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Acharya, S, Bryant, L orcid.org/0000-0002-1972-7395 and Twiddy, M (2017) Altruism or obligation? The motivations and experience of women who donate oocytes to known recipients in assisted conception treatment: an interpretative phenomenological analysis study. *Journal of Psychosomatic Obstetrics and Gynecology*, 38 (1). pp. 4-11. ISSN 0167-482X

<https://doi.org/10.1080/0167482X.2016.1233171>

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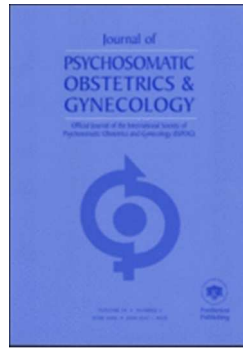
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Altruism or obligation? The motivations and experience of women who donate oocytes to known recipients in assisted conception treatment: An Interpretative Phenomenological Analysis study

Journal:	<i>Journal of Psychosomatic Obstetrics & Gynecology</i>
Manuscript ID	DPOG-2015-0131.R2
Manuscript Type:	Original Research
Keywords:	oocyte donation, motivation, experience, interpretative phenomenological analysis, qualitative methods

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Manuscripts

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3 **Altruism or obligation? The motivations and experience of women who donate**
4 **oocytes to known recipients in assisted conception treatment: An**
5 **Interpretative Phenomenological Analysis study**
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10 **Abstract:**

11
12 *Introduction:* This qualitative study was conducted to explore the motivations and
13 experience of oocyte donors donating to women known to them. *Methods:* Three
14 women who donated oocytes to a close relative were interviewed and data analysed
15 using an Interpretative Phenomenological Analysis approach. *Results:* The two key
16 elements noted were 'motivations for donation' and 'coping with the consequences of
17 oocyte donation'. The motivation for donation was influenced by the familial bond
18 that was strengthened by the donation process in some cases. The concept of
19 altruistic oocyte donation stemmed from the narratives of giving the gift of
20 motherhood and gaining a positive self-image and respect from others. Coping with
21 the consequences of oocyte donation tests the donor identity, their wishes for a
22 positive outcome, concerns regarding disclosure of biological motherhood and
23 detachment from the egg and potential child. *Discussion:* Motivation is influenced by
24 a combination of factors including the rewards of altruistic behaviour, the existence
25 and potential strengthening of the relationship between donor and recipient, but
26 possibly also, a sense of obligation and societal expectations. Oocyte donation can
27 be variously viewed by donors as a unique way of reproductive empowerment or an
28 example of acceding to subtle coercion and thus disempowerment. The study also
29 highlights the clinical as well as ethical importance of providing support services for
30 oocyte donors and recipients.
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56 **Introduction:**
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3 Oocyte donation is an established procedure for women to achieve a pregnancy via
4 assisted reproductive technology (ART). Data from the USA show donor eggs or
5 embryos were used in approximately 11% of the 190,773 ART cycles performed [1].
6
7

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9 Oocyte donation is an intrusive and complex process and has the potential for
10 significant psychological, physical and social impacts on donor and recipient [2, 3].
11
12

13
14 The Human Fertilisation and Embryology (HFEA) Act, UK, 2005 [4] lifted anonymity
15 from oocyte donors and allows donor conceived children to access the identity of
16 their donor when they reach the age of 16. In spite of concerns that this would lead
17 to a reduction in the number of women volunteering to donate oocytes, the first
18 HFEA report on gamete donation in 2014 showed there was an increase in oocyte
19 donation since 2006, although the demand still far outstrips supply [5].
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29 Sister-to-sister donation has been advocated because of the assumption that a
30 common genetic heritage may allow recipient parents to bond better with their child
31 [6]. In support of this, a review reported positive attitudes of infertile couples towards
32 oocyte donation by sisters [7]. The limited literature suggests that oocyte donation
33 between two people known to each other has mainly altruistic motives, and donors
34 are motivated to donate to a family member because of their personal relationship
35 [8-11]. Others have further identified that an empathic understanding of the
36 emotional pain of infertility is part of this motivation [12-15]. However, it has also
37 been argued that because society expects women to be caring and family centred,
38 refusing a donation request from a family member may be difficult [16].
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3 Despite the importance of understanding the motivations and experiences of women
4 who donate oocytes there is a paucity of in-depth research exploring the donors',
5 rather than the recipients' perspective [17]. This study aimed to address this gap
6 using a qualitative interpretative phenomenological analysis (IPA) approach [18]. IPA
7 is used to explore the processes through which participants make sense of their own
8 experiences, by examining the respondent's accounts of the phenomena under
9 consideration [19].
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19 **Methods:**

20 *Recruitment*

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25 Sampling was purposive. Twelve women who had donated oocytes to a known
26 recipient in the previous five years at one NHS hospital in England were invited to
27 take part by letter. None had received any financial reward for donation. SA was a
28 male clinician in the department where the women attended for treatment. None
29 were previously known to SA and he was not involved in their care. Of the six
30 responders, four initially expressed willingness to participate in the research. Of
31 these four, three finally took part. The reasons for non-response or declining to
32 participate are unknown since no further contact was made after the initial invitation.
33 One woman withdrew consent prior to interview without giving a reason and this was
34 respected without further contact being made.
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48 *Summary of the participants*

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51 All three participants were Christian, British Caucasian women who had genetic
52 children of their own. All were biologically related to the recipient. Participants
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3 therefore constituted a homogenous sample. To maintain confidentiality, donor-
4
5 identifying information has been excluded with pseudonyms used throughout.
6
7

8 Anne (30 years) and Debbie (35 years) identified as housewives, each 'happily
9
10 married' to the father of their two children. Both had donated oocytes to their aunts
11
12 three years previously, with whom they had very close relationship. In both cases
13
14 their donation did not result in a successful pregnancy. Susan (38 years) worked as
15
16 a nurse. She was divorced from the father of her two children and identified as a
17
18 'single mother'. Susan's donation to her sister two years previously had resulted in a
19
20 successful pregnancy and she occasionally met her sister's child.
21
22

23
24 Anne was very open and positive about her decision. She had no plans for a future
25
26 pregnancy. Debbie was very 'happy' narrating her story, and although she may have
27
28 liked another child, her circumstances precluded this. Susan appeared to be more
29
30 reticent about the experience during the interviews. She did not rule out having
31
32 further children of her own with a future partner.
33
34

35 36 *Procedure*

37
38
39 The interviews were conducted by SA. The participants were informed of the reason
40
41 for conducting the research, and were aware of SA's credentials before they
42
43 consented to take part. Interviews were held in a dedicated counselling room on the
44
45 Assisted Conception Unit and lasted 45-60 minutes. Participants consented to the
46
47 interviews being audio recorded and field notes being taken. The topic guide was
48
49 based around motivations to donate, experiences of the donation and reflections on
50
51 this experience.
52
53

54 55 *Data Analysis*

1
2
3 The interviews were transcribed verbatim and analysed using Interpretative
4
5 Phenomenological Analysis following the four stage process described by Smith and
6
7 Osborn [19]: (1) Looking for themes in the first transcript, (2) Connecting themes, (3)
8
9 Continuing approach with other transcripts, (4) Translating themes to narrative. The
10
11 reflexive diary kept by SA informed the analysis. The findings reviewed by two
12
13 experienced qualitative researchers (co-authors) to ensure the interpretations were
14
15 well grounded within the original data.
16
17
18

19 Ethical approval

20
21
22 Ethical approval for the study was granted “[detail removed for blind review]”
23
24

25 **Results**

26
27
28 Two key elements of the participant narratives were identified: *‘Motivations for*
29
30 *donation’* and *‘Coping with the consequences of oocyte donation’*. Each of these
31
32 elements comprised a number of sub-themes.
33
34

35 **Motivations for oocyte donation**

36
37
38 The motivation to donate was encompassed within two main themes (1) the familial
39
40 bond and (2) altruism. Both themes have a number of sub-themes.
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42
43

44 (1) The familial bond

45 ***Knowing the potential parents***

46
47
48 Anne and Debbie were willing to go through the invasive process of oocyte donation
49
50 only for someone they knew well. There was a sense of responsibility regarding the
51
52 welfare of any potential offspring.
53
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3 *'I don't think I could do it for a stranger though, I don't know them as a person,*
4
5 *they might just have a child and be not very nice people to that child' (Debbie)*
6
7

8 Anonymous donation would also deny Debbie the chance to know if a pregnancy
9
10 ensued and the sense of fulfilment gained from knowing she had helped the couple.
11

12
13 Susan did not rule out anonymous donation, however, she acknowledged that unless
14
15 she had been asked by her sister she would not have considered donation:
16

17
18 *'Could I have done that for somebody else? I probably wouldn't routinely offer*
19
20 *my eggs.'*
21
22

23 24 **Donation as a means to strengthen the familial bond**

25

26
27 Anne had a strong bond with her aunt, to whom she donated her oocytes.
28

29
30 *'She's the closest thing I've got to a mum now... I love her to pieces, so I'll do*
31
32 *anything for her.'*
33
34

35
36 Debbie felt that donating to her aunt had brought them closer together.
37

38
39 *'That's what motivated me, to know that it is special... I know that they have*
40
41 *all the love in the world to give'*
42

43
44 The act of donation appeared to be intrinsically rewarding for these two women, who
45
46 felt that their action would cement existing bonds, evoke kindness and foster
47
48 generosity. Anne and Debbie described their family as close and that helping
49
50 someone in their family was a natural thing to do. In contrast, Susan said nothing to
51
52 suggest that she shared a particularly close relationship with her sister. Instead, she
53
54 was surprised to be asked since she viewed herself as a less than ideal candidate. '*l*
55
56
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1
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3 *was surprised at [her] choosing me [long pause]. The other two sisters are both*
4
5 *doctors [laughs]... they are more intellectual'.*
6
7

8 ***Donation in the context of the wider family***

9

10
11 The participants provided different perspectives on the role other family members
12 had played in their decision making. Anne and Debbie's family and Susan's wider
13 family (siblings and parents) were 'very supportive'. However, Anne and Debbie
14 revealed that oocyte donation had also provoked some familial disharmony.
15
16
17

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19
20
21 *'I had an argument with my sister-in-law over it; she said the same thing as the*
22 *counsellor, 'this is not your child [to her aunt]'. (Anne)*
23
24

25
26 *'My mother-in-law is a bit old fashioned ... she said you shouldn't mess with nature'.*
27
28 *(Debbie)*
29

30 31 (2) Altruism

32

33 34 ***Giving the gift of motherhood***

35

36
37 Participants felt very passionate about the '*right to motherhood*' and a strong
38 motivation was to help someone else achieve this 'natural' life progression.
39
40

41
42
43 *'It was something she really wanted and having my own two children... I*
44 *would never be without them [laughs], however hard work they are.'* (Susan)
45
46

47
48 *'It's priceless' (Anne)*
49

50
51 *'Best thing in the world...it's a special thing... in whatever shape or form its*
52 *offered to you, whether it's natural, not natural' (Debbie).*
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3 When asked whether the experience of donating oocytes has changed them in any
4 way the participants mentioned that they have even contemplated surrogacy for their
5 loved one to achieve a pregnancy.
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10 *'Although I do not want more children of my own, I have thought about it, it*
11 *would be nice to have a girl but you never know what you are going to get...*
12 *Maybe it is not a need for children of my own because I know we can't really*
13 *maybe support another child... Maybe it's a need for being pregnant, maybe*
14 *surrogacy and being able to give somebody that child...'* (Debbie)
15
16
17
18
19
20
21

22 *'I have read about surrogacy, which I did say to my auntie that I would do as*
23 *well. I would be her oven for nine months, just so she could have something*
24 *that I have already got'* (Anne)
25
26
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28
29

30 **Self-sacrifice**

31
32 Anne stopped smoking and lost weight, to be an oocyte donor, which she described
33 as 'life-changing' sacrifices. In spite of being aware of the ill effects of smoking in
34 pregnancy she did not stop in her own pregnancies, but did so 'for her aunt'. The
35 procedure of oocyte donation is invasive and potentially risky but participants were
36 still willing to undertake the procedure to help others.
37
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45 *'I suppose I had some qualms about the procedure itself but put them aside*
46 *to try and help her'* (Susan)
47
48
49

50 For Debbie and Susan, there were concerns that oocyte donation could be
51 detrimental to their own fertility prospects, should they want to extend their family,
52 although they had no immediate plans to do so.
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3 *'I suppose, at the back of my mind there is consideration I might want another*
4 *one again, at some stage, if I am with someone else... [laughs] I've already*
5 *given eight eggs away (Susan)*
6
7
8
9

10 **Gaining a positive self-image and respect from others**

11
12
13 Donation had provided Anne and Debbie with a positive opportunity to enhance their
14 sense of self-worth as 'givers'.
15

16
17
18 *'I am more of a giving person...I didn't think about it, as soon as she asked*
19 *me my answer was yes' (Anne).*
20
21
22

23
24 *'I'm a charitable person; I'll give if I can' (Debbie).*
25
26

27 In contrast, Susan appeared to wish to avoid a negative judgement on her 'self'.
28

29
30 *'It was something she wanted a great deal so it's not something I could just*
31 *say, no... It would be selfish for me to say no'.*
32
33
34

35 Oocyte donation made them feel they were respected by family and friends because
36 of the contribution they had made towards their family.
37
38

39
40 *'People still now say 'Oh please tell us about it'... 'I don't know if I could do*
41 *that' ... they have a bit of respect' (Debbie)*
42
43
44

45 **Coping with the process and consequences of donation**

46 **Wanting a positive outcome**

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48
49 All donors were not only anxious for a positive outcome for the recipients but also
50 themselves to justify the sacrifices made or effort expended
51
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3 *'I think I would just want to know if they ever did get pregnant. Did I help*
4 *somebody? That sounds terrible but was it for nothing?'* (Debbie)
5
6
7

8 Participants also felt a sense of responsibility to deliver good quality oocytes which
9 could result in a successful pregnancy.
10

11
12
13 *'When it came to the time of harvesting I was more worried about the eggs,*
14 *are they going to be strong enough, are they the right size, are they*
15 *everything that they want, is there enough. I was gutted when it did not work.'*
16
17
18
19 (Anne)
20
21
22

23 Potential donors may not be fully aware of the potential for 'failure'. Anne
24 commented on how '*surprised*' she was when she came to know of the '*relatively low*
25 *success rates*' of oocyte donation.
26
27
28

29 ***Becoming redundant***

30
31
32

33 During the donation process, the donor briefly becomes the focus of attention in the
34 infertility story. They have intense contact with the clinic with daily medication,
35 frequent scans and then finally undergo the oocyte retrieval process. However, the
36 focus then shifts back to the recipient. This shift was recognised by the participants:
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38
39
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41
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43 *'You have got to value the egg donors as much as the people you are trying*
44 *to help in the first place'* (Debbie)
45
46
47

48 ***Disclosure of biological motherhood***

49
50

51 One of the most important concerns post-donation was around the disclosure of the
52 biological mother to the future child and their social circle. Each participant viewed it
53 differently. Anne was unhappy when counsellors brought up the topic since she felt
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3 this was a personal matter and confessed that *'I did not want to know the reality'*.
4
5 Debbie and the recipient agreed that they would be open from the start and tell the
6
7 child that *'she [her aunt] was the mother but he/she was not born from her eggs'*. In
8
9 contrast, Susan had serious concerns, because her sister was reticent towards
10
11 disclosure:
12

13
14
15 *'It's something that ought to be just known' [to prevent] 'possibilities of*
16
17 *explosions later that we don't know about' [and] 'repercussions that could be*
18
19 *passed on through generations'*.
20

21 22 ***Detachment from the egg and potential child*** 23

24
25 A related concept was who had 'ownership' of a baby resulting from oocyte donation.
26
27 Anne appeared to distance herself by describing the oocyte as an inanimate object:
28

29
30
31 *'I flush them away once a month ... once they have left my body, they are not*
32
33 *mine... I don't see an egg as a potential life'*.
34

35
36 Debbie rationalised it as life beginning only when the egg is fertilised, so it is not hers
37
38 as it would require fertilisation by her partner's sperm for it to be 'her' child
39

40
41
42 *'I haven't carried the baby, it's not my baby... I know this child was not made*
43
44 *with him, so therefore it's not our child.'*
45

46
47 Susan, the only person whose egg donation led to a successful pregnancy did not
48
49 find detachment so easy. Her words suggested she saw the child as hers, but being
50
51 reared by her sister
52

53
54
55 *'She would like to believe that he is her own child... urm ... and obviously she*
56
57 *is bringing him up... It is hard seeing your own living [laughs] offspring sort of*
58

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3 *but that somebody else's in some ways... I am sure it's easier for my sister*
4
5 *that it looks more like her husband [laughs] rather than her sister!*
6
7

8 **Discussion**

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10
11 This study aimed to identify motivations for oocyte donation in women who had
12 donated to a family member by exploring their experiences and reflections on this
13 process. A number of key interlinking themes were identified.
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15
16

17 *Motivations for donation*

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19
20
21 Research suggests that altruism shown by the oocyte donor is influenced by her
22 personal relationship with the recipient, her own status as a mother and the wish to
23 alleviate the emotional burden of infertility [13, 20-23]. These findings are consistent
24 with the donors in this study who were willing to undergo the process only because
25 they knew (and approved of) the recipients.
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33
34 Oocyte donation is also said to contribute to the significance of motherhood by
35 assisting others who are denied this option [24]. In these participants, the altruistic
36 theme '*Giving the gift of motherhood*' supported this idea and the concept of a
37 woman's '*Right to motherhood*'. In some societies, having children is widely
38 assumed to be a natural and inevitable part of being a woman [25]. Motherhood can
39 bring a sense of identity and status for some women [26]. It could be argued that that
40 many women in industrialised societies have fewer children than they might wish due
41 to financial considerations, the unequal division of domestic labour and impact on
42 career [27]. Being an oocyte donor might satisfy a personal desire for 'motherhood
43 by proxy' if perhaps the woman enjoyed being pregnant and found motherhood
44 satisfying [28]. It is of note that the idea of surrogacy was raised by two participants.
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3 Anne raised it to suggest her commitment to her aunt's cause. Debbie's thoughts
4
5 may have reflected a desire to be a mother again. For many women who have had
6
7 children, whether or not to have another child is an ongoing dialogue until their
8
9 fertility ends. It is suggested that woman's moral identity as ethical subjects are
10
11 created in the donation process and that the stories these women tell pivot around
12
13 identity construction [29]. The act of retelling their stories was significant because it
14
15 afforded them a way to objectively manifest the subjective meanings they attributed
16
17 to their gift-giving acts. The respect gained from others following oocyte donation
18
19 was important to two of the women interviewed. In contrast, the sudden withdrawal
20
21 of attention from themselves to the recipient was also noted. This situation has the
22
23 potential to undermine the identity as a person of an altruistic, but significant
24
25 individual.
26
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28
29

30 Susan's narrative supports the alternative argument that donors may donate to be
31
32 seen to conform to the 'caring' societal role assigned to women [16]. It is, however,
33
34 difficult to distinguish between choice and conformity in practices of oocyte donation
35
36 between close relatives. This may be called 'corporeal generosity', where the giving
37
38 and receiving between selves and others is 'already in operation' as a fundamental
39
40 element of their relationship occurring 'without any thought at all', which is supported
41
42 by the 'unthinking' way in which Anne described her decision to donate [30]. Good
43
44 family support and a stable relationship may be important factors in helping donors
45
46 cope with the emotional aspects of donation. The two participants who were married
47
48 emphasised the importance of their family's support for their decision. One study
49
50 found that donors commonly had a strong belief that they were in control of their
51
52 reproductive decision-making and also they would have the support of friends and
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3 family, if they decided to donate their oocytes [31]. However, it may also be that
4
5 'support' from a family can be a form of subtle social coercion, as in Susan's case
6
7 the donation had the support of both parents and other siblings.
8
9

10 Susan donated to her sister but Anne and Debbie to their aunt. Because of the
11
12 differences in the outcomes of the donation, this paper cannot throw light on whether
13
14 or not cross-generational or same-generational donation has any implications
15
16 towards the attitude or experience of the donors. However, it is possible that different
17
18 generational power relationships may play a role in the nature of the 'obligation'. This
19
20 area would benefit from further research.
21
22

23 24 *Coping with the consequences of oocyte donation*

25
26
27 Oocyte donation has the potential to be an emotionally and physically challenging
28
29 procedure for which donors can be unprepared, especially in cases where the
30
31 donation fails [23]. In some cases 'detachment' appears to be a coping strategy to
32
33 avoid emotional attachment to a potential or actual child [11-14, 24, 32]. In this study
34
35 Anne and Debbie employed this strategy, however, Susan whose donation led to a
36
37 successful pregnancy found it difficult to dissociate herself from the child.
38
39

40
41 In cases of successful intra-familial donations, genetic relationship and the socially
42
43 defined role of the donor in relation to the resulting child may pose additional
44
45 challenges [12, 22, 33]. Susan was presented with an on-going intrapsychic dilemma
46
47 in that any child born out of the donated oocytes was genetically linked to her but
48
49 she would have no legal or social recognition as a mother. One of the most important
50
51 concerns for both the donor and the recipient seems to be of disclosure of the
52
53 biological mother to the future child and others in the social circle [11-12, 23, 31, 34].
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3 A study exploring the concerns of anonymous donation recipient's feelings
4
5 influencing their decision to enter into treatment demonstrated the contrasting
6
7 attitude between women who were childless and women who had genetic children of
8
9 their own. The participants with children expressed reservations and anxiety about
10
11 how, and if, to disclose to the siblings who would have a different genetic make-up
12
13 [35]. In this study Susan was in favour of full disclosure but it appeared the recipient
14
15 was not. This might indicate that the attitudes towards disclosure before oocyte
16
17 donation may change when a pregnancy is successful, leading to conflict within the
18
19 relationship, although it is not known if the sister had already identified her
20
21 reluctance prior to the donation.
22
23

24 25 26 *Study strengths and limitations*

27
28
29 To our knowledge, this is the first study to explore the motivations and experiences
30
31 of 'known' donors using IPA. IPA enables an in-depth analysis of the experiences of
32
33 these women to in a way previous survey research has not achieved. By design
34
35 however, an IPA study focuses on a very small homogenous sample - here of white
36
37 British women from one NHS service. Therefore these findings cannot be
38
39 generalised to other populations. It is accepted that the sample size was small than
40
41 what was aimed for but this was due to the fact that recruitment was limited by
42
43 resources in terms of the first author's MSc research project and also willingness for
44
45 participants coming forward to be interviewed. However, the sample size meets the
46
47 requirement of IPA studies as prescribed by the methodologists [19]. In IPA 'less is
48
49 more' and it is desirable to examine fewer cases in greater depth than in superficial
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51 and descriptive way. It is quoted that for a beginner conducting IPA studies for a
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53 Masters' level study a sample size of 3-6 participants is adequate [36]. A study of
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3 British women's attitudes towards oocyte donation demonstrated that ethnicity and
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5 religion are important determinants on the possibility of being donors [31]. Oocyte
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7 donation practice varies by country. In most Islamic countries oocyte donation is
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9 illegal [367]. In the USA donors are allowed monetary compensation for donation
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11 [378] whereas, in the UK the donor receives a 'reasonable reward' as recompense
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13 for their time [389].
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17 The findings should be also be considered within the context that the interviewer was
18
19 a male clinician working within the Reproductive medicine unit. This may have
20
21 affected both the way the women told their story and the way the data were
22
23 interpreted. To help address this, the analysis and interpretation was discussed in
24
25 detail with the co-authors who were not involved in the service in any way.
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28 29 *Future research recommendations*

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32 The findings of this study points to a number of areas where further research is
33
34 needed. As ethnicity and religion have implications for motivations, attitudes and
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36 experience of oocyte donation further research in a more diverse group is warranted.
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38 More qualitative research to investigate the motivation, attitudes and experience of
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40 different 'types' of donors are also indicated, e.g. with anonymous, patient and
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42 intergenerational donors. It is important to compare and contrast the views and
43
44 experiences of these different groups to better understand the clinical population.
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48 49 **Conclusion:**

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51 This study demonstrates that motivations for oocyte donation can be complex,
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53 interwoven and sometimes paradoxical. Motivation can be influenced by the rewards
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55 of altruistic behaviour, the potential strengthening of the relationship between donor
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3 and recipient, but possibly also, a sense of obligation and societal demands resulting
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5 in subtle coercion and thus disempowerment. The study provides further insight to
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7 the motivations of known oocyte donors, the emotional consequences of this
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9 donation and the implications for familial relationships. Further qualitative research
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11 will provide a deeper understanding of these motivations, which in turn may change
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13 present practice and help in donor recruitment. The study highlights the importance
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15 of providing patient centred services oocyte donors as well as recipients.
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6 Authors' roles
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9 SA co-designed and implemented the study design, conducted the interviews,
10 analysed and interpreted the results and drafted the article.
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12
13
14 LB and MT had overall responsibility for the post-graduate study of which this work
15 was one part and were involved in co-design, analysis and interpretation of the data,
16 critical appraisal of intellectual content and final approval.
17
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21 Declaration of interests:
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24 The authors report no conflicts of interest.
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28 **Current knowledge on the subject:**
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- 30
31 • Oocyte donation has the potential for significant psychological, physical and
32 social impact for both the donor and recipient
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36 • Oocyte donation between two people known to each other is assumed to
37 have mainly altruistic motives
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41 • Most primary research in this area has used survey methodology, which has
42 not provided an in-depth exploration on the topic
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47 **What this study adds:**
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50 • Motivation is influenced by a combination of factors including the rewards of
51 altruistic behaviour, the existence and potential strengthening of the
52 relationship between donor and recipient, but possibly also, a sense of
53 obligation and societal expectations
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- Oocyte donation can be variously viewed by donors as a unique way of reproductive empowerment or an example of acceding to subtle coercion and thus disempowerment
- The study highlights the clinical as well as ethical importance of providing individualised support services for oocyte donors and recipients

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