereditary disease and increasing the effectiveness of preventive and therapeutic approaches. On the other hand, examined through the concept of nonpaternalistic beneficence, GEDR challenge us to recognize beneficiaries' free agency, as well as the importance to transmit reliable and pertinent information. Ultimately, beyond an individualistic application of the principle of beneficence, socioethics invite us to consider consistency with societal values as a prerequisite for achieving a common good. 

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Introduction

In heated debates, one often hears that a good reason to lift the anonymity of gamete and embryo donors is to allow the transfer of health-relevant information between parties. Gamete and embryo donor registries (GEDR), independently of the lifting of anonymity, can represent a strategy to provide an infrastructure to channel relevant medical and psychosocial information between siblings, half-siblings, donors and donor-conceived people. Consequently, the objective of this article is to examine Canadian GEDR and their potential to benefit to donors, donor-conceived individuals, their siblings, families and descents in terms of lessening the harm associated with failures of the transmission of medically relevant information. In countries (such as Canada) where, legally, donation is still anonymous, finding alternative mechanisms is of great concern.

By allowing the transmission of medical and genetic health-related information between donation parties, a GEDR may seem to be a beneficent mechanism to promote the wellbeing of donor-conceived people (Benward et al., 2009; Foohey, 2008; Johnston, 2002). However, it is not clear to what extent a GEDR represents a risky solution that goes against the will of the donation parties. Thus, by analysing the Canadian situation in light of the principle of beneficence developed by Rivera (2011), this article proposes a bioethical reflection on the use of a GEDR as an infrastructure to channel information that can impact the wellbeing of donor-conceived people, donors, sibling and recipient parents.

According to the 2010 report by the International Federation of Fertility Societies, the number of offspring born from gamete donation is growing yearly (Jones et al., 2011). Many medical, technical and social factors can explain this rise. Progress in laboratory practices, ovarian stimulation protocols, cryopreservation techniques and medical genetics have all contributed to the growing success of assisted reproduction treatment (Bissonnette et al., 2011). Social factors may also contribute to this growth. Because women wait longer before their first pregnancy (Bushnik et al., 2012; Le Ray et al., 2012), more childless women present premature ovarian failure, and, as a result, become infertile before reaching their goal of having a child. In the same vein, epidemiological indicators point out the deterioration of male reproductive health in certain populations (Joffe, 2010; Rolland et al., 2013). Therefore, for these women and men, oocyte and sperm donations are alternatives that are considered to conceive a child (Rolland et al., 2013; Sills et al., 2010).

Simultaneously, gamete donation is the object of vivid ethical debates on the attitude of secrecy surrounding the method of conception and the accompanying donor's anonymity (Daniels et al., 2012; Purewal and van den Akker, 2009; Yee et al., 2011). This trend belongs to what Purewal and van den Akker (2009) call the 'cultural shift' in the general population towards disclosure and the removal of donor anonymity. Following the same line of thought as Daniels (1998, 2007), we are facing a transition from a culture of secrecy to one of open identity (Scheib and Cushing, 2007).

It seems that the world of gamete and embryo donation is entering a new paradigm. However, the secretive

parental attitude appears to be the unsurpassable condition that has to be lifted to make the removal of donor anonymity possible (Pennings, 1997) as well as any other form of contact between donors and their offspring. Moreover, Guichon and Ravitsky (2013) listed only 10 jurisdictions (seven European nations, two Australian states and New Zealand), which, since 1985, have prohibited anonymous gamete donation. Just as important may be the issue of anonymity for the donation community (Hampton, 2005; Johnston, 2002), other mechanisms – nonexclusive to the lifting of anonymity – may be implemented to promote the latter's health.

In this context, from the perspective of a nonpaternalistic principle of beneficence, this article will focus on the practical and bioethical aspects of gamete and embryo donation regarding the transmission of information between donation parties, through the establishment of a GEDR. Reflecting from the Canadian situation, the aim of this article is to highlight the strengths and pitfalls of GEDR. On the one hand, from the perspective of offspring and the health-care system, it can be argued that the implementation of a GEDR is ethically justified as a beneficent action towards lessening the harm associated with the transmission of hereditary diseases, the choice of the most appropriate treatments and prevention options (Benward et al., 2009; Foohey, 2008; Johnston, 2002). On the other hand, following Rivera's concept of nonpaternalistic beneficence (2011), the two criteria for good beneficence are not met. According to Rivera's point of view, for an action to be truly beneficent, it has to be based on pertinent and reliable data and to recognize beneficiaries' free agency.

The first section of this article will present the different types of registries that have been created internationally. In the second section, the previous typology will help to understand the transition that occurred in Canada from the project of a national registry proposed by the *Assisted Human Reproduction Act* to the minimal recognition of institutional registries as suggested by the amendments to the Act. In the third section, building on critiques of the Canadian situation, we will develop a minimal bioethical defence of GEDR using the principle of beneficence. Use of Rivera's criteria against a harmful beneficence will highlight the pitfalls of the beneficent nature of registries. We will pay particular attention to how genetic information is problematic and how a GEDR can constrain beneficiaries' free agency. In the last section, after having emphasized the limits of a GEDR, we will return to the Canadian example and suggest possible alternatives to the current absence of standards on the transmission of information between all donation parties.

Typology of gametes and embryo donor registries

Internationally, as Benward et al. (2009) reported, there is no single model of GEDR. Some registries collect identifying information about the donor (Blyth and Frith, 2009), others only nonidentifying information (Benward et al., 2009); some are mandatory (Blyth and Frith, 2009) and others voluntary (Foohey, 2008). In this section, GEDR will not be differentiated on the basis of the nature of the information

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