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ORIGINAL ARTICLE

Alignment between expectations and experiences of egg donors: what does it mean to be informed?

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Abstract This study evaluated the retrospective perceptions of egg donors regarding information communicated about immediate and long-term risks during the process of becoming an egg donor, and the alignment of that perception with their experiences and expectations of egg donation. Data were collected using an anonymous online survey. Egg donors' demographics, perceptions of being informed about immediate complications and long-term risks, and alignment between their expectations and experiences were analysed. In total, 375 current and former egg donors participated in an online survey about their decisions and experiences. Participants ranged in age from 18 to 57 years, with a median age of 24 years at first donation for compensated donors. The majority of the participants (81%) provided eggs in the USA, and 86.1% reported being compensated beyond direct reimbursement. Overall, 66% of egg donors surveyed reported feeling that their experiences matched their expectations based upon what they had been told during the informed consent process. While most participants (64.8%) felt well informed about potential short-term risks, 55.2% did not feel well informed about potential long-term risks. The findings indicate that while the majority of egg donors felt informed about immediate complications, there are gaps in knowledge about potential long-term risks. Results from this research provide insight into how egg donors understand risks and benefits, and can be used to improve counselling and informed consent forms and processes. The findings also indicate that longitudinal research on the health and well-being of egg donors is needed in order to improve informed consent.

KEYWORDS: egg donation, informed consent, infertility, risks, ethics

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Introduction

The use of donor eggs in assisted reproduction is fast growing. The first reported live birth from a donor egg occurred in Australia in 1983 (Kamel, 2013; Leeton, 2004), quickly followed by another in California in the same year (Bustillo et al., 1984). In the 35 years since these first reported live births, the demand for donor eggs for in-vitro fertilization (IVF) cycles has increased dramatically, almost doubling between 2000 and 2010 (Kawwass et al., 2013). In 2005, out of 134,260 total assisted reproductive technology (ART) cycles, 16,161 involved the use of donor eggs, representing approximately 12% of all ART cycles (Centers for Disease Control and Prevention, 2005). By 2016 – the most recent data provided by the Centers for Disease Control and Prevention – donor eggs were used in 24,300 of a total of 263,577 ART cycles, representing approximately 9% of all ART cycles (Centers for Disease Control and Prevention, 2016). While the percentage of ART cycles with fresh donor eggs has decreased by 3% since 2005, the overall demand for donor eggs has increased by 50% in the same period of time (Centers for Disease Control and Prevention, 2016). While the use of fresh donor egg cycles has decreased, this is likely due to the increased use of frozen eggs and embryos (Shapiro, 2018). The expanding demand for donor eggs is due to several factors: an increase in women delaying childbearing; increased use of egg donation; and gestational surrogacy among same sex couples and single people due, in part, to increasingly restrictive international adoption laws.

The medical definition of a 'donor' is 'a person or organism that supplies an organ or tissue to be used in another body' (Medical Dictionary, 2020). This definition does not specify whether or not payment occurs in the process of supplying, only that 'donation' includes transference of material from one body to another. When it comes to oocyte donation, some donors provide eggs with no compensation, or limited reimbursement for direct expenses, particularly in countries with a more regulated approach to third party reproduction (Hudson et al., 2020; Tober and Pavone, 2018). In the USA, the majority of those who provide eggs do so in exchange for payment, usually thousands of dollars per cycle. Many have called for use of the term 'egg provider' rather than egg donor, as it more accurately reflects the commercial transaction of paid oocyte provision (Baylis, 2014; Beeson et al., 2015; Lafuente Funes, 2019). However, whether a donor is financially compensated or not, and regardless of how the egg cells will be used (e.g. for stem cell research or fertility treatment for another person), the process of ovarian stimulation and oocyte retrieval is the same, as is the requisite for fully informed consent. For the purposes of this paper, although the majority of women in this study were paid egg providers, the term 'egg donor' will be used as it is more encompassing of both paid and unpaid donation, and better reflects the medical definition of 'donor'.

Despite the fact that oocyte donation has been occurring for over 30 years, there is little information available about the immediate and long-term impact on the health and well-being of donors. According to an Institute of Medicine report on oocyte donation for research purposes, 'one of the most striking facts about in vitro fertilization is how little is known with certainty about the long term health outcomes for women who undergo this procedure' (Institute of Medicine, 2007). Egg donors undergo several weeks of hormone injections, followed by surgery under anaesthesia to retrieve the mature eggs from their follicles. While the process of ovarian stimulation is thought to be safe, it is also a medical procedure not without risks.

To date, the majority of existing research on ovarian stimulation has focused on women undergoing the process towards their own intended pregnancy (Chandra et al., 2005; Daniels and Heidt-Forsythe, 2012) and extrapolating this information to donors. There is reason to believe, however, that older women experiencing infertility may not be a comparable group to egg donors, because these women are younger, may respond more aggressively to stimulation protocols, produce higher quantities of oocytes per cycle, and undergo multiple donation cycles (ASRM, 2014). The paucity of research on the effects of ovarian stimulation specific to oocyte donors has serious implications for enabling truly informed consent.

Challenges of informed consent in the context of oocyte donation

Informed consent is an interactive process between a patient and a medical provider that helps to ensure a patient (or research participant) has the necessary information in order to make an informed decision before treatment. The required elements of informed consent include documents and conversations so patients understand: (i) the nature of the procedure; (ii) the risks and benefits of the procedure; (iii) reasonable alternatives; and (iv) risks and benefits of the alternatives (Shah et al., 2020). Informed consent is crucial to the autonomous decision-making of all patients and research participants, including egg donors. Bioethicists have sought to define standards and meanings of informed consent (Beauchamp, 2017; Brody, 1984; Brody, 2001), the challenges of financial incentives on informed consent and decision-making (Carroll and Waldby, 2012; Grady, 2001; Hyun, 2006; Mertes and Pennings, 2007), and how to standardize and measure comprehension of informed consent (Buccini et al., 2009; Skillern et al., 2013, 2014). Others have questioned the vast divide between 'the ideal of consent and actual practice' and seek a balance between individual control and institutional oversight in research settings (Koenig, 2013, 2014). Ensuring fully informed consent can be challenging, there is a natural asymmetry of knowledge between lay individuals and clinical experts, patients and research participants do not always retain all of the information communicated during this process, and there are often gaps between information communicated and information retained (Beskow and Weinfurt, 2019). This has led to increased efforts to determine what type of information matters to prospective research participants (Beskow et al., 2020).

With regard to extracting cells and tissues, informed consent may include not only information regarding potential psychological and physical risks and benefits, and rights and responsibilities, but also information about how materials will be used, stored or distributed, and the nature of the research. However, little is known about how the

informed consent process plays out in clinical and research settings, how information about procedures and risks is communicated to patients, how patients understand and interpret the information being communicated (Axson et al., 2017), and the degree to which experiences match expectations based upon information provided throughout the process.

Some have noted serious deficiencies in informed consent forms for gamete donors for stem cell research, such as lack of clarity surrounding the purposes of the research, in addition to failing to address potential health risks (Niemiec and Howard, 2019). One pilot study of 19 oocyte donation programmes found that donor recruiters downplayed or misrepresented risks during a preliminary telephone call with egg donor applicants, noting, 'Because oocyte-donor programs must alleviate the shortage of donors if they wish to maintain a financially viable business, there is reason to fear that they may minimize or misrepresent risks when recruiting egg donors' (Gurmankin, 2001:3). When those providing eggs may be paid thousands of dollars to undergo a potentially risky procedure with no personal medical benefit – whether for research purposes or to be used for another person's fertility treatment – 'undue inducement' may also be a concern (Carroll and Waldby, 2012; Grady, 2001; Mastroianni, 2001; Mertes and Pennings, 2007).

While informed consent is considered essential, guidelines and legislation surrounding informed consent are highly variable, both in the USA and around the globe. With regard to oocyte provision in the USA, for example, there are no federal laws specifying what information oocyte donors must be given before undergoing the process (Cahn and Collins, 2014), although several states (e.g. California, New York and Arizona) do have regulations specifying that information about the drugs used, the procedures and potential risks must be communicated (Cahn and Collins, 2014; Heidt-Forsythe, 2018). However, even when guidelines or regulations exist, such as in Canada, not all clinic informed consent forms comply with what is required under the Canadian Assisted Human Reproduction Act (Cattapan, 2016).

In the USA, in 2014, the American Society for Reproductive Medicine (ASRM) updated its recommended model informed consent forms for oocyte donors (Crockin and Daar, 2014). However, these are not used uniformly in all clinics, with most clinics choosing to create and use their own forms and consent procedures. As such, there is substantial inconsistency, which could lead to widespread variations in the understanding of risks and benefits among egg donors. In addition, with ovarian stimulation and oocyte retrieval – which takes place over the course of several weeks and includes many different pharmaceutical and surgical interventions – the timing of information provided should also be considered; for example, whether all information is provided in advance of signing contracts, at different stages of the process, or both.

While several studies have analysed informed consent forms for paid egg donors, including what is both present and absent in consent forms for egg donors for fertility treatment and for research eggs, few studies have examined how egg donors themselves understand what is being communicated, the accuracy of what is being communicated, or how their experiences align with the information provided. In a US-based study of 80 oocyte donors, 20% of respondents reported that they were unaware of possible physical complications related to providing eggs (Kenney and McGowan, 2010). In another study of 149 oocyte donors in South Africa, 7% reported that they felt underinformed about potential complications, and 5% reported experiencing complications related to their donations (Thaldar, 2020). Some university-based clinics have increased efforts to improve informed consent for oocyte donors by developing tools to measure information retention and comprehension (Skillern et al., 2013, 2014).

There are many steps to becoming an egg donor, including: psychological counselling; legal counselling; receiving and reading informed consent forms addressing risks and benefits; and opportunities to ask physicians or other medical professionals questions about drugs, procedures and potential risks. However, in the USA and abroad, there are no uniform regulations as to what information is required to be included, and there is substantial variation between clinics and egg donation agencies, and in different geographic locations and regulatory settings. Furthermore, due to the lack of research specifically focused on the health outcomes for women who provide eggs, information provided throughout this process is incomplete, and the detail and quality of informed consent documentation and practice is inconsistent (Blakemore et al., 2019; Cattapan, 2016). In the USA, where egg donors are recruited both directly through fertility clinics with internal egg donation programmes, and through non-medically-licensed egg donation agencies, some have expressed that agencies pose 'critical ethical concerns' when it comes to donor recruitment and informed consent (Klitzman, 2016).

This paper uses survey data from egg donors to address current gaps in knowledge regarding how egg donors perceive the informed consent process and what types of information they feel they need. It will examine the degree to which the experiences of egg donors match their expectations based upon what they recall being told in the process of becoming an egg donor, and the varying degrees of being 'informed'.

Materials and methods

The OVADO (Ova Donation) Project is an ongoing, mixed methods investigation on the decisions and experiences of egg donors in the USA and abroad, and the different medical and cultural settings in which egg donation occurs. Phase I of this project was launched in 2014 and included 30 preliminary egg donor interviews to better understand the range of experiences of egg donors. Twenty interviews with professionals in the egg donation industry were also conducted, including psychologists, attorneys, genetics counsellors, medical practitioners, agency founders and egg donor recruiters, among others. The research was approved by the University of California, San Francisco Institutional Review Board (IRB) (#14-14765).

Information gained from the interviews was used to design Phase II of the research, which included designing and piloting a comprehensive online egg donor survey. This phase was conducted between 2016 and 2018, and included 154 survey participants and 55 additional egg donor

interviews. Phase II participants were also asked for their recommendations on how to improve the survey. By piloting the survey twice over a 2-year time period (2016–2018), it was possible to identify questions that were unclear or garnered inaccurate responses, and incorporate respondent feedback into survey revisions. For a subset of participants who participated in both the survey and open-ended, semi-structured interviews, survey results were cross-referenced to ensure consistency between both sets of data. These combined methods enabled the validity of the current survey to be established. Based upon piloted survey responses and participant suggestions, the current egg donor survey was created, which was launched in February 2019. To date, there have been 375 responses to the 2019 survey. This paper draws upon the 2019 survey data; the 154 earlier survey responses are not included in the current analysis, but did inform the current survey design.

The survey was created in Qualtrics^{XM} (January 2019), an online survey platform. The survey contains 84 questions broken up into six sections, including: consent to participate in research (two questions); demographic information (16 questions); basic questions such as number of donation cycles, compensation per cycle, eggs retrieved per cycle, knowledge of live birth in the oocyte recipient, and desire to meet donor-conceived children (33 questions); donation cycle type such as known, anonymous, identity release and shared donation (three questions); self-reported health conditions pre- and post-donation (15 questions); three sets of Likert-scale questions on satisfaction and informed consent; and final questions on how their experiences could be improved and an option to opt in for future surveys or interviews (11 questions). The survey took approximately 20 min to 1 h to complete, depending upon how many cycles a participant had undergone. As some data were collected on a per-cycle basis, donors who had undergone more cycles required more time to complete the survey.

The link to the online survey and information about the study was provided to egg donor groups on social media, distributed to clinics and agencies, promoted through the We Are Egg Donors (WAED) online community (weareeggdonors.com), word of mouth, and made available on the OVADO Project website (eggdonorresearch.org). After clicking on the website link, or responding to e-mail and social media campaigns, prospective participants were directed to a contact form in order to receive the survey password by e-mail. Password protection helped to ensure that only current, former and prospective donors were able to access the survey in order to help increase data reliability. Prior to initiating the survey, participants were first presented with the IRB-approved consent form, which explained the scope of the survey and participant protections, and contained contact information to report any concerns. Participants were required to provide their initials granting their consent before proceeding to the survey proper.

Given that egg donation practices, consent processes and hormone protocols vary widely between clinics, and in different medical and cultural settings, for this exploratory research it was crucial to draw from as diverse a population as possible, rather than egg donors recruited from single private or university clinic programmes. As such, a 'catchall' approach was used to recruit egg donor participants from a wide range of practices. Recruitment criteria were also intentionally broad, given the overall lack of prior information on the study population and their experiences. This allowed for the inclusion of donors at various stages of the process, including current active donors who were still undergoing repeat cycles and former donors at any time after donation. In addition, prospective donors who had not yet completed one cycle were directed toward a pre-donation survey and were able to complete the follow-up survey after retrieval; prospective donors were not included in the current analysis as they were few in number and the degree to which their experiences would align with their pre-donation expectations was not yet known.

This paper is a preliminary report on an ongoing broader investigation on decisions, experiences, health and well-being of egg donors. It focuses on demographic data contained in the survey, a series of Likert-scale responses regarding perceptions of informed consent and the donation experiences on a five-point agreeability scale, and a tick box of potential immediate and long-term risks associated with egg donation often addressed in the informed consent process. These experiences include reactions to stimulation medications and trigger shots, surgical procedures, recovery, and emotional/psychological ramifications, among others.

On a separate list of possible complications, participants were asked which of the included health outcomes they recalled being advised of during their informed consent and screening processes. The list included known complications associated with egg donation – such as ovarian hyperstimulation syndrome (OHSS) and ovarian torsion – as well as side effects listed for each of the medications or medication classes used in ovarian stimulation protocols [e.g. gonadotrophin-releasing hormone (GnRH) agonist and GnRH antagonist hormones], and potential unknown long-term effects addressed in the literature, such as endometriosis and reproductive cancers (Fiedler and Ezcurra, 2012; Kalfoglou and Geller, 2000; Kramer et al., 2009; Schneider et al., 2017). The possible responses to this section included: 'yes, all of them', 'no, none of them' and 'some, but not all'. Text boxes were provided so respondents could further elaborate on perceptions of informed consent. These statements addressed a range of issues related to egg donation experiences and what donors recalled being told during the informed consent process. Sample statements have been selected from the text boxes and categorized according to the range of responses, including: 'informed about short-term risks', 'somewhat informed about short-term risks' or 'not informed about short-term risks', and 'informed about long-term risks'.

In addition to more general questions about degrees of feeling informed about short-and long-term complications, a separate question was included to specifically address what donors recalled being told about OHSS, the most common, known, immediate complication associated with egg donation. In this question, a chart was provided that explained different types of OHSS in further detail, categorized from 'no OHSS' to 'mild, moderate, severe and critical OHSS', as adapted by ASRM (Fiedler and Ezcurra, 2012; Pfeifer et al., 2016). For this question, participants were asked to indicate if they had been told by medical professionals about this possible complication, and the different degrees of OHSS, by ticking either 'yes', 'no' or 'to some degree' responses. An

optional text box was provided so participants could clarify their answers or add further details.

Responses were exported from Qualtrics to Excel (Microsoft Corp., Remond, WA, USA) for analysis. Statistical analysis was performed using R Studio software. Data analysis for this paper included primarily the use of descriptive statistics to examine the sociodemographic traits of study participants and their perceptions of the informed consent process. Measurements of age and the number of cycles in which participants had engaged were measured as continuous variables. Other variables, including responses to the Likert-scale series of questions, were captured as categorical responses. The results were summarized as the frequency of each level and as a proportion of the total sample, or as median and range for continuous variables.

Results

Demographics

Three hundred and seventy-five current and former egg donors initiated the online survey, of which 274 completed 100% of the survey; 82 surveys were at various stages of completion. Nineteen individuals completed less than 10% of the survey and were excluded from the analysis. The results draw upon 356 completed or partially completed surveys. Total recorded responses per item are indicated in the tables provided.

Two hundred and forty participants reported finding out about the study via WAED, an online international community of over 2000 current, former and prospective egg donors. The remainder found out about the study from a range of sources, including other egg donor groups; articles or social media published about this work; online radio, podcast or video interviews with the principal investigator; referral from a friend or acquaintance; e-mail; or through their agency or clinic.

Participants ranged in age from 18 to 57 years. The median age at first donation for all donors combined was 25 years. The median age reported for compensated donors (n=280) was 24 years, and the median age for uncompensated donors (n=45) was 29 years. Active donors – women who had completed at least one cycle and planned to undergo another cycle in the near future – ranged in age from 18 to 31 years. Inactive donors ranged in age from 20 to 57 years, and included those who had completed at least one cycle and had no plans to undergo another. In total, 52 participants were between the ages of 30 and 38 years at the time of first donation. The majority of these lived in countries where compensation is prohibited or limited (e.g. UK and Canada) and/or where prospective donors are preferred to have completed their own families prior to donation (e.g. Australia and South Africa). US first-time donors over 30 years of age were predominantly uncompensated known donors for friends or family members (n=17).

Egg donors may be differentially selected and compensated according to appearance, race and other traits, particularly in the USA (Almeling, 2007; Deomampo, 2019; Tober and Pavone, 2018; Tober, 2019). As many have addressed, ancestry has meaning and is embedded in cultural understandings of genes, heredity and identity (El-Haj, 2012; Nelson, 2016; Tallbear, 2013). In the context of egg donation, race and ancestry play out in complicated ways when it comes to donor recruitment, as well as how eggs (and egg donors) are marketed and transacted. Simplified categories of 'race' (e.g. as Black, White, Asian and Hispanic) are problematic, as these inaccurately reflect complex individual identities and the range of human variation. These categories can also vary in different cultural contexts. To account for these challenges, and in order to more accurately capture the range of backgrounds with which egg donors in the sample identified, respondents were able to tick multiple categories and choose a primary category with which they identified. As expected, respondents' selections of race/ancestry were highly variable, with most choosing multiple categories. To account for this, those who chose multiple categories were counted according to the primary category selected. For example, if someone selected 'Black/Afro-Caribbean', 'Latinx/Hispanic' and 'Native American', they would be included in Table 1 as 'Black/Afro-Caribbean/mix'. 'Asian' may refer to East Asian, West Asian, South-east Asian, etc. Many egg donors who identified as Jewish considered 'Jewish' to pertain to both religious affiliation and ancestral and cultural identity, regardless of whether or not they were religious. For this reason, 'Jewish' was included under both ancestry and religion. This was also significant as several egg donation agencies specifically seek out Jewish egg donors for their Jewish clients, where religion, culture and ancestry are perceived as intertwined and inherited through genetic material (El-Haj, 2012; Kahn, 2000).

Table 1 Participant demographics.

Participant demographics (n=356)	
	Median [range]
Age, in years, at first donation, median (n=325)	25 [18–38]
Compensated (n=280)	24 [18–29]
Uncompensated (n=45)	29 [18–38]
	n (%)
Active donor (n=340)	
Yes	118 (34.7%)
No	222 (65.3%)
Education (n=352)	
High school/GED	54 (15.3%)
Technical/vocational	42 (11.9%)
Bachelor's	160 (45.5%)
Master's/graduate	96 (27.3%)
Ancestry	
Euro-White/mix	258 (73.3%)
Asian/Asian mix	28 (8%)
Jewish/mix	19 (5.4%)
Hispanic/Latinx/mix	14 (4.0%)
Black/Afro-Carib/mix	15 (3.3%)
Native American/Alaskan Native	12 (3.4%)
Other (unspecified)	6 (1.7%)
Country of residence (n=352)	
USA	285 (81.5%)
Other	67 (19.0%)

GED, general educational development.

Two hundred and fifty-eight respondents (73.3%) identified as white or 'white mix'. The remaining ancestral groups were substantially fewer, with self-identified Asian or 'Asian mix' being the most represented of all other non-white groups at 8% (n=28). Out of 356 responses, four individuals identified as 'transgender' or 'gender non-conforming', plus one who declined to state. Seventy-seven percent (n=274) identified as heterosexual or straight, 14% (n=50) as 'bisexual', 3% (n=10) as 'lesbian', 5.3% (n=19) as 'polyamorous', 'pansexual' or 'other', and three who declined to state. Participants were also highly educated, with over 72% having a bachelor's degree or master's degree or higher, and fewer than 28% having stopped their education at high school or equivalent or vocational school.

Approximately 82% of participants lived in the USA and donated eggs within the USA (n=285), and 19% resided and provided eggs in other countries. Compensation varied dramatically between US- and non-US-based donors, with US donors receiving vastly higher compensation than their foreign counterparts. US donor payments ranged from a low of $500 to a high of $65,000 per cycle on their highest paid cycle, with an overall average of $8083 for all cycles. For foreign donors, compensation ranged from as low as $100 equivalent to as high as $8000, with an average compensation of $1774 US for all cycles. Country of donor residency can be found in Table 2.

Donors from Germany, Finland, Sweden and France travelled to other destinations to provide eggs due to regulations in their home country restricting or prohibiting egg donation. Destinations for travelling egg donation cycles for all respondents included Australia, Canada, Cyprus, India, New Zealand, South Africa, Thailand and the USA (mainly California), with many women travelling to several different destinations on subsequent egg retrieval cycles.

Table 2 Country of residence of donors.

Country of residence	n
USA	288
Canada	18
Australia	9
UK	8
South Africa	7
Germany [a]	4
Brazil	2
Finland [a]	2
Georgia	2
New Zealand	2
Spain	2
Sweden [a]	2
Czech Republic	1
France [a]	1
Kenya	1
Singapore	1
Taiwan	1
Thailand	1
Ukraine	1
Total	353

[a] Travelled elsewhere due to home country regulations prohibiting egg donation.

The majority of egg donors who travelled internationally to provide eggs reported that their recipients were also from other countries; for example, one donor travelled from South Africa to India three times and to Los Angeles twice for recipients from the USA, and another donor travelled from Los Angeles to Thailand to provide eggs to a couple from Spain (Tober and Kroløkke, forthcoming).

Out of 325 participants who responded to questions about compensation, 280 (86.1%) reported being compensated on their first and subsequent donation cycles, unless a cycle was cancelled for medical or personal reasons (n=4). Forty-five participants (13.8%) reported being voluntary, uncompensated donors, 23 in the USA and 22 in other countries. Of the 23 uncompensated US donors, 20 provided eggs to a family member, such as a sister or cousin, or to a close friend, with only one donating anonymously more than 15 years prior to the survey. Six of the known US donors participated in a shared cycle with their known recipient, where half of the eggs went to the recipient and half were frozen for themselves. The 22 uncompensated international donors lived in countries where compensation was either prohibited or restricted by law; of these, six were known donors for friends or family and 16 were anonymous donations. In addition, 20 donors were minimally compensated (less than $1000 US equivalent) or 'reimbursed' for direct expenses, such as travel. Of these, two had provided eggs in the USA more than 15 years prior to the survey, and the remaining 18 lived in countries where only reimbursement for direct expenses was allowed or compensation was limited.

As seen in Table 3, when excluding the four donors who had not yet completed a cycle through retrieval, 326 donors reported a total of 914 egg donation cycles (average 2.76 cycles per donor). Of the four donors who had not yet completed their first cycle, one withdrew from her egg donation programme before starting injections due to fear of potential risks; one had a cycle cancelled by her doctor because she had produced in excess of 62 eggs (beyond what the physician felt was safe); and two had not yet undergone

Table 3 Number of cycles per donor.

Number of cycles per donor	Respondents (n=330)	Responses (%)
0	4	1.2
1	130	39.4
2	66	20.0
3	43	13.0
4	22	6.6
5	23	6.9
6	25	7.5
7	3	0.9
8	2	0.6
9	2	0.6
10	5	1.5
11	2	0.6
12	0	0.0
13	2	0.6
14	0	0.0
15	0	0.0
16	0	0.0
17	1	0.3

their egg retrieval procedures at the time of the survey. These two participants were directed to the pre-donation survey.

Of the 326 respondents who had completed at least one cycle, 130 (39.4%) had completed one cycle and the remainder ($n=196$) had completed two cycles or more. The number of completed donation cycles per donor ranged from one to 17 cycles. The majority (93.4%) of respondents had completed six egg donation cycles or fewer, which is the current ASRM lifetime recommended maximum (ASRM, 2014). However, a total of 17 donors had completed seven cycles or more. The highest was a paid US donor who had completed 17 donation cycles over 3.5 years, for an average of 4.2 cycles per year, or one cycle every three months. Of the donors who went beyond six cycles, one uncompensated donor from Australia reported completing 13 cycles through retrieval. The remaining high-cycle donors ($n=16$) were from the USA and were compensated. Of the high-cycle US donors, two had provided eggs 11 years prior to the survey, two had completed their last donation cycles between 4 and 6 years prior to the survey, and 12 had completed their last cycle within the past 3 months ($n=6$) to 1–3 years ($n=6$).

Both current and former donors were included in this analysis: 42.2% had donated within the 12-month period prior to taking the survey; 35% were between 1 and 6 years since their last donation; and 22% had provided eggs at least 7 years before taking the survey.

Experiences, expectations and degrees of being informed reported by egg donors

The remainder of this paper addresses how research participants perceived the informed consent process, and the degree to which they felt their experiences matched their expectations based upon what they had been told. Respondents who reported an alignment between their actual donation experiences and what they recalled being told during the informed consent process indicated greater satisfaction with the quality of informed consent.

In response to the question on the degree to which their experiences donating matched their expectations based upon what the clinic or agency had told them about the process, a small majority of donors (66.5%) reported that their experiences and expectations were well aligned, with 40.8% responding that they 'strongly agreed' and 25.7% responding that they 'somewhat agreed'. Approximately 28%, however, disagreed with the statement, and felt that their experiences donating eggs did not match their expectations based upon what they had been told. Most participants (64.8%) felt that they had been given enough information regarding short-term risks. However, this trend was reversed regarding informed consent for long-term risks. Over 55% of respondents ($n=165$) indicated that they did not feel well informed about potential long-term complications.

Immediate, short-term complications include minor reactions to medications, pain at the injection site, and varying degrees of OHSS. With regard to immediate side effects from medications, 59.7% of respondents reported some degree of side effects from stimulation medications and 36.1% reported no adverse effects. In addition, 53.4% agreed or somewhat agreed with the statement that they had no complications from the retrieval procedures, and 39.4% disagreed with the statement. In Table 4, side effects are not ranked by type or degree of severity, but rather more generally, to ascertain whether or not they were experienced. Further detail was asked for in other parts of the survey, but is beyond the scope of the current paper.

Categories of 'informed'

There are different categories of information about which donors felt informed or not informed, including all short-term physical side effects and complications; immediate emotional or psychological consequences; and possible long-term side effects, complications, and emotional or psychological consequences. Short-term risks included immediate physical reactions to stimulation protocols, trigger shots, OHSS, and emotional/psychological reactions during the process. With regard to possible immediate complications, participants could indicate which they had been informed about and elaborate on what they recalled being told in a text box. In the text boxes provided, donors often connected what they had been told and whether or not that information was consistent with their experiences. Egg donors' experiences of feeling informed ranged from feeling well informed, to somewhat informed to uninformed, and are discussed below.

Informed about short-term effects

Participants who felt best informed addressed how they had been told about all possible side effects, and were given

Table 4 Cycle 1 survey responses to experiences, expectations, and informed consent.

Statement	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	Total response
My experiences as an egg donor matched my expectations based on what the clinic/agency told me	30 (10.0%)	54 (18.0%)	16 (5.3%)	77 (25.75%)	122 (40.8%)	299
I feel the clinic gave me enough information about potential short-term risks	39 (12.9%)	49 (16.2%)	18 (5.9%)	96 (31.7%)	100 (33.1%)	302
I feel the clinic gave me enough information about potential long-term risks	101 (33.8%)	64 (21.4%)	35 (11.7%)	46 (15.4%)	52 (17.4%)	298
I had no side effects from the medications	91 (30.2%)	89 (29.5%)	12 (3.9%)	69 (22.9%)	40 (13.2%)	301
I had no complications from the procedures	55 (18.4%)	63 (21.0%)	21 (7%)	53(17.7%)	107 (35.7%)	299

full information verbally or in writing, such as pamphlets describing possible side effects and symptoms to look out for. Informed donors also expressed feeling well cared for by the clinic and having more positive experiences than expressed by many less informed donors. For example:

> I was informed of all physical side effects, bloating, swollen ovaries, temporary cysts. I was given ultrasounds before, during and after each retrieval to check my ovaries.They went over most of these [possible complications] then provided me with tons of pamphlets and books explaining the rest.I knew some of the risks (nausea, bloating, cramping, etc.) were a risk, and OHSS. Overall, I feel I really lucked out with my clinic.

Being provided with substantive information, or even being given information on the lack of long-term studies, appears to be associated with increased trust in the clinic and feelings of having 'lucked out' by finding a clinic that was invested in their knowledge and care. One donor who was particularly satisfied with her informed consent process mentioned how her clinic had not only provided pamphlets and in-person counselling, but also a 40-min video that included sections covering different aspects of the egg donation process and a quiz to be completed at the end of each section.

Somewhat informed about short-term effects

Donors who felt 'somewhat informed' felt that they had not been given all the necessary information. Many felt that they had been told about the possible complications, but that the risks, whether physical or emotional, were downplayed. Donors who did not feel fully informed, or informed at the right timing in the process, expressed more mixed experiences:

> They informed me but not in a timely manner. For example, I was informed of the side effects of the injections the day I started injections. And I was told more of the complications of the surgery the day before surgery. So while I was informed, I don't really feel like I was informed ahead of time enough that I could have made a different decision [other] than to go through with it.I was not informed of the possibility of being put on bedrest which is ridiculous for a 23 year old. I knew of the adverse effects, but I didn't really know how uncomfortable they would be.I was asked how I would feel if I one day became infertile because of donating, but was never explicitly told that was a real risk, and in fact was told that because I was young and healthy, the entire process would be mostly risk-free.

Most donors relied upon the clinic or agency to provide them with complete and accurate information on the egg donation process. In addition, some did their own online research. In some cases, donors felt that the information they read through their own online research, or received in their online donor community, was more extensive than the information they received from the agency or clinic. Many addressed how having a better understanding of potential risks, provided by the clinic, would have improved their donation experience:

> I believe my experience would've been better if I had been more informed about risks from the agency directly. I only became aware of any possible complications or side effects once I did my own research.

Not informed about short-term effects

Donors who felt underinformed also expressed having post-donation complications that they were not prepared for and feelings of not having been given accurate information:

> They said complications were extremely unlikely, but I had all of them. Seems like they lied about severity of repercussions.It was never disclosed that nobody was keeping proper track of long-term effects on egg donors. I do not believe I was informed of risks of infertility. I have had ongoing issues since donating that nobody has documented.I was told there were no known or proven side effects from donating...The first cycle the clinic was learning how my body would respond to the medications and I was over stimulated. It was very painful and by the end of the cycle, just walking and sitting hurt. I was severely bloated.They glossed over the risks. The surgical egg removal was horrifyingly painful, but they would not stop. I was disrespected and abused...It was extraordinarily traumatizing. I nearly died from severe ovarian hyperstimulation syndrome.

Donors who experienced complications during or immediately after the donation process typically felt less informed than those who had positive experiences. However, feeling unprepared for possible negative outcomes could have exacerbated their sense of being underinformed when side effects were experienced. For those who had adverse reactions to the process, feeling disrespected and uncared for intensified physical and emotional trauma.

Informed about long-term risks

Over half of the survey respondents [55.2% ($n=180$)] felt insufficiently informed about potential long-term risks. Text responses indicate that these respondents recalled being told either that there are no long-term complications or that long-term risks remain unknown; if possible long-term complications were mentioned, it was brief and without further explanation. Feeling informed about potential long-term risks also occurred on a continuum, from being told there is a lack of information due to lack of research to being told there are no long-term complications. For example:

> They stated there have been no long-term studies on egg donation and how it affected the donor. Symptoms were mentioned briefly and then swept away. The focus was to stay as positive as possible and they did not get into any detail about complications. I was told that 'there is no evidence of long-term complications in the vast majority of donors', which I took to mean that it has been studied and complications were very rare. I've learned that what it actually means is that it has not been studied.

As seen in the statements above, while some donors were informed about the lack of evidence evaluating long-term

risk, others described how information was provided and dismissed. Still others were told that potential long-term complications were non-existent. Donors who recalled being told that there were no long-term studies and risks were unknown also expressed more trust that the clinic provided them with all available information. Respondents who felt that they had been led to believe that studies had been conducted and there were no long-term risks, or who felt that their concerns or questions were not addressed, expressed feeling frustrated and misled.

Informed about OHSS

As seen in Table 5, of the 280 donors who responded to the question about OHSS, 192 (68.5%) reported being informed about all possible OHSS categories; 28 (10%) reported not being informed about OHSS at all; and 60 (21.4%) reported having some information about OHSS, but not all the categories provided in the survey. Parallel to the distribution of responses regarding feeling informed about short-term complications discussed above, 68.5% of respondents felt well informed about all categories of OHSS. Simultaneously, 31.4% of respondents who felt partially informed or uninformed about OHSS mirrors the 29.2% of respondents in Table 5 who strongly or somewhat disagreed with the statement, 'I feel the clinic gave me enough information about potential short-term risks'.

Participants who elaborated in the text boxes provided an array of responses about their knowledge and experiences with OHSS, including:

> OHSS was briefly mentioned, but it was always mentioned in the context of 'worst case scenario'. As in, let us know if you are super bloated (not just middle bloated), or have difficulty breathing/feel dizzy. Nothing was mentioned about mild OHSS.They stated that OHSS is a thing, but not to worry because the biggest risk to a donor is driving to the clinic every day (in reference to a car wreck).I was informed about OHSS and various side effects, but told they were very rare and only 1% of donors experience them. They even told me that in all their time at the clinic no one had experienced OHSS.[I] ended up in the ER twice with severe OHSS and was told that it was less than 1 percent chance.

These responses indicate a lack of consistency between clinics about how potential immediate complications, such as OHSS, are addressed.

Discussion

Several studies have addressed potential complications for egg donors. Some have examined immediate known complications such as OHSS with varying results and levels of caution, ranging from reports that severe OHSS occurs in less than 1% of all donation cycles to as many as 7% in some studies (Fiedler and Ezcurra, 2012; Jayaprakasan et al., 2007; Kalfoglou and Geller, 2000; Luke et al., 2010; Sauer et al., 1996; Sismanoglu et al., 2009; Söderström-Anttila et al., 2016). Potential long-term complications, such as risk for various cancers, are an even greater unknown, as it is difficult to determine cause and effect without long-term, large-scale studies (Ahuja et al., 2003; Beeson and Lippman, 2006; Jayaprakasan et al., 2007; Sauer et al., 1996; Schneider, 2008; Schneider et al., 2017). The wide range of conflicting data on short- and long-term safety/risks complicates the informed consent process; some have highlighted that potential practitioner conflicts of interest may also complicate informed consent (Blake et al., 2015).

Table 5 Reports of being informed about ovarian hyperstimulation syndrome.

Informed (n=280)	Total (%)
No	28 (10.0)
Yes	192 (68.5)
To some degree	60 (21.4)

One prospective study of informed consent with 65 egg donors determined that: (i) donor comprehension is significantly affected by physician counselling efforts; (ii) egg donors had adequate subjective and objective comprehension of the process; and (iii) donor self-reports may not reflect their actual understanding (Skillern et al., 2014). Another retrospective study used an online survey with 80 egg donors who had provided eggs at a range of fertility clinics throughout the USA, and who had donated eggs for the first time at least 2 years prior to taking the survey (Kenney and McGowan, 2010). In this study, while 80% of donors surveyed reported awareness of some physical risks associated with hormone treatment and oocyte retrieval, their awareness of specific possible outcomes was deficient. In addition, 20% reported being unaware of any risks associated with the process (Kenney and McGowan, 2010). While recall bias is a possibility with retrospective studies, there is also potential bias in single clinic site research populations, as medical protocols, donor outcomes, donor OHSS rates and informed consent practices vary between clinics. In addition, both studies drew upon relatively small sample sizes.

Drawing on surveys with 356 current and former egg donors, this study examined the expectations of donors about risks based upon what they recalled being told during the informed consent process, and the degree to which their experiences matched their expectations based upon what they had been told. The paper also includes the suggestions of egg donors regarding how informed consent and clinical care can be improved. Participants were recruited using a self-selected convenience sample strategy that included collaboration with online egg donor groups, egg donation agencies and clinics, and other avenues for recruitment. The inclusion criteria were intentionally left open to include US and foreign donors, donors at any point in the donation process (including some who had donated over 15 years prior to the survey), and compensated and uncompensated donors. Given the paucity of existing research on egg donors, it was considered important to include as wide a range of donors as possible, with the intention to narrow the focus in future studies. The donors in this study were predominantly white, educated, and in their early to mid-20s. According to the study findings, while the majority of donors felt informed about short-term risks, they also felt uninformed about potential long-term risks.

Providing full and accurate information to prospective donors is a crucial element in the egg donation process. The

informed consent process not only ensures that prospective donors have access to all information in order to make informed decisions, but is also crucial to improve the donation process for those who do decide to donate. Given the high education status of most donors in this study, it was expected that donors would feel better informed, or would seek out additional information on their own. However, that was not the case in this study. It is possible that medical professionals tasked with providing informed consent vary in their provision of information.

The findings presented in this paper highlight the presentation of potential risks as a gap in the informed consent procedures for compensated and uncompensated egg donors. This concurs with existing literature that addresses the challenges of providing fully informed consent (Alberta et al., 2013, 2014; ASRM, 2004; Gezinski et al., 2016; Kenney and McGowan, 2010), as well as ways to improve consent by utilizing multi-media platforms (Madeira et al., 2018). Theories of informed consent for medical practice emphasize two conditions for the validity of patient autonomy: understanding and voluntariness (Faden and Beauchamp, 1986; Skillern et al., 2013; Valapour et al., 2011). While this study did not focus on voluntariness, the results indicate that some egg donors perceived being given insufficient information to fully understand the potential risks and health outcomes. This absence of understanding poses ethical concerns regarding the validity of informed consent for those donors who reported being underinformed.

It is possible that the donors in this study who experienced unanticipated emotional or physical side effects were among those least likely to demonstrate alignment between experiences and expectations; further analysis is needed in this area. Additionally, with regard to potential long-term complications, donors who reported being informed of the lack of evidence regarding long-term risks felt better informed than those who were told that long-term risks did not exist or the explanation of risks was minimized. The timing of information was also seen as important. Participants expressed that all information should be given well before initiating the medical process of donation, rather than at each stage of the process (e.g. mentioning possible complications of injections on the day of starting injections).

Most troubling, in the survey text boxes, many donors reported feeling that their clinic intentionally excluded important information. This was especially the case with donors who had provided eggs within the past year, compared with former donors who were 1 year or more post-donation. Feelings of being misled could also be a result of increasing numbers of donors communicating with each other and sharing their adverse donation experiences via online forums. However, some respondents reported specifically asking questions during the informed consent process about risks, or to further explain OHSS, and feeling that their questions were dismissed. Not feeling that their questions were fully addressed added to their feelings of being underinformed. Donors who completed their donation cycles at least 15 years prior to the survey were also more likely to acknowledge the absence of evidence on potential risks at the time of their donations than more recent donors, who expressed frustration about the lack of long-term research on egg donors.

With regard to information about OHSS, several donors who experienced moderate to severe OHSS felt that they were underinformed about this possible complication. Donors who were provided with more detailed information about the degrees of OHSS felt more informed than those who were simply told it is 'rare' or occurs less than 1% of the time. Indeed, 'the risks are less than 1%' statement, which the majority of egg donors reported being told, is highly problematic when it comes to fully informed consent. First, this figure only refers to severe OHSS and not other possible complications (ASRM, 2014; Bodri, 2013; Sauer et al., 1996). Second, the risk of OHSS varies according to hormone protocols, such as ovulation triggering with GnRH agonist rather than human chorionic gonadotrophin (hCG), or combined hCG and GnRH agonist triggers (Melo et al., 2009; Sismanoglu et al., 2009); trigger shots that include hCG significantly increase the risks for OHSS, especially in donors who produce more than 20 oocytes per cycle (Tober et al., 2020). However, egg donors are not usually given information about the different stimulation protocols available, as physicians prefer to use the protocols with which they are most comfortable. The fact that different hormone protocols and their respective risks and benefits are not routinely discussed with oocyte donors directly contradicts informed consent standards that patients should be provided with reasonable alternatives to a particular treatment, and the risks and benefits of alternatives (Shah et al., 2020). Third, some studies have actually reported a range of OHSS occurring between 1% and 7% of the time or more (Bodri, 2013; Fiedler and Ezcurra, 2012; Jayaprakasan et al., 2007; Kalfoglou and Geller, 2000; Luke et al., 2010; Sauer et al., 1996; Sismanoglu et al., 2009; Tober et al., 2020). Finally, the majority of studies on OHSS have drawn upon a sample of women undergoing their own fertility treatment, not specifically egg donors who may have other risk factors for OHSS such as lower body mass index and higher resting antral follicle counts (Budev et al., 2005; Delvigne and Rozenberg, 2002, 2003). It is possible that those who do experience complications related to their donations could feel more satisfied if they were able to prepare for possible complications ahead of time. Addressing the current gaps in available research on the health and well-being of egg donors, in the short term and over time, is thus an essential component of ensuring that informed consent is comprehensive.

While the main focus of this study was the perceptions of egg donors regarding being informed, other information included in this analysis deserves mention. For example, 17 donors reported undergoing between seven and 17 cycles, which is well beyond the ASRM recommendation of no more than six cycles per donor per lifetime (ASRM, 2014). Of these 17 donors, one had provided eggs outside the USA; two had provided eggs 11 years or more prior to the survey; and three had provided eggs 4–6 years prior to the survey, around the same time that ASRM published their opinion on repetitive oocyte donation. This means that 11 US donors in this study completed cycles in excess of the ASRM recommendations after ASRM published its guidelines in 2014. This is a cause for concern: either some donors are not reporting their cycles to clinics and therefore continuing to donate at different sites when they should not; or some clinics or agencies are encouraging donors to continue, or at least not advising them to stop; or a combination of these.

This study had several limitations. The majority of the participants were recruited from the WAED online egg donor community, which may introduce sample bias, limiting the generalizability of these findings. Similarly, as participants were self-selected, it is possible that donors with lower levels of satisfaction or higher incidence of complications were more inclined to participate in the study than those with more positive outcomes. In addition, as the majority of participants had already completed at least one cycle, and many had stopped donating several years prior to the survey, recall bias is possible. However, the benefit of being able to recruit a large number of donors with a range of backgrounds and experiences is especially important for this exploratory phase of research. In addition, it is contended that studies in which all donor participants are recruited from the same clinic, or even a few clinics, or only clinics based in university settings, also raise concerns about potential bias. Informed consent processes and medical practices and protocols vary substantially between practices, so a low percentage of adverse events at one clinic or research site will not necessarily be applicable to others. These differences limit the generalizability of data on egg donors recruited from smaller-scale clinical studies. In future studies, the authors aim to recruit from a broader range of sources in order to resolve potential bias concerns. To resolve these limitations, in addition to recruiting current and former donors to the study, participants are also being recruited before completion of their first cycle, and followed through the process, in order to include pre- and post-donation data.

Conclusion

As far as is known, this is the first and largest study to broadly investigate egg donors' decisions and experiences, understanding of risk, and perceptions of informed consent. Importantly, these findings represent a large sample of donors from a range of clinics and agencies across different regulatory and medical donation contexts.

Findings from this research indicate that while 64.8% of egg donors in the sample felt informed about potential short-term complications, only 32.8% felt informed about possible long-term risks. It is possible that some of the donors who reported feeling well informed were not aware of the lack of research on the health and well-being of egg donors over time, or thought that short-term adverse effects represented all possible adverse effects. One donor who felt particularly well informed mentioned how her informed consent process included taking an interactive video. This suggests that interactive multi-media may improve the informed consent process for oocyte donors. This is consistent with what other research has found on the use of multi-media platforms for improving informed consent among fertility patients (Madeira et al., 2018).

In addition, 66.5% of respondents reported inconsistency between their egg donation experiences and expectations based upon what they had been told in the informed consent process. This suggests lack of uniformity of the informed consent process across clinics, and points to possible areas for improvement. With regard to feelings of being informed about short- or long-term risks, no significant differences were found between responses from the WAED group and others, nor were any significant differences found between responses from US and non-US donors. In addition, 17 participants reported undergoing more than six cycles (the lifetime limit recommended by ASRM). This suggests that a registry-type system to track donor cycles may be in order in the interest of minimizing exposure to risk.

Many have called for research on the immediate and long-term effects of egg donation on donor health and well-being (Beeson and Lippman, 2006; Schneider, 2008; Schneider et al., 2017; Woodriff et al., 2014). The current study is a first step in that direction. Lack of information is a serious barrier to fully informed consent for women considering egg donation. Establishing a mechanism to enable long-term research on the impact of ovarian stimulation on the health and well-being of egg donors would ultimately improve the informed consent process. Further research is needed to understand how medical providers might best communicate both the short- and long-term risks of egg donation. This investigation may help to improve the informed consent process across clinics, egg banks and agencies, so that prospective donors receive consistent and comprehensive information.

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