

*Formal and informal support and counselling for embryo donation and receipt: An Australian qualitative study*

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## **Abstract**

Despite growing numbers of people engaging in embryo donation for the purposes of family building, public access to information about the process may be limited. As such, support and counselling – both formal (i.e., through clinics) and informal (i.e., through online communities) – can play an important role in information provision. This article draws on a subsample of nine people from a qualitative study of embryo donation and receipt in Australia. Themes developed suggest that formal support and counselling provided by clinics can be useful, though can require persistence in order to access and may not sufficiently address needs. In terms of informal support, themes developed suggest that sharing lived experiences in online communities can be important, however there may also be challenges associated with differing viewpoints and threats to anonymity. The article concludes with a discussion of the ongoing importance of formal support and counselling, whilst also suggesting that informal support is an avenue requiring further investigation.

## **Keywords**

embryo donation; embryo receipt; counselling; support; formal; informal

## **What is known about the topic**

- Embryo donation for family building in Australia is relatively infrequent but growing
- Formal counselling can play an important role in the embryo donation process
- Formal counselling is not always offered or available

## **What this paper adds**

- Formal support or counselling through fertility clinics may not address needs
- Informal support or counselling is most useful when it draws on lived experience
- Informal support or counselling can be fraught as a result of disparate viewpoints and threats to anonymity

## **Introduction**

Embryo donation for family building is a growing enterprise in a number of countries around the world (e.g. Authors; Kawwass et al., 2016). Embryo donation for family building, however, brings with it a number of potential complexities. These complexities can include donors feeling that genetic ties signify a right to ongoing connections, the distress that recipients may experience due to not having a genetic tie with a child born from an embryo donation, and concerns about how children born from embryo donation might feel about their relationship to their donors and the family who raises them (de Lacey, Peterson & McMillan, 2015; Goedeke, Daniels & Thorpe, 2015). Given these complexities, support and counselling for all parties is vital, in order to ensure that they are adequately informed and supported in the decisions they make, including into the future. This paper draws on an exploratory Australian interview study to examine the support and counselling experiences – both formal (i.e., through clinics) and informal (i.e., through online communities) – of embryo donors and recipients.

Embryo donation first occurred in Australia in the 1980s (Kovacs, Breheny, & Dear, 2003; Millbank, Stuhmcke, & Karpin, 2017). While embryo donation has slowly increased in Australia, there are still only a relatively small number of babies born as a result of embryo donation. The combined statistics for Australia and New Zealand in 2016 show that there were 455 initiated ART cycles for embryo recipients, resulting in 81 live deliveries (Fitzgerald et al., 2018), an increase on 2007 data which reported 238 initiated ART cycles for embryo recipients, resulting in 28 live deliveries (Wang et al., 2009). The Australian National Health and Medical Research Council (NHMRC) recommends counselling for those involved in donation conception programs (NHMRC, 2017 Section 4.4). Despite this recommendation, there are no laws in any state which make joint counselling with donors and recipients mandatory, and there are no mandatory requirements for the content of counselling

(Millbank, Stuhmcke & Karpin, 2017). Nonetheless, the Australian and New Zealand Infertility Counsellors Association (ANZICA) has guidelines on counselling in relation to infertility (2003, revised in 2018). The revised guidelines specifically detail a minimum standards counselling protocol for embryo donation, which includes a minimum of two counselling sessions with all participants and their partners and, in the case of a known donation arrangement, a third session with all participants. Importantly, the guidelines go beyond the provision of procedural information, encompassing a diversity of topics that are recommended to be addressed in counselling for embryo donation (including reasons for donating, implications for children of donors, attitudes towards disclosure about donor conception, availability of support, and thoughts about contact between families).

Echoing ANZICA guidelines, much of the existing empirical research on embryo donation emphasises the importance of formal counselling for those involved in embryo donation. For example, an Australian study about decision-making in relation to embryos found that participants generally viewed counsellors as the most appropriate sources of information, yet several participants had not undertaken or been offered counselling (Chandler, Stuhmcke, Millbank, & Karpin, 2013). Another study with people involved in fertility clinics in the UK found that counselling was viewed as necessary throughout the process of assisted reproduction (particularly in regards to embryo donation), although it was not always accessible (Machin, 2011). Other studies have also found that participants view ongoing support in the form of counselling as useful for ensuring children's welfare following embryo donation (Frith, et al., 2017). Finally, research on counselling in relation to embryo disposition has found that whilst a majority of participants viewed fertility clinic counsellors as those best positioned to provide information, participants often felt that they had been provided with little information about embryo donation, and that post-IVF correspondence from clinics solely related to financial aspects (Natchigall et al., 2010).

Clearly, then, formal counselling provided by fertility clinics is viewed as an important resource for people donating or receiving embryos for the purposes of family building. Less attention, however, has been paid to other forms of support offered to all parties by fertility clinics, and no research was identified that focuses on informal supports offered outside of fertility clinics (such as user-run online community groups or resources). As such, the present paper sought to explore how a sample of Australian embryo donors or recipients viewed the availability and utility of both informal and formal support and counselling services in regards to their experiences of embryo donation.

## **Methods**

Ethics approval for the study reported in this paper was granted by the authors' university [details removed for peer review].

## ***Recruitment***

For the study reported in this paper a number of strategies were used in order to recruit participants who were embryo donors, embryo recipients, or people with embryos in storage or previously in storage. The call for interview participants was distributed by the *Embryo Donation Network* in Australia to their members, and information about the study was posted to relevant threads on the Essential Baby, Bubhub, and Raising Children Network forums. Some of the participants also shared information about the research with their networks. Despite the wide range of recruitment methods, and 2,500 views on the forums, only 24 individuals or couples emailed for more information or to participate. Of these, 15 individuals took part in interviews. The remaining people who made contact but did not participate either did not respond to follow-up emails to arrange interviews, or were involved in egg donation.

Of the 15 people interviewed, a sub-sample of 9 were included in the analysis for the present paper (see participant section below).

### ***Procedure***

All participants were provided with a detailed information sheet about the study, consent form, and brief demographics form after emailing to express their interest in the study. Each participant returned their signed consent form and completed demographic form via email prior to their interview. Semi-structured interviews were conducted via Skype or phone, depending on the preference of the participant. Interviews were conducted by the second author from April 2017 to February 2018. All interviews were audio-recorded, with the average length of recordings being just under one hour. Recordings were transcribed verbatim by a professional transcription service.

The interviews focused on questions around decision making, support and information, and views on embryo donation and kinship. Findings focused on the latter topic have been previously published (Authors). Three interview questions focused on experiences with support and counseling, both formal and informal, and explored 1) opportunities for formal support or counseling from fertility clinics, 2) types of support or information received, and 3) views on additional support or information options, including informal supports.

### ***Analytic Approach***

A thematic analysis was undertaken focusing on interview responses by the nine participants who were either embryo donors or recipients to the three questions outlined above. The decision was made to exclude those with embryos in storage, given support and counseling needs and experiences may likely differ for this cohort. Interview responses from the sub-sample of nine participants were analysed thematically following the process outlined by

Braun and Clarke (2006): 1) becoming familiar with the data, 2) generating codes, 3) identifying themes, 4) reviewing themes, 5) refining specifics of the themes, and 6) selecting extracts that best illustrate the themes identified. The first author first extracted responses by the nine participants to the three questions outlined above and then read all of these extracts repeatedly, identifying broad codes across this data set. These initial codes identified formal and informal support and counseling as distinct areas of focus. Having developed these codes, specific sub-themes were then developed under the codes of formal or informal support and counseling. These sub-themes were then confirmed by the second author. The first author then selected indicative data extracts to include under each sub-theme, and developed a coherent narrative for each of the sub-themes.

## **Findings**

### ***Participants***

The sub-sample included in this paper was comprised of: embryo donors and those seeking to donate (6 participants), and embryo recipients and those seeking donors (3 participants). At the time of the interviews, 3 participants were in the process of donating their embryos, 2 participants had donated their embryos and a child had been born, and 1 participant had found a recipient to donate to. For those in the recipient category, 1 participant had a child born from embryo donation, 1 participant had an unsuccessful embryo donation transfer and was considering trying again, and 1 participant was still trying to receive embryos. Participants ranged in age from 27-50 years (average 39 years; median 40 years). Participants who had received donated embryos were older than those who had donated embryos. For more participant demographics see Table 1. In order to maintain participant anonymity, rather than referring to participants by individual demographic characteristics in the analysis reported below, they are referred to by whether they were donors or recipients, as well as by a pseudonym.

Table 1: Embryo donor and recipient participant demographics (n = 9)

|                     | Category                     | n (%)    |
|---------------------|------------------------------|----------|
| Gender              | Female                       | 8 (88.9) |
|                     | Male                         | 1 (11.1) |
| Relationship status | Married                      | 5 (55.6) |
|                     | Single                       | 4 (44.4) |
| Sexuality           | Heterosexual                 | 8 (88.9) |
|                     | Bisexual                     | 1 (11.1) |
| State or Territory  | Australian Capital Territory | 1 (11.1) |
|                     | New South Wales              | 3 (33.3) |
|                     | Queensland                   | 2 (22.2) |
|                     | Victoria                     | 2 (22.2) |
|                     | Western Australia            | 1 (11.1) |

### **Views on Formal Support and Counselling Through Fertility Clinics**

Of the nine participants included in the analysis, all spoke about their experiences with, or perceptions of, engaging with fertility clinics. As can be seen in the following subthemes, a minority viewed fertility clinics as helpful, a majority found fertility clinics to be less than helpful, and some participants found fertility clinics to be helpful in specific ways.

#### ***Fertility clinics as reliable and informative***

In terms of positive accounts of fertility clinics, one of the participants spoke about the clinic they had attended in such glowing terms as to refer to staff as ‘family’:

Trudy: I know that I can get support from the IVF clinics because they're basically like my family, like my obstetrician's my family now. I pop in for visits and say hello and I'm really good friends with his receptionist. I dropped in coffees to them the other week. Like it's that bit of family so I know that support is there (donation in process).

This quote does interesting rhetorical work as it shifts the focus on fertility clinics away from a user pays understanding, and towards one in which staff involved in family making become part of the family. This participant went on to note that she didn't feel she needed any further support from the clinic now, though her claims to a kinship narrative allowed her to feel that should she need further support, it would be available. This is clear in a statement made by this same participant further in the interview:

Interviewer: What about in the future? You said that you'd be able to go back for counselling if you wanted it?

Trudy: Yes, I could always ring up [clinic]. I don't know what they'd be able to help me with, but I know at least they're a phone call away if I were to ring and say, "I've donated my embryos, I need to talk to someone."

It is interesting that this participant, despite not having an image of what potential support she might need in the future, felt certain that it would be available to her. Again, it is possible that her claims to a kinship narrative helped foster this sense of security in future support that she expected would be provided by the clinic.

The other participant who spoke positively about the clinic she had most recently attended had previously attended a clinic overseas, where she felt that counselling support was less

than forthcoming. In her experience with an Australian clinic, by comparison, she found the counselling provided to be helpful:

Interviewer: Did you have any kind of support or counselling?

Courtney: I think the counselling that I had through my local clinic really helped. Being aware of what the results would be going in with my eyes open (embryo recipient, transfer unsuccessful).

This idea of having one's eyes opened by counselling speaks to the important role that fertility counsellors can play in ensuring that patients have a thorough understanding of the many facets involved in embryo donation and receipt.

### ***Fertility clinics can be less than helpful***

Accounts of fertility clinics being less than helpful to participants were diverse, touching on a range of topics that suggested less than positive experiences. One example of this appeared to suggest that, post embryo donation, the clinic had stepped out of the picture:

Alyssa: But very much with the clinic, yeah, you kind of – you know, they cut ties and you're kind of left. I mean it would be helpful I think for recipients and donors to be given, you know, contacts for other counselling services (donated embryos).

As this participant notes, referrals for ongoing support post-donation are likely important for many participants, even if, as a participant in the previous sub-theme suggested, they do not yet know whether they might need further support in the future. Another participant inferred a reason as to why fertility clinics might be reticent to give out information:

Jessica: Because obviously the clinics that do the IVF and things like that, they promote their own products and things. They're not really going to be giving this information out, I suppose. (intended recipient)

Here suspicion is raised about the potentially financial motives of fertility clinics, motives that may be perceived at odds with what might constitute holistic and ongoing clinical care. Another participant, whilst not raising the point about clinics having a primarily financial focus, noted that their clinic was less than forthcoming with information:

Interviewer: Are there any other resources that you found useful?

Trish: [Clinic was] limited, like only really when we were asking for it and even then, a lot of the information they provided came directly from [another agency]. (donated embryos)

For this participant, not only did information have to be actively sought out from the clinic, but the clinic was largely drawing on materials provided by other agencies. Certainly, there are multiple agencies and organisations that may support people through the process of gamete or embryo donation, and thus it is reasonable that a clinic would direct patients to the most available sources. At the same time, at least for this participant, external referrals may give the message that the clinic itself provides only limited information.

In the final example included in this sub-theme, a participant indicated that counselling provided by a fertility clinic was less than helpful, due to its focus on making a comparison between embryo donation and adoption scenarios:

Rachel: During the [counselling] session [the counsellor] kept raising – you know, comparison for adoption, and a lot of her concerns were also aimed at children who had been adopted rather than the situation at hand. Where [embryo donation is] just not the same thing. (donated embryos)

Certainly in some countries, such as the US and New Zealand, embryo donation is frequently likened to adoption. In the Australian context, however, this is largely not the case, with the ANZICA (2018) guidelines noting that there is no consensus on whether or not embryo donation is best viewed as a form of adoption, thus recommending that the language of embryo donation is utilised (see also MacCallum, 2008).

***Fertility clinics can be useful, though this can require persistence***

In terms of counselling provided through clinics being of use to some participants, this primarily appeared to relate to the provision of information. As one participant stated, the clinic didn't offer "too much, other than logically thinking things through" (Sam, donated embryos). Another participant similarly spoke about clinic counselling as providing "quite factual things about the rules that the clinic's got and that sort of thing" (Lee, donated embryos). This participant went on to elaborate on the challenges they faced in trying to access information through their clinic:

Lee: It's a really big clinic. They are really busy; it's like a huge, big factory. If you want any info or any options you have to keep asking people and ask the right questions and follow-up with them. You don't get anything given to you or nothing is volunteered, so you have to be quite persistent and proactive. So, I wouldn't have been able to get

anywhere near this far if I hadn't have pushed every step of the way.

(intended donor)

Reference here to a 'huge, big factory' potentially echoes the comments from another participant included above about clinics being focused on financial outcomes. For the participant included here, the information being sought was eventually provided, but this required considerable persistence. This has the potential to leave patients feeling as though they are negotiating with a user-pays system, in which information isn't given out for free.

Importantly, whilst a focus on procedural matters was referred to by most participants included in this theme, one did note that clinic counselling provided additional support in terms of a future-focus:

Interviewer: What about the clinic counselling?

Courtney: Yeah, part of that was just, well, consequences of if x, y and z, you will need to have a conversation with the child and sort of a couple of sessions just going through the consequences of what decisions I made (embryo recipient, transfer unsuccessful).

Whilst this participant potentially appears to minimise the utility of the future-focused approach (i.e., 'just'), it is of no doubt, as the ANZICA (2018) guidelines suggest, that focusing more broadly on the potential consequences of embryo donation or receipt are vitally important.

## **Views on Informal Support through Online Communities**

Of the nine participants included in the analysis, seven spoke about negotiating support in the context of online communities. Such communities included general parenting forums, as well as public and private spaces specific to embryo donation and receipt. The majority of participants spoke about online spaces as important sources of support, especially in terms of sharing lived experiences, whilst a minority raised concerns about online spaces in terms of safety and information.

### ***Online communities provide support and lived experience***

Positive accounts of support provided by online communities commonly emphasized the idea that connecting with other people with similar experiences allowed participants to feel their own journeys reflected, as is evident in the following two examples:

Interviewer: What else have you been looking for?

Jessica: I like to read what other people have gone through, and what they've said about clinics and their experiences. Because I figure that's an actual person. It's not a paid advert trying to get you in for treatment.  
(intended recipient)

Interviewer: What about support groups or online groups, have you engaged with any of those?

Courtney: When I started trying, I joined [parenting website] and have gone through their forums. That helped, [because] even though it's an online community, having a community with other families who have been through or are going through similar situations was useful. (embryo recipient, transfer unsuccessful)

The first example above is interesting as it makes a paired contrast between ‘actual people’, and ‘paid adverts’. This potentially speaks to the perception voiced by the participant in a previous quote that fertility clinics are primarily focused on financial gain. In terms of the second quote included above, the participant notes that even though online communities are not face to face, they nonetheless provide an opportunity to connect with people in similar situations.

Other participants spoke about online communities as providing safe spaces in which to vent, or to feel safe from taboos associated from infertility, as is evident in the following two quotes:

Trudy: [I am part of a closed Facebook group]. I haven't used it a lot but it's been good to be able to vent somewhere, and know that it's not going to be out in the whole world. (donation in process)

Interviewer: What about the importance of informal networks?

Jessica: Oh, yeah. They're amazing. Because you learn so much, and you get information from other people, and you realise - I think too, it's not as bad as it was, but I think it's really a bit taboo still about saying that you're infertile, and you're having troubles, and you're struggling.  
(intended recipient)

In the first quote, whilst the participant was not a regular user of online groups, they nonetheless considered such groups important simply for the fact of their existence: that there was a space available, should she need to vent. In the second quote above, learning and safety

are paired together, such that feeling safe to speak about infertility allows people to access spaces where they can learn from the experiences of others who have gone through similar experiences. The final quote in this sub-theme also highlights that online spaces are spaces for learning:

Trish: [I am part of a network that's] got heaps of resources, and the ladies there answered heaps of questions. They were really helpful with that.  
(donated embryos)

### ***Online communities can be challenging spaces***

Most of the participants saw online spaces as positive spaces, but some also (or additionally) saw them as potentially challenging spaces. For some participants, such as in the following example, online communities were potentially fraught by the differing standpoints of members:

Interviewer: Which forums are you on or were you on?

Alyssa: I am on [an American group] which can be a little bit hard to tolerate at times. They have different views on things in the States. A lot of very strong religious backgrounds they come from, so there's a lot of saving embryos from destruction, yeah, they're doing us a favour by rescuing them. (donated embryos)

To a certain degree this quote is reminiscent of the earlier quote about fertility counselling in regards to embryo donation being less than helpful in the Australian context when it focuses on a comparison to adoption. In the quote above, whilst adoption is not specifically mentioned, the context of the United States is mentioned where, the participant suggests, a

different logic is evident in regards to embryo donation and receipt, one that may be at odds with the views of Australian members.

Another participant raised concerns about anonymity in the context of online communities:

Chloe: I would be interested in [an online group], but then ... if it was online and open for everyone to see, I'm not sure how I feel about that because it's just – anyone can see it. And I seem to think if there's so few people out there, it might be easy to identify and I know that's probably starting to sound paranoid, but I just think – I don't know how open you can be online when you're a minority. (donated embryos)

The point raised in this quote is a reasonable one, and might be especially relevant for children. Not only might disclosure of personal information in online communities run the risk of both donors (and their children) and recipients being identified, but down the track it might mean that children conceived by embryo donation might become identifiable. This is not to suggest that children should not be given details about their conception, but rather that it should ideally come from parents, rather than from children stumbling upon details online.

In the final quote below, from a participant who also praised online communities in terms of information sharing above, nonetheless raised concerns about the veracity of information shared:

Interviewer: What kinds of support or information have you received about embryo donation?

Jessica: It's basically just whatever you Google, on the embryo network sites, the donor angel sites. And people and their blogs. Which again is really random, and you don't know how much of that is right, wrong or the other. It's really scary. (intended recipient)

For this participant, it would seem, whilst having ready access to information through online communities was important, it also brings with it the risk of misinformation.

## **Discussion**

The findings reported in this paper in some ways echo previous research on formal support and counselling. For example, we found, similar to previous research (e.g., Chandler, Stuhmcke, Millbank, & Karpin, 2013; Machin, 2011), that counselling was seen as important, but not always available. Also similar to previous research (e.g., Natchigall et al., 2010), we found that formal support and counselling after the conclusion of IVF treatment was not always available. Importantly, however, it must be noted that of the participants only four had either donated or received embryos, so other participants, if they proceed through the journey of donation or receipt, may have different experiences. The similarity to previous research in regards to availability of counselling, including post-treatment, must thus be viewed in regards to the small number of participants who gave such responses. Extending previous research on formal support and counselling, we also found that concerns were raised about fertility clinics as financial enterprises, and that fertility clinics seemed to primarily provide procedural information. Though again, we would note that at least one participant received counselling with a future-focus, and further, we would note that some participants found such counselling to be positive, such as in terms of 'having one's eyes opened'.

In terms of implications of the findings for formal support and counselling, we would suggest the importance of counselling in the context of embryo donation and receipt adhering closely to the guidelines provided by ANZICA (2018), which as indicated in the introduction to this paper recommend that a diversity of topics are addressed. By comparison, for some participants there was a mismatch between counselling content and what participants required and/or expected. It was also apparent that the purpose and content of counselling varied across clinics and locations, as also noted by Millbank et al. (2017) in their Australian study (and which differs even more widely internationally, Blyth, 2012). In addition, at least for some of the participants, counselling was experienced as a regulatory exercise, rather than one aimed at exploring their needs in depth. As the ANZICA guidelines suggest, and as the participants reported in the present paper seemed to desire, counselling for embryo donation and receipt should address reasons for donating, implications for children of donors, attitudes towards disclosure about donor conception, thoughts about contact between families, and availability of support. The latter is clearly a topic to which participants oriented, and which could have been productively addressed via formal counselling, including in terms of identifying potential sources of informal support.

In terms of informal support and counselling, the findings reported in this paper represent a novel contribution to the literature, which to date has not focused in detail on informal supports. Importantly, the findings highlight that whilst being able to share and engage with the lived experiences of others in regards to embryo donation and receipt in online spaces can be important, such spaces are not without their limitations, especially with regard to concerns about anonymity and the veracity of information shared. This suggests the importance of future research exploring in detail how people utilise and engage with online spaces in the context of donor conception. Given, as noted in the introduction to this paper, that embryo donation is not uniformly regulated in Australia with respect to support and counselling, it is

likely that informal support and counselling spaces may be an important resource.

Understanding how such spaces operate can thus make an important contribution to meeting the needs of those who donate or receive embryos.

Having highlighted the strengths and implications of the findings reported in this paper, it is nonetheless important to acknowledge that the sample size was small and findings were specific to Australia. In addition, we also note that the participants who were interviewed for the study were likely to be an especially motivated sample, and some were specifically recruited through an online organisation. Further, we acknowledge that we have treated donors and recipients as a combined sample for the purposes of this paper. It is likely that these two groups have significant differences, even if the findings reported in this paper would suggest somewhat similar views about support and counselling. Finally, we have noted in this paper that forms of support available have implications for all parties, including children. Future research could usefully focus on the needs of children (both of donors and of recipients) in terms of embryo donation.

In conclusion, the findings reported in this paper contribute to the limited existing literature on the topic of support and counselling in the context of embryo donation. The findings suggest that formal support and counselling, while potentially meeting guidelines to some extent, may fall short of adequately preparing those involved in embryo donation for what may lie ahead. Rather than simply being a procedural requirement, counselling should aim to explore the complexities of embryo donation and receipt (as was true for some of the participants), including allowing for discussion of potentially difficult topics or those that people may not have previously thought about. This should involve opening up new lines of thought that facilitate as best as possible the capacity of people to make informed decisions about embryo donation and receipt, as well as providing continued support which goes

beyond decision making and implications counselling, and also encompasses needs that may arise into the future, including disclosure to children about their donor conception (and indeed the needs of children themselves). Beyond formal support and counselling, that informal sources of support and counselling may play an important and ongoing role is an area that requires concerted attention into the future.

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