

## THE BUSINESS OF EGG TRANSACTIONS AND NEED FOR IMPROVED REGULATION OF THE FERTILITY INDUSTRY IN CANADA

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*In Canada, ethical and legal debates around egg donation have largely focused on the question of whether egg providers should be paid, since payment for egg donation is prohibited through the federal Assisted Human Reproduction Act, 2004. One of the generally overlooked issues, however, is the potential for fertility clinics and agencies to mistreat egg providers. There is little legal oversight of the practices of fertility clinics and agencies in Canada, and scholars have raised concerns about the potential for mistreatment of egg providers. This article examines the medical care of egg providers in Canada by presenting data from qualitative interviews with 14 egg providers. While some egg providers felt well cared for, others were left feeling like a means to an end — they felt that insufficient information was provided for consent, there was an inability to communicate with the clinic, and they were physically mistreated. I argue that not only do egg providers' experiences run contrary to the CMA Code of Ethics, but they also run contrary to laws, regulations, and guidelines that are intended to ensure that people who undergo fertility treatments are not harmed.*

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## I. INTRODUCTION

Egg (or oocyte) transactions involve using another person's eggs for the purpose of achieving a pregnancy. The use of another person's eggs to achieve conception was first performed in 1984 and has become a popular and frequently used part of assisted reproduction. In Canada, data from the 2020 Canadian Assisted Reproductive Technologies Register Plus (CARTR Plus) indicates that provided eggs were used in 2345 assisted reproductive technology treatment cycles.<sup>1</sup> Since eggs are often bought and sold and not donated,<sup>2</sup> I use terms like "egg transaction," "egg provision," "egg provider," and "provided eggs" rather than "egg donation," "egg donor," and "donated eggs." I also use "person" rather than "women" to capture the fact that eggs are not only provided by cisgender women but are also provided by transgender, gender non-binary, and gender non-conforming folk.<sup>3</sup>

The provision of eggs is a physically invasive and complicated process.<sup>4</sup> It involves drug regimes, surgery, and sedation or anesthesia.<sup>5</sup> An egg provider is given fertility drugs to stimulate their ovaries to produce multiple eggs in one cycle.<sup>6</sup> Eggs are extracted in a surgical procedure and may either be fertilized using in vitro fertilization (IVF) or frozen for later use to create an embryo.<sup>7</sup> There are a number of physical side effects associated with egg provision. Physical side effects range from mild side effects like nausea, bloating, bleeding, and infection to more severe side effects like ovarian hyperstimulation syndrome (OHSS) — an enlargement and swelling of the ovaries that can lead to fluid leakage as well as a variety of other side effects<sup>8</sup> — and cancer.<sup>9</sup> The American Society for Reproductive Medicine has also acknowledged that egg providers might need fertility therapy themselves in the future.<sup>10</sup> Psychological risks include depression and regret.<sup>11</sup>

Many ethical and regulatory debates have surfaced in the wake of the development of this technique. The debates often focus on the question of whether egg providers should be paid, given the physical and emotional risks involved with egg provision. In Canada, where this

<sup>1</sup> Lynn Meng et al., "Canadian Assisted Reproductive Technologies Register Plus Report" (PowerPoint delivered at the Canadian Fertility and Andrology Society 67th Annual Meeting, Vancouver, 23–25 September 2021) at 23, online: [perma.cc/J8J8-ZABY].

<sup>2</sup> Kathleen Hammond, "Not Worth the Wait: Why the Long-Awaited Regulations Under the AHRA Don't Address Egg Donor Concerns" (2022) 37:1 CJLS 113 at 114; Alison Motluk, "The Human Egg Trade," *The Walrus* (12 April 2010), online: [perma.cc/V2PA-28NC].

<sup>3</sup> Interview of Jayson by We Are Egg Donors, "I Donated My Eggs as a Trans Man," online (blog): [perma.cc/E5QX-43EG].

<sup>4</sup> Alana Cattapan, "Rhetoric and Reality: 'Protecting' Women in Canadian Public Policy on Assisted Human Reproduction" (2013) 25:2 CJWL 202 at 210.

<sup>5</sup> McGill University Health Centre, "Information Guide for Potential Egg Donors: Your Questions Answered" (24 April 2020), online (pdf): [perma.cc/TGE8-EP8F].

<sup>6</sup> *Ibid* at 2.

<sup>7</sup> Mark V Sauer & Haley G Genovese, "Egg and Embryo Donation" in David K Gardner et al, eds, *Textbook of Assisted Reproductive Techniques*, 6th ed, vol 2 (Boca Raton: CRC Press, 2024) 802 at 802.

<sup>8</sup> Pratap Kumar et al., "Ovarian Hyperstimulation Syndrome" (2011) 4:2 J Human Reproductive Sciences 70 at 70.

<sup>9</sup> See e.g. Jennifer Schneider, Jennifer Lahl & Wendy Kramer, "Long-Term Breast Cancer Risk Following Ovarian Stimulation in Young Egg Donors: A Call for Follow-Up, Research and Informed Consent" (2017) 34:5 Reproductive Biomedicine Online 480.

<sup>10</sup> Practice Committee of the American Society for Reproductive Medicine & Practice Committee of the Society for Assisted Reproductive Technology, "Repetitive Oocyte Donation: A Committee Opinion" (2020) 113:6 Fertility & Sterility 1150 at 1151.

<sup>11</sup> Nancy J Kenney & Michelle L McGowan, "Looking Back: Egg Donors' Reproductive Evaluations of Their Motivations, Expectations, and Experiences During Their First Donation Cycle" (2010) 93:2 Fertility & Sterility 455 at 460.

research largely took place, payment for egg transactions is prohibited through the federal *Assisted Human Reproduction Act*.<sup>12</sup>

One of the generally overlooked issues is the potential for fertility clinics and agencies to mistreat egg providers. This may be tied to their size and lucrativeness of the fertility industry. As Debora Spar explains, “[w]here fertility is concerned ... demand knows no limit.”<sup>13</sup> There are currently about 36 clinics offering fertility services in Canada,<sup>14</sup> and in the United States, there are about 450 fertility clinics.<sup>15</sup>

In Canada, where most medical care is public, fertility clinics are largely privately run enterprises, and there is little legal oversight of the practices of fertility clinics and agencies. Scholars have raised concerns over the potential for mistreatment of intended parents, and especially of egg providers. Legal scholar Vanessa Gruben, for instance, points out the potential conflict of interest that exists in egg transactions where one physician treats both the egg provider and intended parent and how this could lead to potential negative ramifications for the egg provider.<sup>16</sup> Investigative journalist Alison Motluk has documented examples of Canadian egg providers being stimulated to produce more eggs than is safe and receiving little or no follow-up care.<sup>17</sup> In the American context, Diane Tober and colleagues’ survey research on informed consent found that a large percentage of the egg providers they interviewed (55.2 percent) did not feel that their healthcare practitioner had sufficiently informed them about long-term risks.<sup>18</sup> Egg providers in the US have also expressed concern about the high quantity of eggs they are stimulated to produce and have reported feeling that clinics disregard their concerns and treat them like “‘cash cows’ or ‘egg machines.’”<sup>19</sup>

Despite the potential for mistreatment and the concerns that have begun to arise out of the existing literature, no research in Canada has inquired into the medical care of egg providers in Canada. This article aims to help fill this gap by presenting data from qualitative interviews on the experiences of 14 egg providers who received at least part of their treatment from a Canadian fertility clinic. I found that while some egg providers felt well cared for, others were left feeling like a means to an end — they felt that insufficient information was provided for consent, there was an inability to communicate with the clinic, and they were physically mistreated. Not only do egg providers’ experiences run contrary

<sup>12</sup> SC 2004, c 2, s 7(1) [AHRA].

<sup>13</sup> Debora L Spar, *The Baby Business: How Money, Science, and Politics Drive the Commerce of Conception* (Boston: Harvard Business School Press, 2006) at 4.

<sup>14</sup> A Lanes et al., “CARTR Plus: The Creation of an ART Registry in Canada” [2020]:3 Human Reproductive Open 1 at 1.

<sup>15</sup> Centers for Disease Control and Prevention, *2020 Assisted Reproductive Technology: Fertility Clinic and National Summary Report* (US Department of Health and Human Services, 2022) at 12; Centers for Disease Control and Prevention, *2019 Assisted Reproductive Technology: Fertility Clinic and National Summary Report* (US Department of Health and Human Services, 2021); Centers for Disease Control and Prevention, *2018 Assisted Reproductive Technology: Fertility Clinic Success Rates Report* (Atlanta: US Department of Health and Human Services, 2020).

<sup>16</sup> Vanessa Gruben, “Women as Patients, Not Spare Parts: Examining the Relationship Between the Physician and Women Egg Providers” (2013) 25:2 CJWL 249 at 267 [Gruben, “Women as Patients”]. Motluk, *supra* note 2.

<sup>17</sup> Diane Tober et al., “Alignment Between Expectations and Experiences of Egg Donors: What Does it Mean to Be Informed?” (2021) 12 Reproductive BioMedicine & Soc’y Online 1 at 8 [Tober et al., “Alignment”].

<sup>19</sup> Diane Tober et al., “Eggonomics: Vitrification and Bioeconomics of Egg Donation in the United States and Spain” (2023) 37:3 Medical Anthropology Q 248 at 258.

to the Canadian Medical Association (CMA) *Code of Ethics*,<sup>20</sup> but they also run contrary to laws, regulations, and guidelines that are intended to ensure that people who undergo fertility treatments are not harmed.

I begin the article by outlining existing laws, regulations, and guidelines that pertain to egg transactions in Canada and discuss their criticisms. I explain the methods by which I collected the data that I rely upon. I then present the main findings about egg providers' experiences. I conclude by making recommendations on how to improve egg providers' care in Canada that additionally serve as suggestions for best practices with regard to consent and physical care of egg providers for other jurisdictions.

## II. THE REGULATION OF EGG TRANSACTIONS IN CANADA

In Canada, there is a universally accessible single-payer health care system. The federal government is responsible for setting and administering national standards through the *Canada Health Act*,<sup>21</sup> but otherwise has limited responsibility over healthcare. Jurisdiction over healthcare falls to the provinces by virtue of section 92 of the *Constitution Act, 1867*.<sup>22</sup> Health care regulations usually focus on two domains: health care professionals, and health care facilities or institutions.<sup>23</sup> In Canada, because of the division of powers, most existing regulation of health care professionals and health facilities is on a province-by-province basis. The same is true of reproductive health care professionals and fertility clinics. However, professionals who provide fertility care and the facilities where these services are provided are regulated somewhat differently because fertility is one of the relatively few private for-profit health care sectors. This means that it is paid for by private finance (namely, private insurance and out-of-pocket payments) and delivered by for-profit facilities.<sup>24</sup> As such, the fertility industry is regulated differently from publicly funded health care services.

As Vanessa Gruben has pointed out, two principal regulatory tools govern the fertility sector: self-regulation, and voluntary mechanisms (largely clinical practice guidelines).<sup>25</sup> Self-regulation and clinical practice guidelines are both forms of internal regulation, meaning that they flow from members of the health profession.<sup>26</sup> This is in contrast to external regulation, which comes from external authorities such as governments or private organizations.<sup>27</sup> Additionally, the *AHRA*<sup>28</sup> and its related regulations<sup>29</sup> — passed through the federal government's criminal law power — apply to egg transactions.

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<sup>20</sup> Canadian Medical Association, *CMA Code of Ethics and Professionalism* (Ottawa: CMA, 2018) [*CMA Code of Ethics*].

<sup>21</sup> RSC 1985, c C-6.

<sup>22</sup> (UK), 30 & 31 Vict, c 3, s 92, reprinted in RSC 1985, Appendix II, No 5.

<sup>23</sup> Peter D Jacobson, "Regulating Health Care: From Self-Regulation to Self-Regulation?" (2001) 26:5 *J Health Pol Pol'y & L* 1165 at 1166.

<sup>24</sup> Vanessa Gruben, "Self-Regulation as a Means of Regulating Privately Financed Medicare: What Can We Learn from the Fertility Sector?" in Colleen M Flood & Bryan Thomas, eds, *Is Two-Tier Health Care the Future?* (Ottawa: University of Ottawa Press, 2020) 145 at 145–46 [Gruben, "Self-Regulation"].

<sup>25</sup> *Ibid* at 146–47.

<sup>26</sup> *Ibid*.

<sup>27</sup> *Ibid* at 153.

<sup>28</sup> *AHRA*, *supra* note 12.

<sup>29</sup> *Reimbursement Related to Assisted Human Reproduction Regulations*, SOR/2019-193; *Safety of Sperm and Ova Regulations*, SOR/2019-192.

This patchwork of laws, regulations, and guidelines can be divided into: (1) those that deal with informed decision-making and consent; (2) those that deal with the physical care of patients; and (3) those that deal with facilities and equipment. I focus here on the first two. Where laws, regulations, and guidelines are province-specific, I use examples from the provinces of Ontario and Quebec as they have the largest populations in Canada and represent two of Canada's legal traditions: common law (Ontario) and civil law (Quebec).

#### A. LAWS, REGULATIONS, AND GUIDELINES SURROUNDING INFORMED DECISION-MAKING AND CONSENT

Laws and regulations that deal with informed decision-making and consent include the *AHRA* and its related regulations. Underlying the *AHRA* is the premise that “the health and well-being of women must be protected in the application of [assisted reproductive] technologies”<sup>30</sup> and that “free and informed consent must be promoted and applied as a fundamental condition”<sup>31</sup> of their use. The *AHRA* prohibits the use of donated eggs without written consent,<sup>32</sup> and prohibits the provision of eggs by persons under the age of 18 years.<sup>33</sup> The *AHRA* was initially going to require mandatory counselling for gamete providers, but this section<sup>34</sup> was repealed before coming into force as a result of Quebec's challenge of this section of the legislation, among others, as ultra vires the federal government.<sup>35</sup> While the *AHRA* and reimbursement regulations allow for the reimbursement of some expenses with a receipt, the purchase of eggs is prohibited and there are significant penalties for paying egg providers.<sup>36</sup> Early drafters of the law were concerned that egg providers would be exploited if they were paid.<sup>37</sup> The thinking appears to be that egg providers might be so lured by payment that they might be unable to fully evaluate the risks of donation, and thus the consent that they provide might not be informed.<sup>38</sup>

Informed consent is also embedded in the *CMA Code of Ethics*, which is a guide prepared by physicians for physicians that sets out general ethical standards of the medical profession in Canada.<sup>39</sup> It is evident in the virtues that are meant to be exemplified by an ethical physician<sup>40</sup> and the fundamental commitments of the medical profession.<sup>41</sup> It also appears in a number of articles on the professional responsibilities of physicians in the patient-physician relationship. For instance, article 5 requires the physician to “[c]ommunicate information accurately and honestly with the patient in a manner that the patient understands and can apply, and confirm the patient's understanding.”<sup>42</sup> Article 11 requires a physician to “[e]mpower the patient to make informed decisions regarding their health by communicating

<sup>30</sup> *AHRA*, *supra* note 12, s 2(c).

<sup>31</sup> *Ibid*, s 2(d).

<sup>32</sup> *Ibid*, s 8(1). See also *Consent for Use of Human Reproductive Material and In Vitro Embryos Regulations*, SOR/2007-137.

<sup>33</sup> *AHRA*, *supra* note 12, s 9.

<sup>34</sup> *Ibid*, s 14(2)(b).

<sup>35</sup> See generally *Reference re Assisted Human Reproduction Act*, 2010 SCC 61.

<sup>36</sup> *AHRA*, *supra* note 12, s 60.

<sup>37</sup> Alana Cattapan, “Risky Business: Surrogacy, Egg Donation, and the Politics of Exploitation” (2014) 29:3 *CJLS* 361 at 368 [Cattapan, “Risky Business”].

<sup>38</sup> *Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies* (Ottawa: Minister of Government Services Canada, 1993) at 594 online: [perma.cc/X3BN-L5GM].

<sup>39</sup> *Supra* note 20.

<sup>40</sup> *Ibid* at 2.

<sup>41</sup> *Ibid*.

<sup>42</sup> *Ibid* at 4.

with and helping the patient ... navigate reasonable therapeutic options to determine the best course of action consistent with their goals of care; [and] communicate with and help the patient assess material risks and benefits before consenting to any treatment or intervention.”<sup>43</sup> The articles of the *CMA Code of Ethics* are guiding principles and are not legally enforceable, nor do they deal with specific situations such as fertility treatments.

In most provinces, reproductive health care professionals, such as physicians and nurses, are members of self-regulating bodies. This ability to self-regulate is conferred on these bodies by the provinces. In the province of Ontario, for instance, reproductive health care physicians are regulated by the College of Physicians and Surgeons of Ontario (CPSO) and by virtue of the *Regulated Health Professions Act, 1991*.<sup>44</sup> Whether they practice in the publicly funded system or provide privately financed health care services, they are subject to the regulatory oversight of their respective regulatory colleges. The purpose of self-regulation is to promote health and safety and ensure that professionals are regulated in the public interest. The regulatory colleges exercise functions like licensing members, setting practice standards, establishing practice guidelines, providing training and continuing education, and remediating or disciplining members who do not meet the standards of the profession.<sup>45</sup> Practice standards and professional guidelines created by the provincial colleges also embody principles like the *CMA Code of Ethics* in relation to informed consent. The CPSO Practice Guide, for instance, emphasizes that physicians must “ensure that patients are appropriately informed about their medical care.”<sup>46</sup>

Guidance on the practice of fertility medicine in Canada also comes from professional societies like the Society of Obstetrics and Gynecologists of Canada and the Canadian Fertility and Andrology Society (CFAS). The Society of Obstetrics and Gynecologists of Canada and the CFAS provided a joint policy statement on assisted reproductive technologies that emphasizes that obtaining informed consent is “crucial to the ethical acceptability of oocyte transfer between women.”<sup>47</sup> The statement notes that establishing informed consent of egg providers is “very difficult” because of the potential for exploitation and coercion, but that informed consent can greatly reduce the risk of exploitation and coercion.<sup>48</sup> In 2016, the CFAS released guidelines for third party reproduction (“the Third Party Reproduction Guidelines”).<sup>49</sup> While these are currently under revision because of recently released regulations associated with the *AHRA*, they outline important considerations for egg transactions. They recommend that in addition to the consent requirements of the *AHRA*,<sup>50</sup> gamete providers and recipients “must sign consent forms outlining the process, risks and benefits of treatment(s). They must be informed of and acknowledge their right to withdrawal from treatments at any time prior to gamete

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<sup>43</sup> *Ibid* at 5.

<sup>44</sup> SO 1991, c 18.

<sup>45</sup> David Orentlicher, “The Role of Professional Self-Regulation” in Timothy Stoltzfus, ed, *Regulation of the Healthcare Professions* (Chicago: Health Administration Press, 1997) 129 at 130.

<sup>46</sup> College of Physicians and Surgeons of Ontario, *The Practice Guide: Medical Professionalism and College Policies* (Toronto: CPSO, 2021) at 9, online: [perma.cc/EU8X-LGHT].

<sup>47</sup> Renée Martin et al, “Policy Statement: Oocyte Transfer: Sources of Oocytes and the Nature of the Exchange” (1999) 21:2 J Obstetrics & Gynaecology Can 175 at 179.

<sup>48</sup> *Ibid*.

<sup>49</sup> Canadian Fertility and Andrology Society, “Clinical Practice Guidelines for Third Party Reproduction” (April 2016), online (pdf): [perma.cc/KBD5-8EYP] [CFAS].

<sup>50</sup> *AHRA*, *supra* note 12, s 8.

donation.”<sup>51</sup> Risks that egg providers should be informed of are complications of oocyte retrieval and ovarian hyperstimulation.<sup>52</sup> The Third Party Reproduction Guidelines also recommend that all individuals involved in third party reproduction undergo counselling, in separate sessions, prior to treatment.<sup>53</sup> It is recommended that this counselling be in accordance with the CFAS’ Counseling Practice Guidelines.<sup>54</sup> Since the American Society for Reproductive Medicine recommends that egg providers limit their number of stimulated egg transaction cycles to six or less,<sup>55</sup> the Third Party Reproduction Guidelines suggest the same.<sup>56</sup> The Third Party Reproduction Guidelines suggest that physicians and clinics ask potential egg providers how many times they have provided eggs as part of their medical assessment and advise them of the risks associated with multiple egg provisions.<sup>57</sup>

Informed consent is also a principle of the common law.<sup>58</sup> Canadian court decisions have said that a higher standard of disclosure applies to elective procedures like egg provision and IVF.<sup>59</sup> Some provinces and territories have passed legislation that enshrines this principle. The province of Ontario, for example, has the *Health Care Consent Act, 1996*.<sup>60</sup> The HCCA requires physicians to obtain an individual’s informed consent when any treatment is proposed,<sup>61</sup> sets out the elements that are required for consent,<sup>62</sup> and explains what counts as informed consent.<sup>63</sup> In order for consent to treatment to be informed, a person must be given information on the nature of the treatment, the expected benefits of the treatment, the material risks of the treatment, the material side effects of the treatment, alternative courses of action, and the likely consequences of not having the treatment.<sup>64</sup>

In the province of Quebec where the civil law tradition is in place, informed consent is enshrined in articles of the *Civil Code of Québec*,<sup>65</sup> and specific rules with respect to consent in the context of assisted reproductive technologies can be found in the *Act Respecting Clinical and Research Activities Relating to Assisted Procreation*,<sup>66</sup> and the corresponding *Regulation respecting clinical activities related to assisted procreation*.<sup>67</sup> The Regulation makes it explicit that at every stage of assisted reproduction activities, free and enlightened consent must be given in writing from the egg provider,<sup>68</sup> and the intended parent(s).<sup>69</sup> It sets out what both parties need to be informed of before providing consent.<sup>70</sup> These include: (1)

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<sup>51</sup> CFAS, *supra* note 49 at 7.

<sup>52</sup> *Ibid* at 14.

<sup>53</sup> *Ibid* at 11.

<sup>54</sup> Canadian Fertility and Andrology Society Counselling Special Interest Group, “Assisted Human Reproduction Counselling Practice Guidelines” (August 2009) at 18, online (pdf): [perma.cc/BJ2R-L9G9].

<sup>55</sup> The Practice Committee of the American Society for Reproductive Medicine & The Practice Committee of the Society for Assisted Reproductive Technology, “2006 Guidelines for Gamete and Embryo Donation” (2006) 86:4 Fertility & Sterility S38 at S42; CFAS, *supra* note 49 at 18.

<sup>56</sup> CFAS, *ibid* at 18.

<sup>57</sup> *Ibid* at 15.

<sup>58</sup> *Ciarlariello v Schacter*, [1993] 2 SCR 119 at 135 [Ciarlariello].

<sup>59</sup> *White v Turner*, 1981 CanLII 2874 (ONSC); see also *Skeels (Estate of) v Washkiw*, 2006 ABQB 335, SO 1996, c 2, Schedule A [HCCA].

<sup>60</sup> *Ibid*, s 10(1).

<sup>61</sup> *Ibid*, s 11(1).

<sup>62</sup> *Ibid*, s 11(2).

<sup>63</sup> *Ibid*, s 11(3).

<sup>64</sup> Arts 10–11 CCQ.

<sup>65</sup> CQLR, c A-5.01, ss 8–10 [Assisted Procreation Act].

<sup>66</sup> CQLR, c A-5.01, r 1.

<sup>67</sup> *Ibid*, s 19(1).

<sup>68</sup> *Ibid*, ss 19(2)–(4).

<sup>69</sup> *Ibid*, s 20.

adverse effects and related risks;<sup>71</sup> (2) the possibility that the number of eggs retrieved may exceed the needs of the intended parents;<sup>72</sup> and (3) the psychological support that is available at the center.<sup>73</sup> The Québec Commission de l'éthique de la science et de la technologie also released a guideline document on gamete donation<sup>74</sup> that emphasizes the importance of consent for intended parents<sup>75</sup> and egg providers.<sup>76</sup>

## B. LAWS, REGULATIONS, AND GUIDELINES SURROUNDING PHYSICAL CARE OF EGG PROVIDERS

Many of these same laws, regulations, and guidelines also deal with the physical care of egg providers as patients.

For instance, the *CMA Code of Ethics* also provides guiding ethical principles on providing patient care that are embedded in the virtues<sup>77</sup> and fundamental commitments of the profession, like the commitment to the well-being of the patient.<sup>78</sup> It is also evident in the professional responsibilities. Specifically, the *CMA Code of Ethics* recognizes that conflicts of interest can arise because of competing roles (such as financial, administrative, and leadership)<sup>79</sup> but that physicians have a duty to manage and minimize conflicts of interest.<sup>80</sup>

Practice standards and professional guidelines put out by the provincial colleges also set out expectations of the medical profession for standards of physical care. For instance, in Ontario, the CPSO Practice Guide emphasizes the need to manage conflicts of interest between the patient and physician such that a patient's best interests are not compromised.<sup>81</sup> The Government of Ontario is also now taking a larger role in the regulation of the fertility sector since the government's decision in December 2015 to fund one stimulated cycle of IVF for every Ontarian. The Ontario government has called for a regulatory framework tailored to fertility services. This regulatory model will fall within the jurisdiction of the CPSO through the Out of Hospital Premises Inspection Program.<sup>82</sup> The program is mandated by the province but designed and administered by the CPSO.<sup>83</sup> It establishes standards for premises where procedures are performed using anesthesia and where the premises (like a fertility clinic) do not fall under another provincial regulatory oversight scheme.<sup>84</sup> After the public funding was introduced, the Ontario government asked the CPSO to develop and implement a quality and inspection framework to specifically govern some fertility services,

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<sup>71</sup> *Ibid.*, s 20(1).

<sup>72</sup> *Ibid.*, s 20(3).

<sup>73</sup> *Ibid.*, s 20(12).

<sup>74</sup> Commission de l'éthique de la science et de la technologie, *Position Statement: Ethics and Assisted Procreation: Guidelines for the Donation of Gametes and Embryos, Surrogacy and Preimplantation Genetic Diagnosis* (Quebec: Gouvernement du Québec, 2010).

<sup>75</sup> *Ibid.* at 36.

<sup>76</sup> *Ibid.* at 30, 169.

<sup>77</sup> *CMA Code of Ethics*, *supra* note 20 at 2.

<sup>78</sup> *Ibid.* at 3.

<sup>79</sup> *Ibid.* at 6.

<sup>80</sup> *Ibid.*

<sup>81</sup> College of Physicians and Surgeons of Ontario, *supra* note 46 at 10.

<sup>82</sup> Gruben, "Self-Regulation," *supra* note 24 at 159.

<sup>83</sup> College of Physicians and Surgeons of Ontario, "Applying the OHPIP Standards in Fertility Services Premises" (2017), online: [perma.cc/M6P5-CAUB].

<sup>84</sup> *Ibid.*



such as IVF, intrauterine insemination, and fertility preservation for medical purposes.<sup>85</sup> The proposed Out of Hospital Premises Inspection Program for fertility services creates detailed standards for fertility services.<sup>86</sup> For instance, it requires facilities to monitor quality of care and to record, analyze, and report “essential outcome measures” such as wait times for first appointments and first fertility treatments, and so on.<sup>87</sup> As Vanessa Gruben points out, while the proposed Out of Hospital Premises Inspection Program for fertility services represents an improvement to the current regulation of Ontario’s fertility sector, its main weakness is that the standards are determined and enforced by a self-regulating body.<sup>88</sup> There was promise that the fertility sector would come under provincial oversight with the *Oversight of Health Facilities and Devices Act, 2017*.<sup>89</sup> The *OHFDA* would have created a framework to govern independent health facilities and non-hospital medical clinics that provide privately financed care and would have established licensing, inspection, and complaints processes.<sup>90</sup> However, it was repealed on 18 May 2023.<sup>91</sup>

In Quebec, the Collège des médecins du Québec plays a significant role in the regulation of the fertility sector, but there is also extensive government regulation of assisted reproduction. The Collège des médecins du Québec draws up guidelines on assisted reproduction, keeps the guidelines updated, and ensures that they are followed.<sup>92</sup> The provincial government is responsible for licensing,<sup>93</sup> inspection, and oversight.<sup>94</sup> The *Assisted Procreation Act* makes it clear that when a physician is determining whether assisted procreation should be carried out and selecting a treatment, they need to make sure that the treatment does not pose a serious risk to the health of the person and to document this in the patient record.<sup>95</sup>

The CFAS Third Party Reproduction Guidelines also deal specifically with care. The Third Party Reproduction Guidelines highlight that gamete providers “be treated as patients in their own right.”<sup>96</sup> They recommend that relevant screening be performed on egg providers.<sup>97</sup> Even though producing larger numbers of oocytes is correlated with an increase in live birth rates and embryo cryopreservation, the number of developing follicles during ovarian stimulation also correlates with the risk of OHSS.<sup>98</sup> As a result, the Third Party Reproduction Guidelines recommend that there needs to be a balance found, and that balance should err in favour of the goal of minimizing risks to the egg provider.<sup>99</sup> It is recommended that egg providers be provided with accessible and high-quality post-procedure care and

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*Ibid.*

86

Ontario, *College of Physicians and Surgeons of Ontario: IVF Facility Inspection*, 41-2, Proposal No 17-HLTC022 (7 March 2017) online: [perma.cc/5WAF-CMS4].

87

Gruben, “Self-Regulation,” *supra* note 24 at 161.

88

*Ibid.*

89

SO 2017, c 25, Schedule 9 [*OHFDA*].

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Gruben, “Self-Regulation,” *supra* note 24 at 161–62.

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*OHFDA*, *supra* note 89.

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*Assisted Procreation Act*, *supra* note 66, s 10.

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*Ibid.*, ss 15–22.

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*Ibid.*, ss 25–35.

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*Ibid.*, s 10.1.

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CFAS, *supra* note 49 at 8.

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*Ibid.* at 14.

98

*Ibid.*

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*Ibid.*

counselling.<sup>100</sup> Although they are now withdrawn, CFAS also used to have clinical practice guidelines specifically on the management of OHSS.<sup>101</sup>

Two further voluntary Canada-wide programs that assist with patient care are Accreditation Canada and the CARTR Plus. Accreditation Canada is a private not-for-profit organization that has developed three standards relevant to assisted reproduction, including one-on-one work with third party providers.<sup>102</sup> For fertility clinics that have met the standards, Accreditation Canada issues a certificate indicating this. Over 35 clinics also voluntarily provide statistical information about their fertility treatment cycle data to CARTR Plus — a national self-funded database.<sup>103</sup> Data collected is aggregated and made accessible and could be used to rationalize clinical change.<sup>104</sup> In order to encourage clinics to provide their data to CARTR Plus, CFAS has created a Compliance Seal Program.<sup>105</sup> Clinics that have adopted the CARTR Plus framework can apply to CFAS for a CFAS Compliant affirmation that the clinic can then post on their website.<sup>106</sup>

### III. EXISTING CRITICISMS OF LAWS, REGULATIONS, AND GUIDELINES IN CANADA

The ways in which the fertility industry in Canada is regulated have been criticized on a number of grounds. Particularly as it pertains to egg provision, the *AHRA* has been criticized for its underlying presumption that compensation for egg provision is necessarily exploitative, and for overlooking the possibility that coercion and exploitation are possible without financial recompense.<sup>107</sup> In addition to underlying assumptions that egg providers always identify as women, the language of “protecting women” diminishes egg providers’ agency to make decisions about their bodies.<sup>108</sup> The ban on payment has also led to an underground market for eggs.<sup>109</sup> When egg providers participate in this market that is shrouded in “an aura of illegality” and secrecy, they may be less likely to return to the clinic if complications arise or be less likely to speak out if they are mistreated.<sup>110</sup>

Secondly, there are many criticisms of the two principal regulatory tools that govern the fertility sector — self-regulation and voluntary mechanisms.

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<sup>100</sup> *Ibid* at 15.

<sup>101</sup> Beth Taylor & Jason Min, “Canadian Fertility and Andrology Society Clinical Practice Guidelines: Ovarian Hyperstimulation Syndrome: Diagnosis, Prevention and Management” (2013), online (pdf): [perma.cc/L4C6-URJJ].

<sup>102</sup> Accreditation Canada, “Assisted Reproductive Technology (ART) Standards for Laboratory Services,” online: [perma.cc/GX8Z-GKXL].

<sup>103</sup> Lanes et al, *supra* note 14 at 2; V Bacal et al, “The Canadian Assisted Reproductive Technologies Register (CARTR202) Plus Database: A Validation Study” [2020]:2 Human Reproduction Open 1.

<sup>104</sup> Lanes et al, *ibid*.

<sup>105</sup> Canadian Fertility and Andrology Society, “CFAS Compliance Seal Program,” online: [perma.cc/C8LY-XT9T].

<sup>106</sup> *Ibid*.

<sup>107</sup> Cattapan, “Risky Business,” *supra* note 37 at 364, 374–75.

<sup>108</sup> *Ibid* at 362.

<sup>109</sup> Hammond, *supra* note 2 at 115.

<sup>110</sup> Cattapan, “Risky Business,” *supra* note 37 at 370.

Generally, there is a concern that self-regulation will cater to the needs of the profession rather than the needs of the public.<sup>111</sup> Efficacy concerns around self-regulation relate to a lack of preventive measures and oversight, and problems with the complaints function.<sup>112</sup> For instance, as set out above, the *HCCA* deals with informed consent in Ontario. The *HCCA* is administered by the Ministry of Health and Long-Term Care. It provides practitioners protections from liability when they act in good faith within the provisions of the *HCCA*. Although informed consent is regulated in theory under the Professional Conduct Regulation under the *Medicine Act, 1991*,<sup>113</sup> it is unclear how this regulation is enforced since there is no monitoring mechanism laid out.<sup>114</sup> As Colleen Flood and Bryan Thomas point out, there is no regular inspection mechanism to uncover breaches of the standard of care.<sup>115</sup> This means that complaints must generally be brought by patients.<sup>116</sup> However, patients may be ill-equipped to do so, as they may not be able to detect problems with safety and quality, and the complaints process may not be well known to them, or may be difficult for them to navigate.<sup>117</sup> Patients also may not wish to report, given the time, money, and energy it will require, and they may be concerned about jeopardizing the physician-patient relationship.<sup>118</sup> As Flood and Thomas point out, this may especially be the case with fertility services because clinics may be monopolies in certain areas.<sup>119</sup> When sanctions are given, they have often been criticized for being inappropriate or not sufficiently severe.<sup>120</sup> Additionally, Gruben points out that most provinces do not have standards (for instance, in relation to consent, practice standards, and practice guidelines) that are specific to assisted reproductive technologies, despite the unique nature of these technologies.<sup>121</sup>

The second regulatory tool — voluntary mechanisms — has also received much criticism. The first concern surrounds the extent to which health care professionals engage with voluntary mechanisms given that they are voluntary. CARTR Plus, for instance, offers important information about assisted reproductive technologies in Canada, but since disclosure is not mandatory, clinics do not have to provide data. Another example is assisted reproductive technology guidelines. Since guidelines, like the CFAS Third Party Reproduction Guidelines, are not binding, physicians may disregard them for a variety of reasons, such as lack of time or because they disagree with them.<sup>122</sup> The second concern relates specifically to the creation of guidelines and has to do with potential conflicts of interest when the individuals who create guidelines have relationships with the fertility industry.<sup>123</sup> As with self-regulation, the needs of the public may not be paramount.<sup>124</sup>

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<sup>111</sup> Colleen M Flood & Bryan Thomas, “Regulatory Failure: The Case of the Private-for-Profit IVF Sector” in Trudo Lemmens et al, eds, *Regulating Creation: The Law, Ethics, and Policy of Assisted Human Reproduction* (Toronto: University of Toronto Press, 2017) 359 at 369 [Flood & Thomas, “Regulatory Failure”].

<sup>112</sup> Gruben, “Self-Regulation,” *supra* note 24 at 151–52; *ibid.*

<sup>113</sup> SO 1991, c 30.

<sup>114</sup> Flood & Thomas, “Regulatory Failure,” *supra* note 111 at 368–69.

<sup>115</sup> *Ibid* at 369.

<sup>116</sup> Gruben, “Self-Regulation,” *supra* note 24 at 151–52.

<sup>117</sup> *Ibid*; Flood & Thomas, “Regulatory Failure,” *supra* note 111 at 369.

<sup>118</sup> Flood & Thomas, “Regulatory Failure,” *ibid.*

<sup>119</sup> *Ibid.*

<sup>120</sup> Gruben, “Self-Regulation,” *supra* note 24 at 151–52.

<sup>121</sup> Gruben, “Women as Patients,” *supra* note 16 at 278.

<sup>122</sup> Gruben, “Self-Regulation,” *supra* note 24 at 153.

<sup>123</sup> *Ibid.*

<sup>124</sup> *Ibid.*

#### IV. METHODS

Given these concerns and the potential for mistreatment of egg providers, this study sought to better understand the medical care experiences of egg providers. It involved interviews, between 2012 and 2015, with 16 Canadian egg providers about their experiences of care. All participants were given pseudonyms.

Fourteen of the egg providers had completed at least one egg transaction in Canada at the time of interview. These egg transactions had occurred at a variety of clinics across the country. One (Ellen) had only just started her egg transaction, and another (Michaela) had only provided eggs at a US fertility clinic. As such, my focus is on the narratives of 14 egg providers. Of these 14 egg providers, nine providers had engaged in egg transactions once, three providers had engaged in egg transactions twice, one provider had engaged in egg transactions four times, and one provider, Tiffany, had taken part in “15 or 16 [egg transactions] over a span of ten or twelve years.” Tiffany had done one of her “15 or 16” egg provisions in the US and the rest in Canada. Chantelle had done one of her three egg provisions in the US and the other two in Canada. I focus, however, on their experiences at Canadian clinics.

Of the 14 egg providers whom I focus on, 13 self-identified as Caucasian and one self-identified as “Native and African Canadian.” All 14 egg providers identified as women. Four egg providers were students. The others had a wide range of occupations, including secretary, manager of a non-profit organization, legal assistant, small business owner, and homemaker. Ten of the egg providers had engaged in egg transactions anonymously and so had little or no contact with the intended parents. Three egg providers were identified providers, meaning that they met the intended parents through the egg transaction and stayed in contact with them afterwards. Tiffany had done both anonymous and identified transactions.

In Canada, infertility forums and advertising websites have become a popular way for egg providers and intended parents to connect. I recruited egg providers through seven of these advertisement and infertility forums: Kijiji, Craigslist, Toronto Super Ads, opts.com, IVF.ca, ivf-infertility.com, and co-parent-search.com. I posted information about this study on all seven forums and invited egg providers who had posted in these forums to participate. A Canadian infertility support group and an online egg provider community (We Are Egg Donors) also kindly circulated information about this study.

I conducted phone and Skype interviews. Phone and Skype were preferred because egg providers lived in many different parts of Canada and because they afforded participants a greater sense of anonymity. This was important given the private nature of egg transactions. Among other open-ended questions, I asked egg providers about their experiences with egg transactions, logistical details as to how they arranged the transaction, including whether they had worked with an agency, where their fertility clinic had been located, what their experiences were with the clinics and agencies, and their perspectives about the laws in Canada surrounding egg transactions. Twelve egg providers were interviewed once, and four egg providers were interviewed before and after their egg transactions. Egg provider interviews ranged in length from 20 minutes to just under two hours, with an average of 55

minutes. I transcribed and coded all interviews according to conventions outlined by Sonja Foss and William Waters,<sup>125</sup> and Gery Ryan and H Russell Bernard.<sup>126</sup>

## V. EGG PROVIDERS' EVALUATION OF THE CARE THEY RECEIVED FROM CANADIAN FERTILITY CLINICS

Egg providers discussed which aspects of clinic care were most important to them and provided insight into the quality of care that they had received. Their experiences with the clinics ranged across a spectrum. On one end of the spectrum were experiences like those of Michaela who said she felt like a means to an end. She said, “the doctor didn’t really think of me as a patient; he kind of thought of me as more like a carrier of these eggs that he needed.” On the other end of the spectrum were experiences like those of Tiffany, who described herself as having been made to feel like “the important one in the process.” Other egg providers’ experiences ranged somewhere in between. Egg providers’ experiences illustrate the ways in which fertility professionals, physicians in particular, may not be following the laws, regulations, *CMA Code of Ethics*, and guidelines that are intended to ensure that patients are not harmed. In particular, egg providers remarked on specific parts of the informed consent process and their physical care that made the difference between where, on that spectrum, they would situate their experience.

### A. EGG PROVIDERS' EXPERIENCE OF THE INFORMED CONSENT PROCESS

All egg providers said that they had done some research on their own into what egg provision entailed. Egg providers also discussed different ways that they had received information from the clinic about egg provision — from physicians and nurses directly at initial contact and information in the consent form. Two egg providers also attended a group information session on egg provision run by the clinic. Thirteen egg providers had undergone counselling with a social worker, therapist, or psychologist.

Egg providers remarked on the fact that egg provision is difficult to understand until you have gone through it. Tiffany, for instance, said, “you know you had your psych evaluation, you talk to a doctor, you talk to a nurse. It was a full day of tests and talking and stuff ... but none of it was particularly helpful because until you’re actually doing it, you don’t really have an idea.” Another egg provider, Adrienne, said, “you don’t necessarily realize how serious it is until you’re actually kind of down there and in the clinic.” Adrienne and Tiffany’s experiences reflected a common theme among egg providers, namely, that it is a serious process and that it is important but difficult for fertility professionals to adequately convey what egg provision truly involves for the purposes of informed consent.

Nine egg providers said that they ultimately did not feel that their physician adequately informed them. Three recurring issues that arose were situations of: (1) the risks not being

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<sup>125</sup> Sonja K Foss & William Waters, “Coding Qualitative Data” (2011), online (internet archive): [perma.cc/KSS5-3KAA].

<sup>126</sup> Gery W Ryan & H Russell Bernard, “Data Management and Analysis Methods” in Norman K Denzin & Yvonna S Lincoln, eds, *Handbook of Qualitative Research*, 2nd ed (Thousand Oaks, Cal: Sage Publications, 2000) 769.

explained in an accessible way; (2) egg providers feeling as though their physician was downplaying or not sharing all the risks; and (3) physicians not telling egg providers about the lack of long-term data that exists on egg provision.

Lesley was one of the egg providers who felt that the risks had not been explained in an accessible way. She said that the physician gave her a list of possible risks. She said, “and I was like this Latin term, does that mean infertility? And again, at the group information session, they put up the same list, and I just didn’t feel like they explained what any of the words meant.”

Other egg providers were left feeling as though some risks were not shared with them or were downplayed. Stephanie said, “I’m aware of the risks I take by donating. However, I was not told any of the risks from the doctor at the first clinic even after I inquired. He glossed over it but made it seem as though they were slim to none. Liver failure was never mentioned. I had to do all my own research to get the real inside scoop.” Like Stephanie, Brooke also felt as though the risks were minimized. She said, “the doctor even spoke to me briefly saying that out of 8,000 egg providers he has never run into one single problem. But, you know, 8,000, who knows, I could be that one.”

In particular, egg providers felt that they had not been adequately informed about the risk of OHSS. Lesley and Michaela were two of the egg providers who had experienced OHSS directly following the retrieval. Lesley felt as though she had not been informed about OHSS altogether. She said, “they didn’t tell me anything about what was going to happen. They didn’t prepare me at all. I didn’t know I was overstimulated until after I called them.” Lesley felt that she was not given enough information about OHSS, its signs, and symptoms. She not only wanted to be informed about all the risks of egg provision, she wanted to be given enough information to be able to recognize symptoms if they arose. Michaela felt that she had been “fairly well-informed about the process and side effects.” But she said that “the one thing I did find was that they said that the risk of getting OHSS was very low and I was told that several times. After the fact, I’ve actually researched it more and found it’s probably more common than maybe they told me.” Michaela went on to explain that she also felt that she was not adequately informed throughout the process. She said:

And I actually ended up with probably moderate to severe OHSS and needed fluid removed and all that before I could fly home. I also found out after the fact that they knew that I was high risk and had shortened my protocol and decreased a few dosages because of this risk. So, they did act to prevent it to some extent, but I feel that I wasn’t informed that I was high-risk during the process and what that would mean and what I could expect. So, the day of the procedure, I went back to the hotel and had more pain than I was expecting. They sent me home with a prescription and sheet of information about it but never really explained, you know, what this was. And then I went back the next day, and I was severely bloated, nauseous, having trouble breathing because of the pressure and everything, and they said, okay, you have a mild case of hyperstimulation and this means we need to remove fluid. Just being kind of matter of fact and downplaying it. But again, I feel like it was something that they could have acted to prevent better or they could have told me about and then to kind of brush it off as if it’s just something that commonly happens when it’s not necessarily the norm made me feel like it invalidated some of my concerns that I was having about my treatment.

Other egg providers were surprised to find out about the lack of longitudinal data on the long-term effects of ovarian stimulation.<sup>127</sup> Marissa had provided eggs four times, and at the time of interview, she was having her own difficulties getting pregnant, so she had done some research of her own. She said, “you know, the biggest surprise for me was that a lot of the long-term risks on donors’ health haven’t even been studied, and I guess at the time that I donated, no one told me that we didn’t have all that information.”

When asked about the risks of egg provision, Katherine said:

I have given it some thought and I do feel like I am taking a risk. Basically, the answer is that there are no long-term studies for people who have normal fertility that have been exposed to fertility drugs, right. So, it’s an unknown. I certainly don’t have any known genetic predispositions to uterine or ovarian cancers. But that certainly doesn’t mean that I’m not increasing my risk. But I didn’t really know that going in, and it certainly is a risk that I’m taking.

Egg providers’ interviews provided information about the kinds of things that they felt they needed to know to feel fully informed about the egg provision. These were: having the full process, including the hormone stimulation phase, egg retrieval, any fertility medications, side effects, and any physical and psychological risks explained to them prior to the procedure. They also explained what informed consent meant to them. Specific aspects of this were that the “seriousness” of egg provision needs to be conveyed, all risks need to be explained in accurate and accessible language, they should be taught how to spot indicators of OHSS, they should be updated throughout about their treatment protocol, and they should have the opportunity to pull out of the process.

The fact that some egg providers were not informed to this extent is contrary to the goal of the *AHRA* that free and informed consent must be a fundamental condition of assisted reproductive technologies,<sup>128</sup> and of the general principle that consent to medical treatment must be informed.<sup>129</sup> Not providing information on all of the risks (for instance, Stephanie and Lesley), downplaying risks (for instance, Brooke and Michaela), not keeping egg providers informed about their treatment protocol (for instance, Michaela), and not informing egg providers about the lack of long-term data (for instance, Marissa and Katherine) is contrary to provincial practice guidelines such as the CPSO’s practice guide.<sup>130</sup> It is also contrary to the *CMA Code of Ethics*’ virtue of honesty,<sup>131</sup> the professional responsibility to “communicate information accurately and honestly,”<sup>132</sup> and the requirement of health professionals to help patients assess risks and benefits.<sup>133</sup> For instance, a statement like “never having run into a problem with 8,000 egg providers” is likely dishonest and inaccurate. Not disclosing information about all possible risks or the lack of long-term data does not enable the goal of helping a patient assess risks and benefits. Not disclosing side

<sup>127</sup> Tober et al, “Alignment,” *supra* note 18 at 10.

<sup>128</sup> *AHRA*, *supra* note 12, s 2(d).

<sup>129</sup> *HCCA*, *supra* note 60, s 11(2); Art 11 CCQ; *Ciarlariello*, *supra* note 58 at 135.

<sup>130</sup> College of Physicians and Surgeons of Ontario, *supra* note 46 at 9.

<sup>131</sup> *CMA Code of Ethics*, *supra* note 20 at 2.

<sup>132</sup> *Ibid* at 4.

<sup>133</sup> *Ibid* at 5.

effects and risks is also contrary to the common law principle of informed consent and provincial legislation on consent to treatment.<sup>134</sup>

The problems portrayed by these egg providers are also contrary to the “rigorous informed consent” procedure suggested in the joint policy statement of the Society of Obstetrics and Gynecologists of Canada and the CFAS.<sup>135</sup> Although the CFAS Third Party Reproduction Guidelines were not in place at the time that these egg providers had undergone their transactions,<sup>136</sup> these scenarios would be contrary to the guideline that egg providers should be informed of the side effects and risks of ovarian stimulation and retrieval and the potential of OHSS.<sup>137</sup> These guidelines additionally encourage fertility professionals to counsel egg providers on the potential risks of multiple egg provisions.<sup>138</sup> Five egg providers in this study had provided eggs multiple times, with Tiffany, who described herself as a “proven donor,” having provided eggs the most: “15 or 16 over a span of ten or 12 years.” This is far more than the American Society for Reproductive Medicine and CFAS Third Party Reproduction Guidelines recommendation of no more than six egg retrievals.<sup>139</sup> Not only was Tiffany not counselled on the risk of multiple egg provisions, it is important to note that Tiffany’s high number of egg provisions was encouraged by the fertility clinic that she worked with. She says, “yeah, I know it sounds really bad when you say the number. But at the time, it was just, I get a call [from the clinic] and I’m like okay, yeah sure. You know the last time was a long time ago so, sure.” In Tiffany’s case, it is possible that the fertility professional who called her encouraged these egg provisions for the purpose of pleasing the intended parents — the paying patient — at the clinic. If this is the case, this would be contrary to the *CMA Code of Ethics*’ duty to “avoid, minimize, or manage and always disclose conflicts of interest”<sup>140</sup> and would be contrary to provincial practice guidelines.<sup>141</sup>

## B. EGG PROVIDERS’ EXPERIENCE OF PHYSICAL CARE

Physical care was the second key component that affected egg providers’ experiences of care. Four aspects of physical care stood out to egg providers: (1) their relationship with and accessibility of their physician and clinic; (2) the number of eggs retrieved; (3) OHSS and the steps taken by their physician to prevent it or manage it; and (4) the care and follow-up that egg providers received after the egg retrieval.

The first important part of physical care was the connection that egg providers had with fertility professionals at the clinic, usually their physicians. Stephanie did not feel as though she had a good relationship with her physician and had not been able to develop a relationship with anyone else at the clinic. She said, “The doctor didn’t care about me; the staff was always rotating my care and appointments, so I never saw the same nurse or technician twice in a small clinic.”

<sup>134</sup> *HCCA*, *supra* note 60, s 11(3).

<sup>135</sup> Martin et al, *supra* note 47 at 178.

<sup>136</sup> CFAS, *supra* note 49.

<sup>137</sup> *Ibid* at 14.

<sup>138</sup> *Ibid* at 15.

<sup>139</sup> The Practice Committee of the American Society for Reproductive Medicine & The Practice Committee of the Society for Assisted Reproductive Technology, *supra* note 55; *ibid* at 18.

<sup>140</sup> *CMA Code of Ethics*, *supra* note 20 at 6.

<sup>141</sup> College of Physicians and Surgeons of Ontario, *supra* note 46 at 10.



Lesley also felt as though she had not been able to develop a relationship with her physician. She said, “the doctor that was there bounces between that clinic, another clinic, and one in the States. So, this guy’s all over the place trying to do as many as possible. And he does have good bedside manner. He was decent, but he was not present.”

Related to the relationship with the physician or fertility professional was the ease by which egg providers could reach the clinic. Marissa described this as the clinic “being there if I needed them.” Sarah described her experience with the clinic that she worked with. She said:

The protocol is very clear, and they’re always a phone call or an email away. They were a very good clinic to work with. You’re never left hanging by any means ... Still to this day, even though it’s already been done, if I have any questions, I can easily email them and they’d get back to me.

Sarah felt as though she could easily get a hold of her clinic if she needed to and that the clinic staff remained accessible to her, even having finished the egg transactions. Alex’s clinic was not as accessible: “I called a couple of times with just like questions and stuff, mostly about the hormone dosages, and I don’t think they ever got back to me once. A couple of times it did cross my mind, like what if something really serious happened? Would anyone take care of me?” By not being accessible to answer questions throughout, Alex felt as though the clinic staff were not providing adequate care.

Another aspect of physical care that affected egg providers’ overall assessment of care was how many eggs had been retrieved. Specifically, egg providers did not want to feel as though they were, as Katherine puts it, “being pressured to pump out as many eggs as possible.” Katherine explained that she was happy. As she explains, “I’m getting genuine support from the clinic and I’m not being pressured to pump out as many eggs as possible. I feel like less of an egg factory.”

Five egg providers gave details on how many eggs had been retrieved. Adrian said, “They got 26 eggs out of me,” Lesley said, “18 eggs,” Tiffany said, “My retrieval numbers ranged from 20 to a couple times up in the 40s.” Vanessa said that 30 eggs had been retrieved, and Michaela said that 29 eggs had been retrieved.

Vanessa explains, “I think it was my first cycle they took out 30 or some eggs. I looked seriously pregnant. I felt like they just kept pumping me full of hormones. That seems like a lot of eggs, too many eggs. Like is that really necessary?”

Michaela, who had OHSS, and whose experience is discussed in the section on informed consent, said:

I actually asked the doctor to tell me how many eggs when he was done just because I was curious. And he said oh 20 to 30 something like that. I was like okay, that seems like a lot. So, I was looking through my chart the next day while waiting to be seen and it said 29 eggs, which I didn’t know necessarily was that good until I started doing more research afterwards and I realized that was probably more than enough and again borderline putting me at risk to get that number. And again, I felt like they maybe didn’t act with my health in mind so much as this final product of let’s get 29 eggs from this person.

Michaela and Vanessa's quotes echo a common sentiment which is that "too many" eggs had been retrieved from them and that retrieving more eggs was prioritized over their best interest.

A third aspect of physical care that egg providers mentioned was the way in which their physicians had mitigated OHSS. Seven egg providers indicated that they had OHSS with at least one of their egg transactions. Amelia had experienced OHSS at her first clinic. At the second clinic, Amelia had spoken to her doctor about her concerns with OHSS. Amelia said:

When I started to think about doing a donation again, there was no way I would do the donation if I was at risk again for OHSS. So, when I went and spoke with my doctor, they said that now they do a new procedure where there was no risk of me overstimulating. And when I did the second donation this time, I was completely fine. I had no problems whatsoever. I felt great the whole time, there was no problems. So, I was very happy about that.

Amelia's physician had adapted the procedure to mitigate OHSS, thus making her physical care a priority. Lesley had the opposite experience. She said:

The clinic tried to run it through like cattle. It was gross. I told them that I had a thyroid problem in the past and that I'm highly sensitive to hormones. They didn't keep an eye on that. Like not that I have a thyroid thing, but they did not keep an eye on the hormone levels. They should not have given me as much stimulant as they did. Like to the point where they overstimulated me.

Lesley felt that the physician had not listened to her concerns and had not tried to prevent OHSS.

The last aspect of physical care discussed by egg providers was aftercare. Literature in this area in Canada has indicated that fertility clinics neglect this aspect of care.<sup>142</sup> Almost half of the providers in this study felt that they had not received proper aftercare. Egg providers described there being no follow-up after the egg retrieval, not being able to get a hold of the clinic after the retrieval when they called, or having their symptoms downplayed by the clinic after the retrieval. Lesley was among the egg providers who were unable to get a hold of her clinic after the retrieval. Lesley said:

They had no follow-up. No follow-up at all. And I asked when I went in and I was like, "Do you guys do like post-care?" And they were like, "Of course we do. We wouldn't just abandon you." Then they turn around and abandon you. They're like that guy who just sweet talks his way into your pants. As soon as they got my eggs, they treated me 180. Before they were treating me like I was a princess, that I was the great provider. But then as soon as they got what they wanted out of me, not the parents, the clinic, they treated me like dirt. Absolute dirt.

Stephanie, on the other hand, was eventually able to get a hold of the clinic which she felt downplayed her symptoms. She said:

Unfortunately, I ended up with severe OHSS and landed up in the hospital for a week on IV fluids, morphine, daily blood work, and chest x-rays. The day following the procedure, I was so ill I couldn't stand up straight,

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<sup>142</sup> Gruben, "Self-Regulation," *supra* note 24; Motluk, *supra* note 2.

the swelling started, and I was in immense pain from my ribcage down. I began violently vomiting the following night for seven hours straight, and when I called the clinic to let them know what was going on, they had me come in for an ultrasound, and I was told my condition was perfectly normal. I should have been told to go to the hospital then and there. My ultrasound showed, from what I was told, “a little bit of free fluid” in my abdomen. This pain and nausea continued for three to four days until I finally went to the emergency room because breathing became difficult. Long story short, I don’t feel I was given proper aftercare at the clinic the procedure was done at. I had more than a little bit of free fluid, and actually had fluid in my lungs.”

Lesley and Stephanie’s experience echoes a finding of A. Kalfoglou and J. Gittelsohn, in which seven egg providers that they interviewed had been made promises by clinic staff while being recruited.<sup>143</sup> These promises were not kept once the egg providers were engaged in the process.<sup>144</sup> Lesley’s metaphor of the guy sweet talking his way into her pants reiterates a feeling felt by egg providers who did not feel as though they received adequate care, as feeling “used,” or as a means to an end.

Generally, all actions by physicians that lead egg providers to feel like a “means to an end” are contrary to the *CMA Code of Ethics*’ commitment to respect for persons<sup>145</sup> as they devalue the equal and intrinsic worth of an egg provider. Some of the actions by physicians that were described by the egg providers additionally run contrary to other parts of the *CMA Code of Ethics*. The “commitment to the well-being of the patient” includes duties to provide appropriate care and management across the care continuum.<sup>146</sup> Inaccessibility of the physician throughout the process and lack of aftercare for the egg provider runs contrary to this (for instance, Stephanie, Lesley, and Alex). The commitment to the well-being of the patient also involves duties to “act to benefit the patient,” “[t]ake all reasonable steps to prevent or minimize harm to the patient,” and to “disclose to the patient if there is a risk of harm or if harm has occurred.”<sup>147</sup> Stimulating egg providers to produce quantities of eggs in the amounts described by some egg providers (for instance, Tiffany, Michaela, Vanessa, and Adrian), not listening to patients who advise their physician about pre-existing conditions that should be taken into account (for instance, Lesley), and not keeping egg providers informed about issues and risks (for instance, Michaela) runs contrary to these commitments and puts the well-being of the patient at risk. These kinds of actions contradict the CFAS Third Party Reproduction Guidelines’ recommendation that physicians should follow a stimulation regime that minimizes the risk of OHSS.<sup>148</sup> Not disclosing that an egg provider is at elevated risk for OHSS (for instance, Michaela), or minimizing or not being upfront with an egg provider who is presenting symptoms of OHSS is contrary to the duty to disclose a risk of harm or to disclose if harm has occurred (for instance, Stephanie and Michaela).

Additionally, it is possible that some of the egg providers, including the seven who had OHSS, were stimulated to produce an overly large number of eggs because physicians prioritized having a large number of eggs for intended parents — the paying patient. If that

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<sup>143</sup> AL Kalfoglou & J Gittelsohn, “A Qualitative Follow-Up Study of Women’s Experiences with Oocyte Donation” (2000) 15:4 Human Reproduction 798 at 802.

<sup>144</sup> *Ibid.*

<sup>145</sup> *CMA Code of Ethics*, *supra* note 20 at 2.

<sup>146</sup> *Ibid.*

<sup>147</sup> *Ibid.*

<sup>148</sup> CFAS, *supra* note 49 at 15.

is the case, this contradicts the CFAS Third Party Reproduction Guidelines' recommendation that balancing the interests between egg providers and intended parents should "err in the goal of minimizing risks to the oocyte donor."<sup>149</sup> Similar to encouraging egg providers to undertake more than the recommended six egg retrievals, it would be contrary to the duty to avoid a conflict of interest duty in the *CMA Code of Ethics*<sup>150</sup> and provincial practice guidelines.<sup>151</sup>

Finally, the lack of aftercare described by egg providers (for instance, Lesley and Stephanie) is contrary to the *CMA Code of Ethics*' professional responsibility to "continue to provide services until these services are no longer required or wanted."<sup>152</sup> It would additionally be contrary to the CFAS Third Party Reproduction Guidelines that post-procedure care "must be available and offered" to egg providers.<sup>153</sup>

## VI. CONCLUSION AND RECOMMENDATIONS

The findings of this study paint a mixed picture of egg providers' experiences in Canada. While some egg providers received high-quality care, others received care that runs counter to existing laws, regulations, and guidelines, the *CMA Code of Ethics*, and also what we expect in terms of proper medical care. The data provides an indicator of what egg providers want to be informed of, how they want to be informed, and what their expectations are with respect to the physical care they receive.

Egg providers' experiences make it clear that much more oversight is needed of the fertility industry in Canada. The re-release of the CFAS Third Party Reproduction Guidelines and re-issue of the CFAS OHSS management guidelines would be a helpful first step. In revising and re-issuing these guidelines, CFAS should look, for instance, to the 2021 American Society for Reproductive Medicine guidance on egg donation for suggestions on best practices.<sup>154</sup> Given the problems with self-regulation and voluntary mechanisms, it would be ideal if, like in Quebec,<sup>155</sup> each province created legislation that explicitly lays out what is required for consent to egg provision and that deals with physical care for egg providers. Alternatively, the colleges could create practice guides that deal with these two issues. These guidelines or practice guides would help inform the legal obligations of health professionals, for instance, in the case of a claim for injury in tort.

With respect to consent, information needs to be provided to egg providers in accessible ways, risks should not be downplayed, and egg providers need to be made aware where there is a lack of data on long-term risks. For physical care, either legislation or college guidelines should address things like the number of times someone should provide eggs, the number of eggs that should be retrieved, OHSS management, and aftercare. Importantly, there also

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<sup>149</sup> *Ibid* at 14.

<sup>150</sup> *CMA Code of Ethics*, *supra* note 20 at 6.

<sup>151</sup> College of Physicians and Surgeons of Ontario, *supra* note 46 at 10.

<sup>152</sup> *CMA Code of Ethics*, *supra* note 20 at 4.

<sup>153</sup> CFAS, *supra* note 49 at 15.

<sup>154</sup> Practice Committee of the American Society for Reproductive Medicine & The Practice Committee for the Society for Assisted Reproductive Technology, "Guidance Regarding Gamete and Embryo Donation" (2021) 115:6 Fertility & Sterility 1395.

<sup>155</sup> *Assisted Procreation Act*, *supra* note 66.

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needs to be increased recognition that this for-profit industry is ripe for conflicts of interest. Ways to address these potential conflicts of interest should be included in any legislation or guidelines, and the colleges need to pay very close attention to complaints and concerns filed by egg providers regarding the care that they received. Additionally, significantly more oversight of the fertility industry is necessary to ensure that laws, regulations, guidelines, and codes of ethics are complied with.

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