

# Distributive Justice and Infertility Treatment in Canada

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## Abstract

An exploration of distributive justice in Canadian infertility treatment requires the integration of ethical, clinical, and economic principles. In 1971, American philosopher John Rawls proposed a theoretical model for fair decision-making in which “rational” and “self-interested” citizens are behind a “veil of ignorance” with respect to both their own position and the position of other decision-makers. Rawls proposed that these self-interested decision-makers, fearing that they are among the least advantaged persons who could be affected by the decision, will agree only upon rules that encode equality of opportunity and that bestow the greatest benefit on the least advantaged citizens. Regarding health policy decision-making, Rawls’ model is best illustrated by Canadian philosopher Warren Bourgeois in his panel of “volunteers.” These rational and self-interested volunteers receive an amnesic drug that renders them unaware of their health, social, and financial position, but they know that they are representative of diverse spheres of citizens whose well-being will be affected by their decision. After describing fair decision-making, Bourgeois considers the lack of a distributive justice imperative in Canada’s *Assisted Human Reproduction Act*, in contrast to legislation in European nations and Australia, summarizes the economic and clinical considerations that must be provided to the decision-makers behind the “veil of ignorance” for fair decisions to occur, and considers altruism in relation to equality of access. He concludes by noting that among countries with legislation governing assisted reproduction Canada is alone in having legislation that is void of distributive justice in providing access to clinically appropriate infertility care.

## Résumé

Une exploration de la justice distributive dans le cadre de la prise en charge de l’infertilité au Canada nécessite l’intégration de principes éthiques, cliniques et économiques. En 1971, le philosophe américain John Rawls a proposé un modèle théorique de processus équitable de prise de décision dans le cadre duquel des citoyens « rationnels » et « intéressés » sont placés sous un « voile d’ignorance » en ce qui a trait à leur propre position et à la position des autres décideurs. Rawls a proposé que ces décideurs « intéressés », craignant faire partie des personnes les moins

avantagées pouvant être affectées par la décision en question, consentiraient seulement aux règles qui prescrivent l’égalité des chances et qui accordent les plus grands avantages aux citoyens les moins avantagés. En ce qui concerne la prise de décision en matière de politique de santé, le concept de groupe de « volontaires » du philosophe canadien Warren Bourgeois constitue la meilleure illustration du modèle de Rawls. Ces volontaires « rationnels » et « intéressés » reçoivent une drogue amnésique qui leur fait oublier leur position sanitaire, sociale et financière, sans toutefois leur faire oublier qu’ils agissent à titre de représentants de diverses sphères de citoyens dont le bien-être sera affecté par leur décision. Après avoir décrit ce qu’il entend par « processus équitable de prise de décision », Bourgeois traite de l’absence d’un impératif de justice distributive au sein de la *Loi sur la procréation assistée* du Canada (contrairement à celui que l’on retrouve dans la législation des pays européens et de l’Australie), résume les considérations économiques et cliniques dont il faut faire part aux décideurs sous le « voile d’ignorance » pour que des décisions équitables soient prises, et traite de la relation entre l’altruisme et l’égalité de l’accès. Il termine sa réflexion en notant que, parmi les pays qui se sont dotés d’une législation régissant la procréation assistée, le Canada est le seul dont la législation ne compte pas d’impératif de justice distributive pour ce qui est de l’accès à des soins de fertilité cliniquement appropriés.

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## BACKGROUND

In his book, *A Theory of Justice*,<sup>1</sup> American philosopher John Rawls proposed a theoretical model for fair decision-making in which decisions are made by persons who are “rational” but also “self-interested.” However, the decision-makers are sequestered behind a “veil of ignorance” regarding their own position and thus their own best interest.<sup>1</sup> Further, despite not knowing what their interests are, Rawls’ fair decision-makers must be aware that they have interests, be committed to furthering their interests as much as possible, and know they could be affected by the decision.<sup>1</sup> Rawls proposed that these rational and self-interested decision-makers will agree only upon rules that encode equality of opportunity and that will be of greatest benefit to the least advantaged, because they fear they will be among the least advantaged citizens affected by the decision.<sup>1</sup>

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Justice in health care generally refers to distributive justice, regarding equality of access to and benefit from health care resources.<sup>2</sup> Canadian philosopher Warren Bourgeois<sup>3</sup> illustrates Rawls's veil of ignorance model in relation to distributive justice in health care policy-making with his panel of "amnesic volunteers." Bourgeois proposes that rational and self-interested<sup>3</sup> volunteers be recruited to serve on a health policy panel with the understanding that they will be injected with an amnesic drug that renders them unaware of their own and the other panel members' health, social, and financial positions, as well as blocking their capacity to sense their own and all other bodies of volunteers.<sup>3</sup> Before decision-making begins, the panel members are told that they are representative of diverse communities that could be affected by the decision<sup>3</sup>: for example, one is an Olympic athlete and another is a person with quadriplegia; one is a millionaire and another is financially impoverished; one is an elderly woman and another a woman in her 20s. However, they are not told which of these they are, and cannot make that determination because of the amnesic drug. The panel members are then provided with the clinical, social, and financial information required to make a rational and self-interested health policy decision,<sup>3</sup> such as the appropriate number of baths a person with quadriplegia should receive each week, or the acceptable number of months to wait for hip replacement surgery, or whether infertility patients should have access through public funding to appropriate clinical treatment.

Psychologists who asked research participants to make decisions from behind the veil of ignorance<sup>1</sup> have confirmed that such decision-makers will decide along the lines of equality of access and make decisions that are of greatest benefit to the least advantaged.<sup>4</sup> Others conducting similar experiments have found that although their research participants were highly influenced by the veil of ignorance procedure to decide in favour of benefiting the least advantaged, they also considered the average wealth being generated in the society in making their decisions.<sup>5</sup>

#### **LACK OF A DISTRIBUTIVE JUSTICE IMPERATIVE IN CANADA'S ASSISTED HUMAN REPRODUCTION ACT (2004)**

Canada's *Assisted Human Reproduction Act*<sup>6</sup> provides a set of prohibitions and regulations for the ethical practice of assisted reproduction. The *Act* is consistent with governance in countries such as Sweden,<sup>7</sup> France,<sup>8</sup> Germany,<sup>9</sup> Australia,<sup>10</sup> the Netherlands,<sup>11</sup> Norway,<sup>12</sup> Israel,<sup>13</sup> and Belgium<sup>14</sup> in its protection of women undergoing assisted reproduction (sections 2, 6, 7, 8, 12, 14, 16, 18) and the children born thereof (sections 11, 16, 17, 18), as well as in the prohibition of activities that commodify women (sections 2(f), 6, 7, 12) and reproductive tissues (sections 5(3) 7, 12).<sup>15</sup>

However, Canada is alone among these countries in not satisfying the ethical requirement of distributive justice, as Canada is alone among these countries in not providing equality of access through public funding for clinically appropriate infertility treatment. This lack of public funding explains to some extent the observation by Collins<sup>16</sup> that Canadian women have only one seventh the chance of women in these countries to access IVF. I refer to women in this paper with the understanding that men are also affected by assisted reproduction practices, although not equally (*Act*, section 2(c)), and that socioeconomically disadvantaged men also suffer from the lack of distributive justice in access to infertility treatment in Canada.

Although distributive justice through equality of access to clinically appropriate infertility treatment could not be prescribed in Canada's federal *Assisted Human Reproduction Act*,<sup>6</sup> as health care funding is under provincial aegis in Canada, distributive justice is promoted in section 2(e) of the *Act*: "persons who seek to undergo assisted reproduction procedures must not be discriminated against."<sup>6</sup> Examples of the bases of such discrimination follow: "including on the basis of sexual orientation or marital status."<sup>6</sup> As the *Act* uses the word "including," the prohibition against "discrimination," rather than being confined to these two examples, could include "on the basis of socioeconomic status." Thus "discrimination" against the socioeconomically disadvantaged in infertility treatment could be considered unjust under the *Act* in legal as well as ethical terms. If socio-economic discrimination had been precisely enshrined in *Canada's Charter of Rights and Freedoms*,<sup>17</sup> alongside discrimination based on sexual orientation (under Supreme Court interpretation)<sup>18</sup> and race, the *Assisted Human Reproduction Act*<sup>6</sup> would have been able to legislate against discrimination on socio-economic grounds.

It must be acknowledged that political realities exist in Canada regarding the funding of IVF at both the provincial and national levels. This is because some Canadians believe that IVF is not an activity that should be carried out in Canada and that public funding would not only increase the frequency of IVF being performed but would also appear to add to its moral worth. Indeed public funding for IVF was discontinued in Ontario because of strong lobbying that focused on the concern of the Royal Commission of New Reproductive Technologies<sup>19</sup> that IVF was not definitely proven to be effective in conditions other than completely blocked fallopian tubes. With the passage of the *Assisted Human Reproduction Act*,<sup>6</sup> and multiple studies, including a randomized Canadian study,<sup>20</sup> demonstrating the effectiveness of IVF for infertility factors other than completely blocked fallopian tubes,<sup>20-23</sup> these non-economic arguments against funding of IVF may have weakened.

## **ECONOMIC CONSIDERATIONS**

In contrast to countries such as France, where comprehensive and complete health care funding is considered sufficiently important to justify whatever taxation is required, economic considerations in Canada must be part of distributive justice-based health policy decision-making, as it is necessary to acknowledge the claim of “fixed” provincial health care budgets. (It has been suggested that an increase of approximately 2% in income tax would meet Canada’s health care demands.<sup>24</sup>) When deciding on whether to permit public funding for clinically appropriate infertility treatment, panel members behind a veil of ignorance need to be provided with economic considerations both for infertility patients and for the provincial health care budgets.

### **Economic Considerations for Infertility Patients**

The rational and self-interested decision-makers behind a veil of ignorance will be told that without public funding of clinically appropriate infertility treatment many women are compelled to accept strategies such as mortgaging their house or borrowing money from family members and friends in order to access IVF. The decision-makers will be told that these strategies are not possible for women whose social experience has confined them to the poor-wage employment that denies house ownership and whose family members and friends are similarly situated financially. Panel members will also be told that international adoption, which represents 90% of infant adoptions for Canadians,<sup>25</sup> is generally also beyond the financial capacity of these women, and that the names of many of these women “languish on long Children’s Aid Society adoption lists,”<sup>26</sup> as birth mothers generally prefer adoptive parents who can provide a “white picket fence” environment for the infant they are giving up for adoption.<sup>26,27</sup> Panel members will be provided with information that relates the importance of having a child to financial considerations, such as the information in a paper by Hughes and Giacomini<sup>28</sup> (referring to Dalton and Lilford<sup>29</sup>) that “to have a healthy child, subfertile couples may accept a 20% risk of death and give up 29% of their income.”<sup>28</sup>

Economic considerations for infertility patients have financial, emotional, and clinical costs. Delaying fertility treatment because of financial considerations frequently reduces the effectiveness of treatment because of the increased age of the women.<sup>30</sup>

### **Economic Considerations for Canadian Provinces**

The panel members will be provided with economic information relevant to provincial health care budgets, including the information that not funding IVF results in high financial expenditures for the neonatal intensive care<sup>31–33</sup> of the children born prematurely of high-order multiple

pregnancies because their mothers could not afford IVF and took gonadotropin fertility drugs without the protection of IVF<sup>15,34</sup> and restricted embryo transfer.<sup>35</sup> In addition, as many of the survivors of neonatal intensive care have physical and cognitive challenges,<sup>33,36–43</sup> their long-term medical and social support will be very costly. These expenditures could exceed what the province would spend on universal access to clinically appropriate infertility treatment.

The mean costs of the intensive care of neonates born at the gestational ages of 24 weeks and 28 weeks (mean hospitalizations of 79 days and 66 days, respectively) is US \$222 563 and US \$146 121, respectively (December 2003).<sup>36</sup> The American College of Obstetricians and Gynecologists reported in 2003 that “hospital costs averaged \$202 700 for a delivery at 25 weeks.”<sup>37</sup> It is probable that Canadian neonatal intensive care is less expensive, but even at half the US cost, the care of preterm neonates is extremely high.

Collins<sup>16</sup> reported that the average cost per IVF/ICSI cycle in 2002 would be US \$9547 in the USA and US \$3518 in 25 other countries,<sup>44–49</sup> and the average cost-effectiveness ratios in 2002 would be US \$58 394 per live birth in the USA, and US \$22 048 in other countries. In 2006, the Australian Health Policy Institute<sup>50</sup> estimated the average cost of a non-donor IVF cycle that results in a live birth is \$32 903” (or Can \$35 764 at the exchange rate of August 6, 2007).<sup>50</sup>

Collins estimated that funding IVF would cost American employee health plans only \$3.14 in 1995.<sup>51</sup> The potential cost savings of providing care for fewer persons born prematurely because of multiple pregnancy could mitigate this cost to health plans. Hughes and Giacomini<sup>28</sup> believe that Americans are willing to help the socioeconomically disadvantaged have access to IVF, referring to the findings of Neumann et al.<sup>52</sup> that people in Massachusetts were “willing to pay substantial amounts so that others would have access.”<sup>28</sup>

In their public funding, provinces could choose to allow infertile women of all socioeconomic conditions to access as many IVF cycles as they require to have the number of children they desire, as is the case in Australia, or provinces could be more restrictive, as is the case in other countries.

## **A RAWLSIAN ANALYSIS OF LACK OF EQUALITY OF ACCESS TO IVF IN CANADA**

Bissonnette<sup>53</sup> and Claman<sup>54</sup> draw attention to the prohibitions in Canada’s *Assisted Human Reproduction Act* as having created new access problems for infertility patients rather than addressing the pre-existing access problems. These new access problems affect both socioeconomically

disadvantaged infertility patients and those who are financially better off.

Pursuant to the *Act*, socioeconomically disadvantaged Canadian women can no longer barter half their oocytes in return for the opportunity to undergo an IVF cycle. Although I believe oocyte bartering to be problematic ethically and clinically,<sup>55–58</sup> without it Canadian women who have clinical indications for IVF but who are not able to pay have little chance of having a child. Financially better-off women with oocyte depletion resulting from advanced reproductive age,<sup>59</sup> cancer treatment,<sup>60,61</sup> or other conditions<sup>62–64</sup> can no longer legally purchase oocytes from university students and other socioeconomically disadvantaged Canadian women, including infertility patients. Instead many women with the financial resources purchase oocytes either on the “black market” in Canada (as described in a 2007 Canadian Broadcasting Corporation documentary),<sup>65</sup> in the United States<sup>66,67</sup> or in Eastern European countries,<sup>68–70</sup> where no such legislation protects socioeconomically disadvantaged women from the potential physical harms of IVF medications and surgery<sup>71–79</sup> or the psychological harms of IVF<sup>80–82</sup> and oocyte donation.<sup>83–88</sup>

Although the *Assisted Human Reproduction Act* has legislated that, within Canada, women with oocyte depletion who are unable to pay for IVF (and who never had access to the oocytes of other women) and women who are able to pay have equal lack of access, Rawls would likely not be egalitarian in this sense.<sup>89</sup> Rather, Rawls would likely apply his belief that if equality could not be achieved to benefit the least advantaged, as is the case in Canada where public funding for IVF could not be prescribed in a federal *Act*, it is better for one group to have \$100 and another group to have \$10 than for both groups to have \$10.<sup>89</sup>

There are also regional differences in the lack of equality of access to IVF in Canada. Bissonnette in his 2006 report in support of the government of Quebec’s “Challenge to Canada’s *Assisted Human Reproduction Act*” points to twice as many IVF cycles per population being performed in Ontario as in Quebec.<sup>53</sup> This discrepancy, I believe, may be largely due to the fact that for women who have bilaterally blocked fallopian tubes (20% of infertility patients),<sup>90</sup> IVF is publicly funded in Ontario but not in Quebec. Thus socioeconomically disadvantaged women in Ontario with this infertility factor have access to IVF, while similarly disadvantaged women in Quebec with this same infertility factor are denied access.<sup>58</sup> It is likely that women in the Atlantic provinces and in the territories have access to fewer IVF cycles per population than women in Quebec, as there are proportionately more socioeconomically disadvantaged women in those locations. Again, Rawls would likely believe that as equality in access could not be prescribed in

Canada’s *Assisted Human Reproduction Act*, and it is better for one person to have \$100 and another \$10 than for both to have \$10,<sup>49</sup> it is good for socioeconomically disadvantaged women in Ontario with bilaterally blocked fallopian tubes to have access to IVF even though women with the same infertility factor in other provinces and territories do not have access.

### **ALTRUISM AND DISTRIBUTIVE JUSTICE**

Altruism,<sup>23,91–94</sup> although generally considered a good,<sup>93</sup> can be neither prescribed by decision-makers (behind a veil of ignorance or in any other model) nor expected. Regarding infertility treatment, however, altruism could promote equality of access and benefit the least advantaged citizens through increasing the donation of cryopreserved embryos no longer required for reproductive purposes. In countries where legislation similar to Canada’s *Act* regulates assisted reproduction, but where being able to have a child is facilitated by public funding of clinically appropriate infertility treatment,<sup>7–14,95</sup> altruism directed towards infertility patients is increasing to varying degrees. An in-depth exploration of altruism is beyond the scope of this paper and can be found in the writings of Noonan,<sup>94</sup> Fehr and Fischbacher,<sup>93</sup> and Dawkins.<sup>95</sup>

Ethical problems exist regarding altruistic donation of oocytes<sup>87,96–98</sup> as they do for donation of other tissues from live donors.<sup>99–101</sup> In countries where legislation regulates assisted reproduction,<sup>7–14,102</sup> including Canada (2004),<sup>6</sup> it is legal (and thus likely considered ethical) for women who have completed their families to undergo an IVF cycle to provide oocytes for women with oocyte depletion, as long as they are not being paid to do so. The legislation in these countries<sup>7–14</sup> (including Canada<sup>6</sup>) requires comprehensive counselling before a woman can choose to accept the physical<sup>71–79</sup> and psychological<sup>80–82</sup> risks of the infertility drugs and surgery inherent in making such a donation, and the psychological risks of donation itself.<sup>83–88</sup>

From their own research and that of others<sup>103–105</sup> on altruistic oocyte donation from known donors, and the research of European investigators on anonymous oocyte donation,<sup>106,107</sup> Canadian researchers Yee, Hitkari, and Greenblatt point out that although “altruistic donation is in general, a more morally and ethically acceptable form of donation than paid donation, donor recruitment continues to be a major challenge.”<sup>86</sup> They believe that “legislation alone is unlikely to achieve societal attitudinal changes without complementary measures to raise the public awareness of the need for, and the value of, gamete donation.”<sup>86</sup> However, rather than Canadian provincial governments raising the public awareness of this need and this value, their lack of public funding of IVF may impart the opposite.<sup>86</sup>

A culture of altruism could also promote the donation of cryopreserved embryos that are no longer required by the infertility patients for whom they are being stored. Currently, approximately 20% of such embryos are donated to help other infertility patients, with the remainder being either discarded or donated to research.<sup>108–112</sup> The main reason for what might be considered a low rate of donation to other infertility patients from empathetic potential donors appears to be the desire to avoid genetic relationships, including potential consanguinity issues, in their children.<sup>78,113,114</sup> The small number of cryopreserved embryos that are donated to other infertility patients in Canada is possibly attributable to the fact that lack of public funding allows only 14% of Canadian women access to IVF for appropriate clinical indications.<sup>16</sup> Thus after having the number of children they desire, only 14% of infertility patients in Canada could donate their remaining cryopreserved embryos to other infertility patients.

## CONCLUSION

I believe that rational and self-interested members of a provincial health policy panel, sequestered behind a veil of ignorance and provided with the relevant scientific, clinical, and economic information, would decide upon public funding of IVF for women with appropriate clinical indications. This distributive justice-based decision-making would result in equality of access for all women who require IVF to be able to have a child, and would be of greatest benefit to the least advantaged infertility patients. Further, public funding of IVF would theoretically avoid the high-order multiple pregnancies that have occurred because women who could not access IVF used gonadotropin fertility drugs without the protection of the restricted embryo transfer that is part of IVF. This would allow health care funds currently used for the neonatal intensive care and long-term clinical and social support of children born prematurely as a result of their mother's lack of access to IVF to be distributed to other components of the health care system. If the Federal Minister of Health, who stated on Canadian Broadcasting Corporation News (April 30, 2007) that "Canadians who want to start a family should be able to use assisted reproductive technology" meant all Canadians, rather than just those of better financial means, then he should encourage his provincial counterparts to respect the ethical requirement of distributive justice and include appropriate infertility treatment in Medicare.

Such a distributive justice-based decision would not only be ethically, economically, and clinically sound, it would be compassionate and Canadian.

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