

How to facilitate decisions about surplus embryos: patients' views

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BACKGROUND: In Victoria, Australia, legislation governing fertility treatment provides that surplus human embryos must not be stored for longer than 5 years. Couples must then choose one of three options: discard, donate to research or donate to another infertile couple. Previous research suggests that many people find these decisions difficult and emotionally distressing. This study aims to elucidate the nature of these difficulties and to identify ways in which the decision-making process could be facilitated. **METHODS:** This project used a combination of qualitative research methods. In total, 42 people agreed to participate in either a structured interview or a group discussion. All participants had completed IVF treatment and had surplus embryos in storage. The aim of the interviews was to discuss participants' decision making regarding their surplus embryos. Data were thematically analysed. **RESULTS:** Most participants described the decision-making process as difficult and emotional. Findings indicate that participants could be assisted by more information about each of their current options, and opportunities to talk to others in similar situations. Many responded positively to the idea of having more options, including choice about which research projects to donate to (directed research), and about the recipients of their donated embryos (directed donation). **CONCLUSIONS:** This study suggests that there are practical ways to assist people in making decisions about their surplus embryos, which could be easily implemented. In addition, the study demonstrated interest in the possibility of directed donation to other couples.

Keywords: frozen embryos; embryo donation; embryo disposition; embryo research; patient attitudes

Introduction

Cryopreservation of surplus embryos is now an integral part of IVF procedures and the number of embryos in storage around the world is steadily increasing (Eydoux *et al.*, 2004). In Australia, legislation and guidelines determine the length of time that embryos can remain in storage. Storage limits vary between states. In Victoria, legislation that came into effect on 1 January 1998 (Infertility Treatment Act, 1995) provides that human embryos can remain cryopreserved for a maximum of 5 years (with some possibility for extension). Patients with surplus embryos approaching the legal storage time limit must then decide among three options: to donate their embryos to another infertile couple, to have their embryos disposed of and, as of June 2003, couples can also choose to donate their spare embryos to research. The third option follows the enactment of federal legislation permitting embryo research under some conditions (Research Involving Human Embryos Act, 2002). Surveys conducted prior to this legislative change reveal that >80% of Victoria couples dispose of excess embryos rather than donate them to another couple (Oke *et al.*, 1998; Tinney *et al.*, 2002; Kovacs *et al.*,

2003). Whether the recent option of donating surplus embryos to research will affect patients' decisions remains to be seen, but surveys from Victoria (Hammarberg and Tinney, 2006) and other states in Australia (McMahon *et al.*, 2003; Burton and Sanders, 2004) suggest that substantial numbers of patients would consider this option.

Several studies have reported on the fate of supernumerary embryos (Kovacs *et al.*, 2003; Lornage *et al.*, 1995; Hounshell and Chetkowski, 1996; Darlington and Matson, 1999) and on patients' attitudes or intentions regarding the option of disposal (Kloch *et al.*, 2001; Svanberg *et al.*, 2001), donation to others (Söderström-Antilla *et al.*, 2001; Newton *et al.*, 2003; Adsuar *et al.*, 2005), or donation to research (McMahon *et al.*, 2003; Bangsbøll *et al.*, 2004; Burton and Sanders, 2004). Although some data exist on patients' attitudes to all three options, it is limited in that data describe the hypothetical intentions of oocyte recipients about surplus embryos (Nachtigall *et al.*, 2005), or because it describes the intentions of people who did not have embryos in storage and who had not yet commenced IVF (Laurelle and Englert, 1995) or who had not necessarily completed IVF treatment (Lyerly *et al.*, 2006).

Evidence suggests that people's intentions regarding spare embryos change after IVF treatment (Lornage *et al.*, 1995; Hounshell and Chetkowski, 1996; de Lacey, 2005) and following the birth of children (Cooper, 1996; McMahon *et al.*, 2000), and are predicted by the success or otherwise of fertility treatment (Lornage *et al.*, 1995; Newton *et al.*, 2003).

A few studies have examined how Australian couples who have completed fertility treatment make final decisions about their surplus embryos and how they decide among all three options (McMahon *et al.*, 2000; Hammarberg and Oke, 2000; Tinney *et al.*, 2002; de Lacey, 2005; Hammarberg and Tinney, 2006). These reveal that many couples find decisions about the destiny of their surplus embryos very difficult and emotionally stressful. Similar findings have been reported in Victoria, despite all couples receiving mandatory counseling, including information about the options available for supernumerary embryos, prior to IVF treatment. (Hammarberg and Tinney, 2006). Many couples describe feeling uncomfortable with all of the available choices and reveal postponing the final decision for as long as possible (McMahon *et al.*, 2000; Söderström-Antilla *et al.*, 2001; Tinney *et al.*, 2002; Hammarberg and Tinney, 2006). A significant number of couples, when finally contacted, revealed that they did not return to claim or dispose of their frozen embryos because these decisions are difficult and emotionally too stressful (Oke *et al.*, 1998; Newton *et al.*, 2003; Hammarberg and Tinney, 2006).

It has been argued that more attention needs to be paid to the decision-making process regarding surplus frozen embryos (Nachtigall *et al.*, 2005; Lyerly *et al.*, 2006) and that the prolonged stress associated with these decisions may have an adverse effect on patients' health and wellbeing (McMahon *et al.*, 2000). Although some quantitative analysis has been undertaken (McMahon *et al.*, 2003; Newton *et al.*, 2003; Hammarberg and Tinney, 2006), little qualitative work has been done to identify the nature of the difficulties associated with decisions about surplus embryos or to elucidate factors that might assist this process. One such study investigated different models for embryo donation procedures (Newton *et al.*, 2003), describing attitudes of couples with spare embryos to the possibility of 'conditional donation' (i.e. donation is limited to preferred recipients according to the donor's preferences). Another study explores factors that might encourage or dissuade people from donating spare embryos to research and suggests that potential donors desire more control over the consent process and the types of research they support (McMahon *et al.*, 2003). Each of these studies employs quantitative methodology and questionnaires. Two qualitative studies report on the intentions of oocyte donors (Adsuar *et al.*, 2005) and oocyte recipients (Nachtigall *et al.*, 2005) regarding their surplus embryos but it remains unclear whether the fact that these surplus embryos were formed from donated oocytes affects decision making about their disposition. Previous research suggests that people's attitudes towards embryo donation and embryo disposition are affected by whether or not they share a genetic tie to the embryo (Sehnert and Chetkowski, 1998).

Two recent studies present detailed qualitative data on patients' decision making regarding surplus cryopreserved

embryos (de Lacey, 2005; Lyerly *et al.*, 2006). Lyerly *et al.* (2006) report on seven broad themes that informed participants' decisions about embryo disposition. These include feelings of responsibility towards embryos, views about the moral status of embryos, perceived lack of options for fate of surplus embryos and desire for alternative options for embryo disposal. However, the study does not clearly distinguish between couples who had completed IVF treatment and those who did or did not actually have cryopreserved embryos. That study reports on semi structured in-depth interviews of a total of 46 individuals at different stages of IVF treatment, only 7 of whom had embryos crypreserved for 5 years or more (Lyerly *et al.*, 2006) of which 2 individuals intended to use their embryos for further IVF treatment.

In summary, although several studies report on patients' attitudes and their decision-making about the fate of surplus embryos, our study represents one of few in-depth qualitative investigations of patients' attitudes to all three commonly available options for supernumerary embryos. Our study acknowledges that there may be important differences between the attitudes of patients with embryos formed from donor gametes and non-donor gametes, and focuses only on the views of patients with genetic ties to their surplus embryos. Further, our study is not limited to hypothetical decision making but reports on the views of patients who had completed IVF treatment with surplus embryos and who were required because of legal time limits to make final determinations about embryos surplus to their needs.

Aims of Study

Using qualitative methods, our research explored the diverse range of patients' views on all three currently available options for surplus embryos. The research also explored patients' views on hypothetical scenarios. Our study was designed to answer specific questions about the decision-making process that could not be accessed through quantitative analysis. The advantages of qualitative research methods to gain insight into complex behaviours and attitudes are well recognized (Berg, 1994; Dyer *et al.*, 2002). Although qualitative research does not have the statistical power or the generalizability of quantitative research, it provides valuable information about complex issues.

The specific aim of our study was to identify and describe factors that might assist people in making final decisions about the fate of their surplus embryos. We investigated people's attitudes to decisions about their excess embryos and what factors influence their decisions. We discussed participants' ideas and their responses to researcher-generated hypothetical scenarios for facilitating decisions about supernumerary embryos.

Methods

Ethics

This study was approved by the University of Melbourne Human Research Ethics Committee, the Epworth Hospital Human Research Ethics Committee, and the Monash Private Surgical Hospital Research

Ethics Committee. Participants' privacy has been protected by removing names and other identifying information.

Recruitment

Individuals living in Victoria (Australia) who had completed IVF treatment and had surplus embryos in storage approaching the legal storage limit of 5 years were eligible for participation. Participants were recruited from Melbourne IVF clinics and support groups. Methods for recruitment included advertising in newsletters and circulating information brochures.

Both couples and individuals were invited to participate. Couples or individuals who did not have (or had not had) surplus embryos in storage or who had embryos formed from donor gametes were excluded from the study. No other exclusion criteria were applied.

Sample

A total of 42 individuals, 11 men and 31 women, participated in the study. They were interviewed individually, as couples or in groups. 9 male-female couples, 2 men and 22 women participated in interviews. Female participants ranged in age from 28 to 44 years and males from 30 to 49 years. All participants except one had biological children or were pregnant at the time of interviews. Thirty seven participants lived in Melbourne; five participants lived in regional or rural Victoria.

Procedure

Interviews were conducted between April and September of 2004. Participants were offered the option of small group discussions of no more than eight people or face-to-face interviews as a couple or individually or a telephone interview. Three group discussions were conducted with a total of 15 participants. In addition, 7 couples and 13 individuals participated in an individual interview, 5 of which were telephone interviews (5 individual participants).

Each individual interview was ~1-h duration and focus groups were between 1.5 and 2.5 h in length. With participants' permission, all 27 personal interviews and 3 group discussions were audio-recorded and transcribed.

The purpose of the interviews was to:

- (i) Collect a range of patients' views about their decisions in relation to their excess embryos, including their experience of the decision-making process.
- (ii) Collect a range of views from patients' in response to hypothetical scenarios generated by the researcher.

The same interview schedule was used in both individual interviews and group discussions. The interview schedule was semi-structured, with open-ended questions. The interview process encouraged participants in both personal interviews and group discussions to reflect on their decision, discuss the reasons behind their decisions and to describe their experiences of the process.

At the beginning of the interview, participants were asked what decisions they had made, or what their intentions were, regarding their surplus embryos. In addition, participants were asked how they felt about the decision-making process, and how sure they were of their decision. Participants were also asked to describe their reasons for choosing their preferred option and to describe how they felt about each option in turn (donations to research, disposal, donation to another couple).

Towards the end of the interview, a series of hypothetical scenarios were presented. Participants were asked whether their preferences would change if any of the following possibilities were available:

- (i) directed research—having information about or choosing the research project for which you would provide embryos.

- (ii) self disposal of embryos
- (iii) directed donation—having information about or some element of choice about the recipients of your donated embryos
- (iv) negotiated levels of ongoing contact with any child born from your donated embryos
- (v) guaranteed anonymity following the donation of surplus embryos

Data collection

The data focused on three different aspects: (i) ascertaining how and why participants chose, or intended to choose, between the available options, (ii) collecting ideas generated by participants for facilitating the decision-making process and (iii) eliciting responses to researcher-generated hypothetical scenarios for the disposition of surplus embryos.

Data analysis

Although different modes of data collection affected the depth and quality of the data, the data were not analysed separately. Thematic analysis as described by Patton (1990) was used to identify major themes, which were then organized into categories. To facilitate a detailed examination of this project's interview data, transcripts were entered into a computer software package designed for qualitative research (Atlas.ti). Using Atlas.ti, data were systematically analysed. This computer package was used to store and manage data, as well as locate, code and annotate findings in the data according to categories.

Limitations of the Research

This research was carried out in Victoria, Australia which has particular legislative requirements.

Legislative changes permitting embryo research in Victoria came into effect on 19 June 2003. At the time of interviewing, only one of Melbourne's IVF clinics had been granted a licence to carry out research on supernumerary embryos. The option of donating to research may therefore not have been available to all participants.

It is also worth noting that Melbourne clinics do not routinely offer options for embryo disposal or directed donation to research or other couples. Therefore, the discussion about directed donation to research or other couples is in response to a hypothetical scenario.

Finally, the research method did not include analysis of thematic differences between men and women because the male sample size was inadequate for a meaningful comparison. Differences within couples, or between couples and individuals were not analysed as the focus of the research was to identify themes and not to analyse contrasting views.

Results

All participants in the sample were coming to the end of their legal storage time and having to make final decisions about their excess embryos. Four participants (one couple and two individuals) stated that they had finalized the disposition of their excess embryos—one couple had donated their two surplus embryos to another infertile couple and two participants had discarded their surplus embryos at the time of

interviews. The remaining 38 participants had not made their final decision. From this group, 11 participants stated that they were unsure about what they would do with their surplus embryos, while 27 participants indicated that they had clear intentions about the fate of their surplus embryos. Participants suggested factors that might ameliorate the decision-making process. These included more information about the currently available options and better-targeted timing of this information.

The findings demonstrate widely divergent views about how embryos should be treated and the meanings participants attached to their embryos. On the one hand, embryos were described as potential life, potential children and like 'our babies'. Conversely, other participants described embryos as 'a bunch of cells' not dissimilar to any other disassociated human matter.

In the following discussion of the findings, the text in '*italics*' indicates a direct quote from a participant. These quotations have been selected to illustrate the main themes and to demonstrate the diversity of views. The quotations are not intended to be representative of the sample, nor generalizable.

The first section describes the degree of difficulty in making the final decision. The second section describes responses to hypothetical scenarios.

As is customary in reporting qualitative data with smaller sample sizes, we adopt the following descriptors: when a response is common, the word 'most' is used; 'several' and 'some' are used interchangeably to indicate more than two participants.

Degree of Difficulty in Making Final Decisions

Participants described varying degrees of difficulty in making a final decision. These difficulties were underpinned by conflicts stemming from religious, social, emotional and moral factors.

Four participants described no difficulty in making decisions about the fate of their surplus embryos. These participants described feeling confident about what they would decide, believing that only one option was right for them and feeling no conflict over choosing between options. All other participants described their decisions as being difficult and the source of some emotional and moral distress.

Many participants described a degree of conflict in making their decision. Although many participants described wanting to '*help others*', they also described feeling uneasy about the possibility of a future child or sibling to existing children being '*out there*'. Some participants also described conflict stemming from their religious convictions. Those participants who expressed religious convictions described difficulties in destroying a potential life.

Some participants described making decisions about their surplus embryos as being more difficult after successful IVF treatment or the birth of a child. Two female participants said that they were contemplating a further IVF cycle despite not wanting any more children. For these women, another IVF cycle was preferable to them making a decision among disposal, donation to research and donation to others.

The following sections illustrate some of the difficulties participants described when deciding among the following options:

- (i) donation to research;
- (ii) directed donation to research;
- (iii) disposal;
- (iv) donation to others; and
- (v) directed donation to other couples.

Donation to research

Participants were asked whether they had considered, or would consider, donating their surplus embryos to research. Some participants expressed the view that it would be wrong to destroy embryos because they are potential children or special entities that should not be used for research purposes. However, most participants described discarding embryos as '*a waste*'. They described donation to research as an option that made good use of embryos, which would otherwise be destroyed. One participant described getting '*some use out of them*'.

I think if people are only going to destroy embryos, I can't see why research isn't a good way of using them . . . It makes sense to at least have some use out of them.

A few individuals described their decision to donate spare embryos to research as stemming from a reciprocal obligation to '*give back*' what they themselves had been given. One participant referred to the '*early pioneers*'.

I feel an obligation that we're the recipient of a product of other people's research, that other people have gone before us, taken the risks with IVF, made the hard decisions to donate their material to IVF research and I feel that we've got it a bit easy in that we can just sort of rock up and obtain the benefits of IVF for ourselves. I feel that if I was in the position to have stuff to donate, that it would be my obligation in terms of returning the favour. . . I feel that IVF would never have happened in the first place without the early pioneers'.

But not all participants felt that donating to research was the best option. Some felt that it was better to help other couples directly by donating their embryos to them. One couple described preferring their embryos given to another couple rather than being used for research.

I'd rather give someone a chance of having a baby than giving some to research . . . We've got three little children and we are very lucky and I want to give someone else that chance instead of going to research

Many participants, however, described the issue not in terms of how best to help others, but rather as what was the right way to treat embryos.

No, I couldn't do that (donate to research), . . . I couldn't bear the thought of them being poked or cut up.

For several individuals, embryos represented '*their children*' or '*a being*'. One participant described using the embryo for research purposes as '*callous*'.

It's so callous and it's even worse than destroying them in some ways. I know that as a medical person there is value in research but I'm not putting my embryos in for it.

Several participants indicated that they were unsure about what embryo research might entail. One couple likened embryo research to images from 1950s horror films with descriptions of 'mad scientists' involved in medical research. However, another participant expressed confidence in people who work in medical research, trusting that they would use the embryos for 'positive research'.

I don't know very much about the research and what they would do. . . . I don't think I would want to know the details. . . . I think if you chose to donate to research, then just let the researchers do their stuff really. They are the experts, let them do it. I don't think they are going to be mad scientists—they are someone's embryos, I'm sure they would respect that.

In general, participants indicated that a lack of information about how embryos were used in research made them reluctant to agree to donate their embryos to research. Several participants suggested that they might donate to research if they were provided with more information and a better understanding of what would be 'done to' their embryos.

Directed donation to research

Participants were asked to comment on the information they had, or would like to receive, about embryo research. They were also asked whether the type of research projects proposed might influence their decisions about whether or not to donate to research and whether people with surplus embryos should be able to specify the kinds of research for which their embryos could be used.

Although some participants questioned the benefit of providing information about research to lay people as they would not be able to understand its implications, most participants stated that they would like information about the types of research projects proposed and what these would involve in terms of the fate of their embryos. Participants provided reasons for why they would like information about research projects utilizing surplus embryos. One participant referred to ethical concerns and concerns about the privacy of genetic information.

I'd want to say I want to know, and I'd want to know for two sets of reasons. I want to know in terms of ethical kind of stuff, but I guess I'm also a bit suspicious too about DNA kind of stuff—it's not just that this can be used as some kind of research—it's also, my genetic information, and where is that ending up.

Other responses reflected concerns about what was done to research embryos and at what stage of embryonic development the research was carried out. Participants said that they would be more likely to donate surplus embryos to research if they had information about particular research projects. One participant suggested that more information about the research process may promote more donation to research.

You don't get a great deal of information so I don't actually understand the process of what happens when they go to research and what bits go where or what they do. So if I knew more about

that, I might be more inclined to do that rather than [dispose of them].

Data suggest that participants differentiated between types of research. Participants said that they would be more likely to donate surplus embryos to research if they could direct their embryos to particular projects. For example, several participants suggested areas of research that they would like to support. They indicated that they would like their embryos to be used for research with direct medical benefit such as research on childhood illnesses, multiple sclerosis, cystic fibrosis, diabetes and cancer. They also indicated that stem cell research was an area to which they would be willing to donate their surplus embryos. However, one participant suggested that some particular types of research, such as cosmetic research, would not be supported.

I think if it was research for med students or something that mattered I guess I would [donate to research]. If it was cosmetics, I'd say no, forget it. If it was something like research for curing or containing things like MS or something, I'd be more disposed towards it, depending on what it was.

This participant also supported using embryos for training medical students. However, another participant described feeling uncomfortable with the donation of embryos for training purposes.

I don't know how I feel about that [using surplus embryos to help train IVF technicians]. I guess people have to be trained but I don't see that as reason to potentially destroy an embryo . . . surely embryology can be taught through other embryos, not [human] ones?

A key theme in relation to donation to research was that the lack of knowledge or understanding about the type of research could be a factor in making decisions about surplus embryos. It was suggested that people with spare embryos would be more likely to donate these to research if they had some assurance about the research aims, methods, and applications.

Disposal

Participants were asked to comment on the option of discarding their surplus embryos. At the time of interview, two participants had already disposed of their embryos and four other participants indicated that disposal was their future intention. Among those intending to discard their embryos, reasons for this preference included terminating emotional attachments. They spoke in terms of closure, explaining that if the embryos continued to exist that they would continue to be linked or have emotional ties to them. One participant referred to an 'emotional roller coaster'.

I think about this quite often. It's like when is this fraught with emotion going to end? If you donate them, regardless of the type of person, you are always going to wonder about the child. If you donate them to research, you sort of fear that in ten years time they are going to turn around and say, 'Ten years ago, [clinic] were doing this and this to the embryos and that to the embryos', and all the other things. When is this emotional roller coaster going to stop? I think probably discarding them may be even my way of getting off the roller coaster.

Those participants who did not support disposal gave two main reasons for not discarding their surplus embryos. Some described their surplus embryos as a potential child or a living entity that should be protected, while others described the destruction of an embryo as wasteful in the face of other options.

Several participants explained that the way they viewed their surplus embryos had changed since having children. Some women described feeling maternally towards the embryos or thinking about them in relation to their existing children. One participant made a connection between the surplus embryo and her children that were also the result of IVF.

I suppose the whole experience of the IVF has made me feel that it's a baby because I've seen the embryos under the microscope ... to me, it's every bit as much a baby as what the other children are that have been the outcome of this project.

Several participants asked for details about the disposal process. One participant suggested that she would feel better about disposing of her embryos if she could bury them and plant a commemorative tree. Several other participants responded positively to the possibility of taking control of, or personalizing the disposal of, their excess embryos.

Donation to others

Participants were asked whether they had donated or would donate their surplus embryos to another couple and about their reasoning regarding this intention. All participants stated that donation to others was a good and altruistic thing to do and no in principle objection to the practice was raised by any of the respondents.

Although donating embryos to others was described as 'brave' and 'unselfish', most participants stated that they would find this option too difficult. A few participants indicated considerable moral distress and feeling conflicted at being unable to donate to others while believing this to be the 'right' thing to do. One participant illustrated this conflict.

In our hearts we would dearly love to be able to donate our two embryos to a couple that have been unable to have a baby but we don't think that we could, I suppose psychologically, cope with having an 18 year old come knocking on our door in a number of years and say, 'Hi, you are my biological parents'.

Participants gave varied reasons to explain why donating embryos to others would be too difficult. Many participants expressed the belief that a child that results from a donation would still be their child. One participant referred to the ongoing distress that would be caused by donating embryos to others.

I don't think I could [donate to others]. I think it would bother me all my life, just thinking, 'I wonder what my child is doing?' because it is our "child".

Several participants described a sense of responsibility towards a child born from surplus embryos. They described the sense of responsibility as stemming from their biological relationship to such children. One participant spoke about the sense of responsibility as inevitable.

Yes, see we actually created, we went into a process which we knew full well could create several embryos. So how can we not feel responsible for them?"

One participant described donation of her embryos as 'abrogating her responsibilities'.

Once a child comes into existence you have certain responsibilities, donating those embryos is abrogating those responsibilities. ... By disposing of those embryos you are discharging your responsibility.

Other participants spoke of the strong emotional tie that they believe would exist between them and any children born as a result of their donation. One participant described worrying about seeing the child and feeling connected to the child.

If I was to give the embryos for donation—this was what was going through my head. I thought I would end up seeing that child somewhere and I won't be able to disassociate.

Another common concern regarding embryo donation revolved around the future welfare of children born from such donations. Some participants expressed disquiet about how the child might be raised and by whom. However, other participants indicated that they felt quite sure that couples who were on IVF waiting lists would do 'as good a job' of parenting as they would.

Finally, participants talked about the significance of the gender of any child that resulted from their donation to others. For example, some participants commented that they had 'always wanted a girl' or a boy, and that they would feel distressed to learn that one of their donor embryos had produced the girl or boy that they had always desired. One participant explained that if she could determine the gender of her surplus embryos she might decide differently about their fate.

Hypothetical Scenarios

The following section describes participants' responses to some hypothetical scenarios. In the first scenario, participants were asked to respond to the possibility of donating their embryos to particular individuals. In the second scenario, participants were asked to respond to the possibility of maintaining ongoing contact with children that resulted from their donation. In the third scenario, participants were asked to respond to the possibility of remaining anonymous following embryo donation.

Hypothetical 1: Directed donation to other couples

Participants were asked for their opinion on the possibility of directing their donation to particular individuals and how they felt about the possibility of selecting the recipients. Although some responses indicated that this would be a welcome option others were troubled by how to guarantee a 'good outcome'.

Several participants said that they might be more likely to donate if they knew something of the recipients and their family life. They suggested that the following information about recipients might prove helpful to potential embryo donors: knowledge of family background, occupation, religion,

sexual orientation, health status and previous criminal record. In general, comments reflect the desire that children born from embryo donations are raised 'in a stable and loving home' by people who have the means to support them. Some participants suggested that they could more easily donate to a sister or good friend. Others however, felt that a closer relationship with the recipients might make it difficult or confusing both for the child and the adults involved. A few people felt uncomfortable about the possibility of choosing the recipients of their embryos and described this as unfairly discriminatory.

Hypothetical 2: Ongoing contact

Participants were asked to respond to the possibility of maintaining ongoing contact with children that resulted from their donation. More specifically, they were asked for their views on embryo donation programmes that allow donors and recipients to negotiate the level of ongoing contact between themselves and the resulting children [e.g. the Snowflakes Embryo Adoption Program, <http://www.nightlight.org/snowflake-adoption.htm>].

Many participants said that such programmes would result in conflict and confusion for the recipients, donors and children. In particular, they described the consequences of continuing an emotional tie with their surplus embryo — donating in an open embryo adoption programme would only extend involvement and emotional ties with their embryos. One participant discussed the importance of obtaining some closure with regard to surplus embryos.

Conversely, some participants responded that the possibility of making contact with these children would make it easier for them to go ahead with donation to others. One participant suggested keeping contact via an occasional letter. Another participant described having 'some kind of role' though not as a 'parent'.

If we can play a role in their lives in some way but not as parents. I always feel for the adoptive parents because I'd hate them to think that we were kind of moving in on their territory. ... [we] might be interested in that [ongoing contact]. If we could somehow be in some kind of role, have something to do with them.

Another participant suggested taking on the role of an 'auntie'. She spoke about the importance of keeping some connection with the child developing from her embryo and wanting to have some role in that child's future life.

At least [in the hypothetical] I could still be considered an auntie ... or I'm part of that child's family, the child is still a part of me, and I'm still a part of them, and I can sort of overlook and be a part of their life and feel as if I am still contributing, even if it's in the background and you don't have any say over their day-to-day living. ... That for me would have probably changed the way that I would have thought about it.

Some participants however said that it would be unfair for a child to have several adults in potentially competing roles and others spoke of the difficulty that ongoing contact would create for recipients because of the possibility of undermining their parenting role.

Hypothetical 3: Anonymity

Participants were asked for their views on the hypothetical possibility of remaining anonymous following embryo donation (as opposed to the current legal requirement in Victoria that donors must provide identifying information which is made available to children born from donor procedures, on turning 18 years of age, at their request).

Again, responses to this hypothetical were varied. Some participants said that donor anonymity would make them decide *not* to donate their embryos. Other participants said that a guarantee of ongoing anonymity would make it easier for them to donate surplus embryos to another couple. However, they were skeptical that guarantees of anonymity were ever possible.

Most participants were opposed to donor anonymity on the grounds that it was unfair to children or because children have a right to information about their genetic identity. Conversely, some participants said that children have no right to information about their genetic identity. They said that providing information about genetic parents confuses notions of what gives people their identity. These participants talked about the fact that parenthood is not limited to genetic contributions, but more importantly determined by nurturing roles. One participant referred to the development of a child's identity.

I feel the people that raised the baby, who nurtured them and cared for them, should be thought of as the parents. That they came from other genetic material is part of who they are but, no, I don't think they should have access to information about who those people might be ... I think that could be confusing for a person's identity and I think personal identity comes from where they grow up and how they grow up or how they're brought up.

One participant commented that she would have some difficulties in donating to couples in Australia, even if she were guaranteed anonymity, because of the possibility that she might recognize 'her child'. Another participant expressed concern that, in the absence of information about their genetic heritage, children born from embryo donation might later encounter and marry their biological siblings.

Making Decisions about Surplus Embryos Easier

It is widely acknowledged that many couples find it very difficult to make decisions about their surplus embryos. When participants were asked what, if anything, would assist them in making or coming to a decision, three main themes were identified.

More information about the specifics of each of the options

As previously illustrated in relation to the option of donating to research, many participants spoke of their desire for information about what happens to embryos that are donated to research and the specific nature of the research projects. Similarly, regarding disposal, a few participants suggested more information about how embryos are handled and what happens to embryos that are discarded would clarify matters and facilitate decision making. For donation to others,

participants suggested that information about how many couples are on waiting lists and how long they must wait would influence their decisions.

Participants also asked what information is available to children born from donor procedures, who controls the release of this information to children, and what legal issues are connected with donating embryos. Some participants suggested that statistical information about what choices others had made would be useful. The timing of information also seemed to be important. One participant said she felt 'bombarded' with information at the start of her treatment and others concurred that their information needs changed over time, especially after the birth of children (when their feelings about embryos potentially changed).

More options

In relation to research, most respondents stated that they should be able to, and would like to, make choices about the research projects in which their embryos would be used. Participants indicated a need to feel that the research was worthwhile, and the desire to be able to specify the types of research they would support with their donation.

Regarding the disposal of surplus embryos, some participants responded positively to the possibility of more personalized forms of disposal such as taking embryos home or performing a ceremony to acknowledge their demise. In relation to donating to others, some participants said that directed donation (choosing or knowing about the recipient couple) would be a welcome option. As reported earlier, a few participants were positive about the option of on-going contact with the child, while others said that the option of complete anonymity of donors would be preferable to them.

Opportunity to talk to others

Several participants remarked that reflecting on the issues and hearing other points of view, as they had done for the purpose of the group interviews conducted in this study, had been beneficial in thinking over their options. They suggested that it would be helpful if opportunities for this sort of discussion could be offered routinely. In addition, they said that the opportunity to hear from children born from donations, from couples on the donor embryo waiting list, and people who have donated to other couples, might be helpful.

Discussion

Although currently the available options for the dispositions of surplus embryos for couples residing in Victoria, Australia, are limited, the reasons for choosing between these options were found to be many and varied. As with previous studies (Robertson, 1995; Hammerberg and Tinney, 2006; Lyerly *et al.*, 2006), our research shows that views about the moral status of embryos influence decisions about surplus embryos. Consistent with studies by Hammerberg and Tinney (2006), Söderström-Antilla *et al.* (2001) and McMahon *et al.* (2000), some participants in the current study described embryos as potential life. They felt that it would be wrong or callous to carry out research on embryos because they are a potential

life that should be preserved. Notions of preserving the life of the embryo were also evident in the decision to donate to others. Conversely, some participants in our study described embryos as 'a bunch of cells' not dissimilar to any other disassociated human matter.

As found in earlier studies (McMahon *et al.*, 2003; Hammerberg and Tinney, 2006), participants who were considering donating to research described discarding embryos as wasteful or selfish. Participants who did not intend to donate to research indicated that they would consider this option under some conditions. They indicated that they would be more likely to donate surplus embryos to research if they had information about, and could direct their embryos to, particular projects.

Our study confirms earlier reports (McMahon *et al.*, 2000; Söderström-Antilla *et al.*, 2001; Hammerberg and Tinney, 2006), and shows that underlying the decision to donate to others is both a desire not to waste embryos that could be used to help others and concerns about preserving the life of an embryo. The decision not to donate was for many couples tied up with their relationship to the embryos. Previous research suggests that some couples equate surplus embryo with 'virtual children' and embryo donation with 'child relinquishment' (de Lacey, 2005). Similarly, our study identifies the following four main reasons given by participants for ruling out donation of embryos to others: (i) the belief that a child that results from donation would still be 'my child', and according to many participants, would also 'belong to my whole family' (siblings and grandparents), (ii) the strong emotional tie that some individuals believe would exist between them and any children born as a result of their donation, (iii) the notion that individuals in a position to donate embryos believe they have responsibilities to children resulting from their donation and (iv) concern about the future welfare of children born from such donations, including how the child might be raised and by whom.

Earlier work (Newton *et al.*, 2003) suggests that people in a position to donate embryos to others have strong preferences regarding the hypothetical possibility of both conditional donation (donation limited to particular individuals according to the donors preferences) and unconditional donation (donation without conditions attached). Similarly, several participants in our study expressed interest in obtaining information about possible recipients and some responded positively to the possibility of directing their donation to recipients of their choice according to some preferred characteristics. Further, a few participants indicated that they would welcome the possibility of ongoing contact with children born from their donations. The desired contact ranged from an occasional letter to a role like that of an 'aunt' in the future child's life.

With regard to the requirement of providing identifying information, most participants in our study agreed with the current Victorian legislation and believed that children have a right to know their genetic origin. Most participants felt that complete donor anonymity would be unfair to children and would make it less likely that they opt for donation to others.

Our study also found that some people might feel different about donating surplus embryos to research and might take up this option if they were able to direct their embryos to

particular types of research. Many participants suggested that a lack of information or understanding about what research entailed influenced their decisions about this option. This finding agrees with an earlier report that couples might feel differently about donating to research if they had some control over or could specify the type of research project for which their embryos would be used (McMahon *et al.*, 2003). It is interesting to note that in a Swedish study (where donation of embryo to others is not permissible) (Bjuresten and Hovatta, 2003) 92% of couples preferred donating their supernumerary embryos to stem cell research rather than letting them be discarded. It is possible that this high level of interest in donating to research is due in part to the detailed and comprehensive oral and written information about the specific project that is given to each patient.

One point of convergence in this study was that most participants described the process of making a decision about surplus embryos as difficult and emotionally fraught. Our study concurs with earlier work where patients describe making decisions about their surplus embryos as among the hardest decisions they have ever had to make (de Lacey, 2005) and reveal postponing these decisions for as long as possible (McMahon *et al.*, 2000). As previously reported, participants in our study revealed that factors that might ameliorate the decision-making process include more information about the currently available options and better-targeted timing of this information (Nachtigall, 2005; Lyster *et al.*, 2006). Some interviewees suggested that additional options including the possibility of directing their donations to particular recipients or specified research projects would assist them in deciding on the fate of their surplus embryos. Our study concurs with findings from Lyster *et al.* (2006) and indicates that some couples might respond positively to the option of taking control of the disposal of their embryos, e.g. allowing ceremonial committals.

A notable and unexpected finding of this study was that most participants who were interviewed in the group interview stated that they had enjoyed the interview process. They suggested that the opportunity to hear other points of view, to talk to others in a similar situation and to hear from donors, recipients and persons born from donor procedures may be helpful in considering their options.

Conclusion

Participants' attitudes to the available options regarding surplus embryos and their responses to hypothetical options in this study provide valuable insights into the influences behind patients' decision-making regarding their surplus embryos. These insights illustrate factors that could be considered and implemented by IVF clinics, both in Australia and internationally to help with the dilemmas faced by many people deciding the fate of their surplus embryos. Information about factors that influence decision-making is also useful to clinics addressing the build up of embryo banks and the increasing numbers of abandoned embryos and to those interested in encouraging donation of embryos to research or other couples.

Previous studies have reported that many individuals find the need to make decisions about the fate of their surplus embryos

very difficult and emotionally fraught. Our study confirms this finding and elucidates some of the reasons that couples find these decisions difficult. We present some options for ameliorating patient's decision-making process.

Although our the research was carried out in Victoria, Australia, clinics in many countries face similar issues. The fate of surplus embryos poses a dilemma not only for couples but for fertility clinics around the world, where increasing numbers of human embryos accumulate in long-term storage (Kovacs *et al.*, 2003; Hoffaman *et al.*, 2003; Eydoux *et al.*, 2004). Although thousands of surplus embryos are disposed of each year (Kovacs *et al.*, 2003; Hoffaman *et al.*, 2003; Bangsbøll *et al.*, 2004), it is reported that the number of embryos currently available for research, such as stem cell research, does not currently meet demand (Hoffman *et al.*, 2003; Bangsbøll *et al.*, 2004) and that hundreds of infertile couples are on waiting lists for donor embryos (Kovacs *et al.*, 2003).

The need to explore factors that might encourage donation of surplus embryos to research (McMahon *et al.*, 2003; Burton and Sanders, 2004) and to other couples (Kovacs *et al.*, 2003, Fuscaldò and Savulescu, 2005) has previously been raised. Interestingly, the US Department of Health and Human Services released \$1 million in grants to launch embryo-adoption public awareness campaigns (US Federal Register, 2002). The findings of our study may facilitate both of these options.

We conclude that there are a number of simple steps that could be implemented by IVF clinics around the world to help people in making final decisions about their excess embryos. These include providing more and targeted information, providing directed research options, organizing group discussions to support and assist in decision-making and inviting donors, recipients and persons born from donor procedures to share their experiences of embryo donation. This study also shows that there is positive interest in directed donation to other couples. Although this is obviously a complex issue, it is worthy of further consideration. It is in the best interests of couples with surplus embryos, other infertile couples, researchers and IVF clinics to address the difficulties these couples face and to assist them to come to a final decision.

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