Journal of Assisted Reproduction and Genetics (2019) 36:1999–2005
https://doi.org/10.1007/s10815-019-01527-5

ASSISTED REPRODUCTION TECHNOLOGIES

Experiences and psychological outcomes of the oocyte donor: a survey of donors post-donation from one center

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Received: 27 June 2019 / Accepted: 8 July 2019 / Published online: 13 July 2019

Abstract

Purpose To assess the experiences and psychological outcomes of oocyte donors from one fertility center.
Methods An anonymous survey was distributed via a secure email to 161 donors who underwent oocyte donation—anonymous, directed/known, and recruited agency—between January 2008 and January 2019 at the NYU Langone Fertility Center.
Results Thirty-six donors completed the survey with the majority between 2 and 10 years since donation. Respondents reported a high prevalence of psychiatric symptoms or diagnoses post-donation. The majority of donors reported positive thoughts and feelings toward their donation process as well as to the knowledge of children born from their donation. Negative comments about donation were in the minority but focused on unexpected aspects about the process or outcome. Based on qualitative analysis, thoughts about family or "family-oriented thoughts" were the most frequent theme in respondent comments. 62.5% of respondents reporting that they would be open to identity-disclosure or open donation after experiencing the process.
Conclusions Despite a high reported prevalence of psychiatric symptoms, the majority of respondents felt positively about the donation experience as well as the prospect of open donation or identity-disclosure post-donation. Further research on long-term psychological outcomes, related to all aspects of donation, is important as the counseling and informed consent of oocyte donors continues to evolve. These data will be particularly important with regard to the aspect of disclosure, both planned and unplanned, in the modern era of electronic information sharing.

Keywords Oocyte donation · Psychological outcomes · Disclosure · Donor

Introduction

Oocyte donation—the stimulation and retrieval of oocytes or eggs from a third party—is indicated for use by couples in which the female recipient suffers from infertility, including (i) hypergonadotropic hypogonadism, (ii) diminished ovarian reserve, (iii) advanced reproductive age, (iv) carrying a known genetic disease, (v) a history of poor egg or embryo quality, and/or (vi) poor response to in vitro fertilization (IVF), as well as use by single males and partnerships or individuals in the LGTBQ community building families with gestational carriers [1]. Since the inception of oocyte donation in the 1980s, the Society for Assisted Reproductive Technology (SART) estimates that approximately 100,000 American women have undergone oocyte donation [2]. As the use of this technology increases, many new ethical issues will likely arise [3, 4]. One such issue—notwithstanding the known potential medical risks to the donor during and just after the cycle—is the possibility of an impact to the donors' future medical and/or psychosocial health.

The American Society of Reproductive Medicine (ASRM) recommends long-term physical and psychological follow-up of donors [3]. With the help of advocates [5, 6], the process for conducting this follow-up will hopefully become more systematized and streamlined. Currently, the focus of this follow-up is primarily medical and physical outcomes. This is possibly because these tangible aspects of the donation process are inherently easier to measure. However, the psychological outcomes of all parties involved are no less substantial and no less worthy of sustained analysis. While there has been extensive research on the psychological wellbeing of recipient offspring [7, 8], especially with regard to disclosure and identity [9], the

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long-term psychological impact on the donor has received substantially less attention. With the increased availability of direct-to-consumer (DTC)/at-home genetic testing, the idea of protected anonymity and/or guided disclosure for donors and recipient offspring will likely change [9]. It is therefore imperative to understand the current psychological outcomes of the oocyte donor to identify the potential psychological benefits and risks that will face the twenty-first-century donor.

In this study, we sought to assess the current thoughts and opinions of oocytes donors on (1) knowledge of offspring, (2) the process of oocyte donation, and (3) a final "take-away" from the experience.

Materials and methods

An anonymous quantitative and qualitative survey was developed with the help of a psychologist with experience with oocyte donors. Institutional review board (IRB) approval was obtained by the New York University (NYU) School of Medicine (IRB# s18-00698). The survey contained 29 questions divided into three sections: (1) 10 general or demographics questions, (2) 11 medical and family history questions, and (3) 8 psychological and psychiatric questions. The medical and family history data were designed as part of a separate study and reported elsewhere. Section 3 included one multiple choice question regarding psychiatric health updates "have you ever been treated for, diagnosed, or ever experienced symptoms of (a) depression, (b) anxiety, (c) Bipolar Disorder, (d) Schizophrenia, (e) Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD), or (f) Other" as well as 6 free-response or open-ended questions, and 1 question with a Likert scale response to determine psychological outcomes. All oocyte donors—directed, recruited anonymous, and agency—who underwent at least one cycle of oocyte donation between January 2008 and January 2019 at the NYU Langone Fertility Center were identified as potential subjects. All subjects with a working email address were invited by HIPAA compliant secure e-mail to complete the anonymous web-based survey. Exclusion criteria included donors with contact information but no self-reported email address as well as screened donors who did not donate during the inclusion time period. Of note, the survey did not require subjects to self-identify what type—directed, recruited anonymous, or agency—of donation was made. Descriptive statistics are reported as total *n* and percentage for quantitative data. The qualitative data from section three (psychological/psychiatric) was coded based on a priori themes determined by trained psychologists with experience with oocyte donors for each question individually. Responses were coded by one investigator and then confirmed by two further investigators for consensus and are reported as unedited free text.

Results

Demographic data

One hundred sixty-one donors met inclusion criteria and had emails successfully delivered. Thirty-six donors completed the survey, for a response rate of 22.4%. Table 1 displays the demographic data of the respondents. The majority of respondents identified as Caucasian. When asked if each respondent identified with a religion, the majority did not identify as religious; however, some were spiritual but not religious and some identified as atheist. However, 11 respondents reported identifying with a religion including Judaism, Christianity, Catholicism, and Islam. At the time the survey was completed, most respondents reported they were currently single or not married, with the next largest percentage reporting they were currently married. The majority of respondents reported their donation was between 2 and 5 years ago with most first donations occurring when respondents were between 25 and 30 years old. Most respondents reported only one donation ($n = 14$) but 6 reported donating twice, another 6 donors reported donating three times, and 9 reported four or more donations at the time of survey completion. 57.1% ($n = 20$) reported they have not yet tried to have children or are not interested, 31.4% ($n = 11$) reported they have not had children but might in the future or are currently trying, 2.9% ($n = 1$) reported she had adopted children, 8.6% ($n = 3$) reported they have biological children, and no donor reported they had built their family using donor oocytes.

Psychiatric health updates

Respondents were asked to report any psychiatric symptoms ever experienced as part of the multiple choice question. Twenty-four respondents chose to answer this question with most choosing Depression (52.9%, $n = 9$) and/or Anxiety (58.8%, $n = 10$). No donor respondent reported treatment or an experience with Bipolar Disorder, Schizophrenia, or ADD/ADHD and 29.4% ($n = 9$) reported "other."

Knowledge and associated feelings of known children born from donated oocytes

Respondents were asked if they knew of children born from their donated oocytes. 68.8% ($n = 22$) reported they did not know if children were born and 31.3% ($n = 10$) reported they had confirmed knowledge of livebirth. The study was not designed to identify which donors were directed or anonymous. However, two of the ten respondents self-identified with free-response comments as directed donors with confirmed knowledge of the livebirths in their family (to their

Table 1 Donor-respondent demographic data

Question	Response	Percent of respondents (*n*)
Do you identify with a race/ethnicity?	Yes, I am Caucasian	77.1% (27)
	Yes, I am Hispanic	5.7% (2)
	Yes, I am American Indian	2.9% (1)
	Yes, I am Asian	8.6% (3)
	Yes, I am "Other"	2.9% (1)
	No, I do not identify	2.9% (1)
What is your marital status now?	I am currently single / never married	44.4% (16)
	I am currently married (civil marriage, domestic partnership, etc)	33.3% (12)
	I am in a serious/committed relationship (heterosexual, LGBTQ)	11.1% (4)
	I was married but am now widowed	2.8% (1)
	I was married but am now divorced	6.3% (3)
How old were you at the time of your first donation?	18–20 years old	5.7% (2)
	21–24 years old	31.4% (11)
	25–30 years old	54.3% (19)
	31–35 years old	8.6% (3)
How long ago was your first donation?	1–12 months	8.8% (3)
	1–2 years	14.3% (5)
	2–5 years	40.0% (14)
	5–10 years	24.3% (12)
	> 10 years	2.9% (1)
How many times did you donate?	1 time	40.0% (14)
	2 times	17.1% (6)
	3 times	17.1% (6)
	4 or more times	25.7% (9)

known familial recipients). The other eight respondents did not provide information as to how they learned or confirmed the livebirth. The 10 respondents who reported knowledge of livebirth were offered an optional sub-question: "if you know children were born from your eggs, how do you feel about it?" Responses were coded into four a priori determined themes: positive, neutral, negative, and associated with provoked personal feelings about family or "family-oriented."

Six donors wrote positive comments about their feelings toward knowledge of children born from their donation.

> "I feel good about it."

> "I am fascinate[ed] to know about the children born from my eggs. I would love to meet them and their families some day!"

> "I am very happy for the couple in question."

> "Great. I am happy that I helped someone have the child they wanted. Sometimes I wonder if the child(ren) is/are healthy because their genetics feels like my responsibility. I'm a big advocate for reproductive freedom and donating my eggs solidified that belief for me."

> "Wonderful, the entire point of me donating eggs was to help couples conceive children."

> "I feel like the check cashed and they got a baby. Win-win. This isn't emotional for me – it's just a truly awesome outcome for everyone."

Interestingly, no responses for this question were coded as neutral or negative.

Four donors composed responses associated with personal feelings about family or their own families.

> "Fine. They are my cousin's kids, they're cute, I see them every couple of years. One of them looks quite like me. It's nice but I don't feel maternal towards them as I do my (adopted) son."

> "I was very happy to hear the news but also felt a sadness because I always wanted another child but didn't have a healthy relationship. I still would in the next 5 years if a miracle happens and I find the right partner."

> "They are my niece and nephew, I love them dearly and so happy I could do that for my sister and brother in law."

> "I feel like my genetics are out there, and that's comforting. It allows me to rest easier about my husband's and my decision to not have children ourselves."

Feelings and opinions about oocyte donation post-donation

The survey also included three questions about how each donor felt about oocyte donation now having completed the process. First, donors were asked: "There is a trend of moving from anonymous oocyte donation to Open donation (donor remains anonymous but contact may be initiated once the offspring is 18 and level of contact is determined mutually by the donor and offspring) and to ID-disclosure donation (donor identity is disclosed to offspring once they turn 18). Knowing what you know now, would you be open to Open or ID-disclosure oocyte donation?" 62.5% ($n = 20$) donors reported they would be open to Open or ID-disclosure donation after undergoing the process of oocyte donation. 21.9% ($n = 7$) reported they were unsure and 15.6% ($n = 5$) said they would not be open to Open or ID-disclosure donation.

Second, donors were asked to do a personal reflection and answer the following question: "Knowing what you know now, would you have made the same choice to donate your eggs?" Responses were again coded into four categories: positive, neutral, negative, and associated with provoked personal feelings about family. Six donors left comments; 2 positive, 2 neutral, 2 negative, and no comment associated with thoughts about family.

Positive Comments

> "I was so happy to give couples, who could probably afford anything in the world, the one thing they couldn't do themselves. And I was honored to be chosen by them."

> "It was one of the best decisions of my life."

Neutral Comments

> "It was a super safe procedure and a supportive environment and while it was difficult to do while working fulltime, it was a fulfilling experience."

> "I love helping people but am not sure – I have had a lot of hormonal problems."

Negative Comments

> "I was too young at the time and didn't know it'd be taxed almost 50%"

> "I attempted to donate eggs twice. The first time the donation was successful. The second time, I began hormone therapy but was told that egg retrieval was not going to happen before completing the cycle. My first donation experience was great and I am happy to have done it. The second attempt was not a good experience for me."

Family-Oriented Comments

None

The third question in this category asked donors if they would recommend donating oocytes. 58.1% ($n = 18$) reported they would recommend donating eggs, 6.5% ($n = 2$) said they would not recommend donation, and 35.5% ($n = 11$) said they weren't sure if they would make that recommendation. Responses were again coded into the four categories aforementioned.

Positive Comments

> "Yes, and I advocate for other women to do so all the time. I wish that I still could, it was an amazing process for me."

> "Most of my friends are probably too old for it now, but whenever I disclose that I've done it, I always speak about the experience in the highest regard. It was a lot of work while I was doing it, but I did it 5 times and put the money towards my nest egg which has grown quite a bit over the space 10+ years. I have no regrets."

> "I have recommended it to my friends. My sister has subsequently also donated."

Neutral Comments

> "It's a personal decision. For me, it felt like the right thing to do, but I can't say what would be best for others."

> "I think it would be strange to recommend something that is such a personal choice. I definitely tell people about my positive experience, but I would never assume that someone else should undergo surgery, inject themselves with many hormones, and potentially bring genetic relative they will never know into the world just because it worked for me."

> "Very much depends on the situation, too many factors involved to say for sure."
> "I had a good experience. Just want to be 100% of allll[sic] of the risks."

> "My experience was mostly positive, but I think I would advise friends who are considering it to wait

> until there are more studies about the long term effects, especially if they want to have children of their own someday. I also feel like there should be more transparency about donor's rights to negotiate their compensation."

Negative Comments
None
Family-Oriented Comments

> "For the right person, sure. Best for those who don't want children of their own. I will regret it if one day I want children and I'm having difficulty. I'll always wonder if this was the cause/I did something to cause it."

Overall final thoughts from oocyte donors

Finally, the survey asked if donors would be interested in maintaining future contact about health, reproductive, and psychological outcomes. 81.3% ($n = 26$) reported they were interested in future contact. The concluding question was a free-response text box encouraging donors to "Please feel free to leave any other comments here." Responses were coded into the previous four categories (positive, neutral, negative, and family-oriented) and an additional category, ethically-oriented, was also utilized.

Positive Comments

> "Thanks for checking in with me!"

> "Thank you! Each time I went through the process everyone was so kind and supportive."

Neutral Comments
None
Negative Comments

> "The difference between my first and second donation experiences was quite drastic. During/after my first donation, I felt minimal physical side effects, the process seemed to occur smoothly, and I felt supported by your office's medical staff. I was fulfilled and happy with the outcome. The second donation, on the other hand, was not a good experience for me. My body did not respond well to the birth control pills that I was given ahead of the hormone injections (skin breaking out, mood swings, etc), and I did not feel fully "recovered" until months after the donation cycle ended. Ultimately, I was told that the cycle was unsuccessful because my follicles were not developing at the same rates. I was also told that this could have been an indication of decreased fertility since my first egg donation.…"

Family-Oriented Comments

> "I am curious if any of my eggs remain, and I would be interested in retrieving them for my own use if so. I know I was told this would be unlikely back at the time of donation, but I would like more information about the status of my eggs if any remain. Thank you!"

Ethics-Oriented Comments

> "I appreciate you all reaching out. I have donated at many facilities and this is the only one that has reached out for a survey like this. As you know, there is not nearly enough long-term study on egg donors. Two of my friends and myself would be considered very high volume donors. We have all done it 10+ times and are all nervously curious if it will manifest into health problems down the line."[Note: Our center follows the ASRM guidelines on total number of cycle donations]
> "Overall, I love helping people but wish there was more concrete knowledge and studies about the effects following donation."

> "I feel there should be more transparency in the selection process early on, specifically with regards to the psychological evaluation, as well as sensitivity toward the mental health needs of applicants. For prospective donors who already experience some mental health symptoms, this non-therapeutic psychological evaluation can be very uncomfortable and possibly damaging to their mental health. For some, this may be their first time meeting with a mental health professional and the first time being given any sort of diagnosis or feedback. Having that experience when the purpose is non-therapeutic is distressing. I found the psychological evaluation to be the most uncomfortable part of the whole experience and I do not suffer from any clinical mental health issues. I also know from a friend who has mild anxiety who also applied to be a donor and was denied, that she felt like instead of getting an informed explanation of why she was denied, the medical risks of donation were highlighted to her in a way that they were not for me, to caution and discourage her against participating. This part of the process, as well as a need for more studies about the long-term effects of egg donation is the reason I have chosen not to donate again."

Discussion

Although gamete donation is well-intentioned, the practice raises questions about the ethical balance among donor, recipient, and family. As it relates to the recipient, all four core principles of medical ethics—autonomy, beneficence, non-maleficence, and justice—favor providing this service to those who would otherwise experience the harm and difficulties of unintended childlessness and the inability to raise children outside of adoption. However, weighing these considerations from the perspective of the oocyte donor reveals the tenuous nature of this balance, especially with regard to psychological outcomes. The Practice Committee of ASRM details the elements of screening oocyte donors and providing them with information regarding the risks and benefits prior to donation [1] which were followed for each of the donors in this study. The majority of comments from respondents were positive, including those who knew of live-born-related offspring. Multiple donors in this study commented on thoughts and feelings about family and fertility post-donation. These remarks raise the question as to whether there is a relationship—albeit one that is inherently difficult to quantify and predict for each donor—between a donor's own reproductive outcomes and the ultimate impact of the donation process. From a non-maleficence standpoint, this aspect of informed consent seems slightly obscure and complicated. Previous studies have shown that donors have remarked on the potential impact of their donation on their own family [10] further highlighting the difficulties in this particular area of informed consent.

Despite the thorough screening processes and commitment of dedicated teams at fertility centers and agencies across the country, some oocyte donors do not adhere to the counseling about donation limit [1], evidenced by the respondent comment about donating more than 10 times. As noted above, our center follows the guidelines [1] and no donor completed more than 5 cycles at our center or divulged information of prior number of cycles in excess of the recommendations. This scenario highlights the issue of relying on the donor to provide honest information during the screening process and emphasizes the need for a national donor database as there is not currently a process in place to track the number of prior or subsequent cycles on a national or even international level as a matter of health and safety. While donors should and can, obviously, make autonomous decisions about their bodies and lives, it exacerbates the process of counseling these high-frequency donors about personal long-term effects. Moreover, these effects may also impact future partners and offspring as well as recipient families and offspring born from the donated oocytes. It is less likely that these donors are not well-counseled but more probable that these donors have not internalized the counseling and thus do not appreciate the full impact that repeated donation may have, which is a concept that should be further studied. Previous studies have also highlighted that donors' expectations, about compensation and follow-up [11, 12], are often not well matched with actual outcomes. While the results of our study suggest these donors are likely in the minority, there were three comments related to this topic. Thus, it is important to consider that donation might have the largest psychological impact on this minority, which will require targeted ways to help clarify these expectations upfront during counseling.

As noted above, in the era of social media, information sharing, and DTC/at-home commercial genetic testing, anonymity in gamete donation has never been harder to maintain. There is already a trend toward greater openness among donors and recipients [13] and some who are seeking this information with DNA registries [14]. We may have crossed the Rubicon whereby maintained anonymity is no longer feasible at all. As a result, like it or not, open identity or identity-disclosure may simply be the only new normal for disclosure experience, which makes counseling by a trained psychologist with expertise in this field essential [15]. Of the donors who knew of children born from their donation, none submitted negative responses. In addition, the majority of donors in this study were open or felt positive to the idea of donation with disclosure and previous studies suggest that disclosure donation models seem to be going well [6]. Perhaps, further dedicated study on the psychological outcomes from directed or known donations to contrast the outcomes from "accidental" or unanticipated disclosures from genetic testing would help facilitate the counseling and conversation surrounding this issue. The popularity and growing market for genetic information sharing suggests that these conversations are of the utmost importance.

It did not go unnoticed that a majority of respondents in this study reported psychiatric symptoms of depression, anxiety, and other mental health disorders. The survey did not distinguish those donors who had only symptoms versus a full diagnosis and associated treatment, nor did it assess the severity of the reported symptoms or diagnoses. Although additional variables may be worth measuring in future studies, the data are significant, particularly given that Williams and colleagues reported that some donors may minimize their psychiatric symptoms during screening [16]. If such minimization is accurate, there are multiple unanswered questions that stem from the results of our study. Is there a baseline trend toward a higher and under-reported disposition for psychological diagnoses in the donor population? If there is not, is the high number of reported psychological symptoms related to donation or its long-term outcomes? Would these symptoms be different based on an open model of disclosure? The survey was not designed to evaluate an incidence of psychiatric disease before and/or after donation. Thus, we are not able to comment or make a comparison with the psychiatric symptoms in a matched non-donor population, but this is an important point that deserves future investigation. The above list of questions is not exhaustive, but it underscores the need for further study on the psychological outcomes of oocyte donors.

The principal strength of this study is the direct self-report of thoughts and outcomes of oocyte donors. In addition, the inclusion of all types of donors adds to the generalizability of the data to all-comers to oocyte donation. However, there are multiple limitations to this study, including the small sample size of respondents and the overall moderate length of time since donation (62.3% between 2 and 10 years). In addition, the nature of an anonymous survey invites the possibility of both selection and recall bias to our results. Donors from our center were also majority Caucasian and overall likely from a major metropolitan area, both of which may limit the generalizability. Our data stress the need for further study on the psychological outcomes of oocyte donors. Data from donors who have completed their reproductive lifespan as well as a stratification of outcomes from the open disclosure donations, truly anonymous, and unplanned disclosures will help elucidate these outcomes.

In conclusion, the results of this study show that the majority of donors had positive thoughts and comments about their donation experience and the majority would be open to identity-disclosure or open identity donation. Long-term psychological outcomes and the contribution of oocyte donation and the disclosure experience need further clarification. As part of the counseling and screening of potential oocyte donors, reading the thoughts and comments from prior donors, such as those from this study, may help to match potential donors' expectations with outcomes. The proliferation of electronic information sharing has already materially changed the process for oocyte donation. In order to meet the new demands of society today, it is imperative that we provide the appropriate counseling and support for all parties involved in gamete donation—particularly for the oocyte donor.

Acknowledgements The authors gratefully acknowledge the donors who participated in this study.

Author contributions All authors contributed to study conception and design. Data collection and analysis were performed by Jennifer Blakemore and Paxton Voigt. The first draft of the manuscript was written by Jennifer Blakemore and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Compliance with ethical standards

All procedures performed in this study were in accordance with the ethical standards of the institution (NYU School of Medicine Institutional Review Board, #s18-00698).

Informed consent was obtained from all individual participants included in the study.

Conflict of interest The authors declare that they have no conflict of interest.

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