Infertility patients’ beliefs about their embryos and their disposition preferences

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BACKGROUND: Little research has been done on how beliefs of infertility patients about their embryos are related to their disposition decisions. The objective of this study was to describe how patients speak about their embryos, in moral (e.g. status) and non-moral terms, and to investigate how patients’ narratives are related to their disposition preferences.

METHODS: In-depth interviews based on the method of interpretative phenomenological analysis were conducted with patients undergoing IVF/ICSI treatment between May and July 2006.

RESULTS: Seven couples and 11 female patients were interviewed. Six major themes emerged from the narratives of the participants when they spoke about their embryos: (i) a medical-technical perspective; (ii) feelings; (iii) genetic link to oneself and/or one’s partner; (iv) symbolic meaning of the relationship between the infertile partners; (v) moral status and (vi) instrumental value. All but two participants spontaneously considered the embryo disposition options as a two-stage decision sequence. In the first step, they considered donation to another couple for reproductive purposes. At this stage, the presence of the themes ‘genetic link’ and ‘symbol of the relationship’ was linked with a clear reluctance to donate. In the second step of the decision-making process, the option of donation for research and discarding were considered. At this stage, participants’ confidence in medical science and the instrumental value they attached to the embryo were related to their decisions.

CONCLUSIONS: Patients’ conceptualization of their embryos plays an important role in embryo disposition decisions. Our research showed that patients deal with these decisions in a two-stage decision sequence.

Key words: embryo disposition / decision-making / qualitative research

Introduction

In the aftermath of an IVF treatment, couples who still have frozen embryos in storage will have to address the question of what to do with those embryos, and make an embryo disposition decision (EDD). Since July 2007, Belgium has a law on medically assisted reproduction and the disposition of supernumerary embryos and gametes by which patients are obliged to decide the disposition of possible left-over embryos prior to their first treatment (Pennings, 2007). Their EDDs are thus based on a hypothetical scenario.

Several studies have suggested that a significant number of patients find the EDD a difficult decision (McMahon et al., 2000; Klock et al., 2001; Skoog et al., 2001; de Lacey, 2005, 2007; Hammarberg and Tinney, 2006; Fuscald et al., 2006). From the few qualitative studies that have addressed the complex nature of infertility patients’ conceptualization of their embryos, it is known that patients have a variety of concepts and that their understanding of embryos has implications for their views about the disposition options (McMahon et al., 2000; de Lacey, 2005, 2007; Nachtigall et al., 2005; Parry, 2006; Fuscald et al., 2007). However, some of these studies only focused on one or two of the disposition options (Parry, 2006; de Lacey, 2007), whereas other studies focused on a specific type of patient, for instance, only patients who used donor material (Nachtigall et al., 2005).

Furthermore, it has been described how patients psychologically respond to the decision-making process, resulting in a dynamic process from reassurance by having surplus embryos to avoidance of the disposition decision and subsequent confrontation with it.
Infertility patients’ embryo disposition preferences

(Nachtigall et al., 2005). However, apart from this psychological journey that patients go through, it still remains largely unclear how patients deal with the decision as such.

Some of the studies that have been conducted have showed alleged inconsistencies in patients’ thoughts about their embryos and their decisions, especially regarding the link between the moral status of the embryo and patients’ disposition preferences (Laruelle and Englert, 1995; McMahon et al., 2000). Laruelle and Englert (1995) were the first to address the seemingly irrational finding that patients who thought of their embryos as children also decided to have these ‘children’ discarded. In addition, some studies have identified aspects other than the moral status to be relevant for the meaning that infertility patients attach to their embryos, such as feelings about embryos (McMahon et al., 2003) and the genetic link between patients and their embryos (Laruelle and Englert, 1995; McMahon et al., 2000; de Lacey, 2005, 2007).

An improved comprehension of the patients’ decision-making about their embryos will thus require exploring the full range of possible meanings that patients attach to their embryos (themetic analysis). An exclusive focus on patients’ moral views about their embryos would be too strict (Lyerly et al., 2006). Once these meanings are clarified, the relationship with the decision-making process and its outcome (process analysis) can be examined.

The objective of this study was 2-fold: (i) to describe how patients speak about their embryos in moral and non-moral terms (themetic analysis) and (ii) to investigate how patients’ narratives regarding embryos are related to how they weigh the disposition options in the course of deliberation (process analysis).

Therefore, we conducted a qualitative interview study, a method that has proven to be effective in studying conceptualization of embryos by fertility patients (McMahon et al., 2000; de Lacey, 2005; Lyerly et al., 2006; Fuscaldo et al., 2007). Even so, two additional aspects were essential to this study’s method.

First and foremost, we wanted to examine patients’ general concept of the embryo and not only patients’ narratives relating to specific subjects such as disposition preferences, moral status or feelings regarding embryos. To do so, we analysed primarily their thoughts and experiences about their embryos when freely talking about their treatment or answering more general and open questions.

Secondly, we asked participants to rank cards with the disposition options, based on the hypothetical scenario that they had supernumerary embryos, and to describe their thoughts while doing so. This method allowed us to grasp participants’ thoughts about each of the separate items, as well as their considerations when weighing one option against another, and to delineate the process of decision-making. Previous studies about patients’ disposition decision-making did not focus on all three options (simultaneously) or studied patients’ decisions retrospectively. Therefore, they could not give insight into the actual process of deliberation in which patients weigh disposition options against one another.

**Method**

**Participants**

Infertility patients undergoing IVF/ICSI treatment were selected through purposeful sampling to guarantee maximum variation on the following characteristics: undergoing a fresh or frozen cycle, presence of children, children from IVF/ICSI and/or cryopreserved embryos and treatment history (number of planned embryo transfers, including cancelled cycles).

A nurse or midwife selected the patients based on a sampling table containing inclusion criteria (the characteristics presented as profile categories and subcategories with combinations of criteria) and exclusion criteria (non-Belgian patients and patients for whom donor gametes were used). The researcher adapted the sampling table regularly and equally increased the number of patients wanted per (sub)category based on the ongoing interviews. When enough participants with a certain characteristic were included, only patients with other characteristics were approached. This process was stopped when data saturation was reached for embryo themes and preferred disposition options. Between May and July 2006, a total of 23 participants were contacted, of which 5 refused to participate.

Selected patients were contacted by their physicians during their next consultation and received written and oral information about the study. They knew that their participation or refusal was not linked in any way to their treatment, and that participation or refusal would have no impact on their relationship with the fertility team. After receiving patients’ consent, the researcher contacted the patients following their consultation or treatment to schedule the interview. Written consent was obtained from all participants before the interview. The Medical Ethics Committee of the University Hospital Ghent approved the study.

**Interviews**

The study is based on the method of interpretative phenomenological analysis that aims to illuminate participants’ subjective life-world, experiences and emotions, through an interactive process with the interviewer’s interpretations (Smith and Osborn, 2008). This method has been used increasingly over the last decade in studies about healthcare phenomena, for which the individuals ‘lived experiences’ were the main source of data (Turner and Coyle, 2000; Fade, 2004; Brocki and Wearden, 2006; Osborn and Smith, 2006; Todorova and Kotzeva, 2006).

All in-depth interviews were conducted at the Infertility Centre by a researcher who was not involved in patient care (V.P.). Interview duration ranged from 25 to 60 min, with an average of 38 min. The interviews were recorded and transcribed verbatim by an independent transcriber and checked for accuracy. They were made anonymous: names for persons and places were replaced by pseudonyms.

The questionnaire was semi-structured and questions or topics were based on a study of the literature. At the beginning of the interview, (open) questions were asked to invite the participants to speak about their embryos in their own words. Four different topics were addressed during the interview: the freezing of embryos (preferences, perceived effects, knowledge of procedures, etc.); the meaning of embryos outside the female body (descriptions and metaphors used, reactions to embryos that do not survive thawing or embryos not suitable for transfer); the disposition of supernumerary embryos: decision-making process (importance of the decision, need of information, etc) and existing preferences (choices and reasons) and patient characteristics: age, education, life stance (religion; system of principles and beliefs), treatment history (fertility problem, number of treatments, pregnancies, complications and current number of frozen embryos). To encourage participants to discuss their disposition preferences, they were asked to place four cards with the following options presented at the clinic in order of preference: to continue storage for future transfers to themselves, to donate for science, to donate to other infertile couples and to destroy the embryos. Participants were asked to explain their order of preferences and whether it would stay the same or change in a range of different hypothetical situations: if they would be able to choose the receiving couple (directed donation) and could choose whether a future child that results from
embryo donation would be allowed to contact them (anonymous versus identifiable donation).

**Analysis**

The qualitative data analysis software Atlas.ti was used to support the analyses through several layers of emerging concept (Muhr, 1997). The transcripts were divided into a total of 1417 text quotations. Recurrent themes were coded inductively through data analysis using a list of 115 codes and defined during an iterative process. The principal analysis was carried out by V.P. Investigator triangulation for reasons of validation was achieved through a second (E.D.) and a third researcher (G.P.) analysing, respectively, all and a selection of the transcripts. These analyses confirmed that similar themes were emerging. Themes were labelled and defined by consensus between the three researchers in a process of repeatedly reading the data and checking for alternatives and counterexamples. In the same way, links between themes were discussed and labelled. Once final labels and links were agreed, all text quotations were re-coded by consensus between two researchers. In the Result section, quotes are used to illustrate the themes and other findings.

**Results**

**The participants**

Seven couples and 11 female patients (n = 25) who attended the clinic without their partner were interviewed (Table I). All participants were partners in a heterosexual relationship. Female patients were aged between 24 and 39 years. Ten patients underwent a fresh IVF treatment cycle whereas eight patients underwent a cycle using cryopreserved embryos. Ten participants already had one or more children.

Four women had experienced a miscarriage (two pre-IVF and two post-IVF). Two of them also had an ectopic pregnancy (one pre-IVF and one post-IVF).

At certain times during the course of the interview, two of the women became emotional and tearful. One of them, who had a total of eight treatment cycles without the hoped-for result, cried copiously although she did not want to discontinue the interview.

**Themes**

Six major themes emerged from the narratives of the participants when they spoke about their embryos.

- **Medical-technical theme.** One theme showed a medical-technical perspective on the embryo. The way participants spoke about their embryos appeared to be mainly based on the scientific discourses of the clinical personnel. A high number of the quotes in the medical-technical theme expressed associations of embryos with chances of a successful outcome or descriptions of the quality of the embryos. Some participants described the embryo as an instrumental object or thought of it as an ingredient of a medical-technical procedure.

  - John: At that point we still look at it in a technical way. We don’t see it yet to you?
  - Interviewer: … When you think about that embryo, what does it mean to you?
  - John: At that point we still look at it in a technical way. We don’t see it yet as the basis for the development of the child. … It still is something technical.

All but one participant used this medical-technical perspective when talking about their embryos. For nine participants, this theme was documented in at least half their quotes about their embryos, and for one of those participants it was the only theme. In addition, some participants expressed a kind of fascination for their treatment and/or the procedures applied to the embryo.

- Karen: Well, that is something special. I find it special … An embryo, when it starts to grow again after being frozen, I do find that a miracle that it starts to divide again and so … That, I think is special, yes. I wouldn’t go all emotional about it, but I do think it is something special.

- **Feeling.** When speaking about the embryo, 10 participants expressed both positive and negative feelings. The occurrence of these feelings ranged from a small portion (2/14 in one participant) up to nearly half of the quotes of these participants. The feelings expressed were mainly hope when anticipating treatment outcome and disappointment in reaction to previous treatment failure. For 7 of these 10 participants, quotes were found to describe their coping strategies. Patients expressed their attempts to create a distance towards the embryo in order to protect themselves from getting too emotionally attached and hence to decrease the chance of getting hurt in the process.

  - In both positive and negative feelings, a link is found with the medical-technical theme. All participants who wanted to protect themselves from getting too emotionally attached, spoke about their

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<td>Children of both partners, from previous IVF/ICSI treatments using cryopreserved embryos</td>
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*Including planned transfers that were cancelled, transfers from both IVF and ICSI treatments, transfers of both fresh and cryopreserved embryos and the planned transfer in the current treatment cycle.
embryos in medical-technical terms. For some, this was a consciously applied technique.

John: It is also a bit to protect myself from . . . This is what you do, you know. When you see it as something technical.
Gina: We don’t believe in it: that it would be the first time now and that it would be successful right away.
John: Yes, that is to protect yourself from being hurt, even though it . . .

When an emotional attachment was expressed, frequently in describing the hope they projected into the embryo, participants also referred to the chances of treatment success or the quality of the embryo.

Sandara: You put all your hope in it; you see. You think: ‘right, we do have another chance, those in the freezer are still there, maybe one of those will . . .’. And especially last time, when they survived that [thawing], than we really thought that it would work.

Only one participant spoke about feelings for the embryo itself. She talked about feelings of attachment towards and sympathy for the embryo. She also named the embryos after her husband and saw them as little copies of him.

Peggy: My husband’s name is Bart. I always say ‘It’s a little Bart’ . . .
Peggy: I am sorry for that . . . I was sorry that that third [embryo] . . .
That they had tried to put it in the freezer and that it didn’t get there, and that in the end, it didn’t get anywhere.

Genetic link. Thirteen participants attached meaning and value to the embryo based on the linkage between the embryo and the gamete providers (e.g. the infertile partners; no patients using donor gametes were included in our study). However, they seldom literally talked about genes but more often referred to the genetic link in the following terms: being a part of or belonging to the genetic parent.

Sandara: Even an egg, that’s also a part of you, right.
Frances: [About a child from a donated embryo] Well, that still is your own child, right.
Emily: Especially you see, it is from your genes.

No links were found between this theme and the other themes except for the theme of symbolic meaning. For four participants, the genetic link as such seemed to be relevant.

Symbolic meaning. In the narratives of nine other participants, reports were found that went beyond the pure genetic link to describe the meaning of the embryo. These participants did not refer to the fact that the embryo was related to each gamete provider as such but more to the specific combination of gametes. The literal interpretation of the way participants explained this, ‘something of the two of us’, could be based both on the idea of ownership by the partners and on the idea of the origin of the embryo as a result of the combination of (parts from) both partners. Because of this combination, the embryo was portrayed as if it were a symbol of the relationship or union between the partners and viewed as something very private. As Linda said:

Linda: Because it is something personal! I mean, it is ours really.

Most participants spoke about this symbolic meaning with great emotion. When asked why she would not donate embryos to another couple, Beth described this as follows:

Beth: And one of the two of us! If it would be from, for example, just an egg of mine or just a sperm cell of his . . . That would be something else, but really . . . of the two of us? No.

Seeing the embryo as something of both partners was also mentioned as a reason not to accept donor embryos themselves or even donor gametes.

Deborah: Yes, we have already said that: either it is from the both of us, or . . . like it is with adoption or so, but not: an egg from someone else. You know! That’s like a piece of you and your partner, to say it bluntly, has nothing to do with it. And I would find that a bit difficult, so, I don’t know if I really would . . . me? An embryo from someone else?

In three cases, the fact that the embryo was seen as more significant than gametes was described referring to the moment of merging of gametes and to the fact that the product of this merging was a combination of parts of people in a partner relationship. Tessa, when talking about donating embryos or gametes, and John, discussing the creation of embryos for science, described it as follows:

John: Science has to make progress somehow, right? But that is not really something of one couple, that is sperm of the man, an egg of . . .
Tessa: If it were just your egg that you would donate, I would not have a problem with it. But the fact that it is an embryo, that I consider something totally different altogether. That’s already something of yourself and your partner. That’s combined already, you see. But an egg, I wouldn’t mind that.

Moral status. The moral theme was found in the narratives of 11 participants, varying from 1 in 10 up to half of the participants’ quotations. This theme consists of two subthemes: the intrinsic moral status of the embryo and the instrumental value the embryo can have for potential ‘users’. The intrinsic moral status can be seen as a position on a continuum between two extremes: full moral status comparable with a person and no moral status comparable with a thing. In descriptions of participants who discussed the moral status of the embryo, all main positions were found: child, potential child, living entity and thing.

Peggy: I always think of it as that little human being, I don’t know [laughs].
Marco: You cannot think of it as a bunch of cells, right? That’s not just a bunch of cells, right? That’s life you know . . .
Sandara: It is an embryo all right, but it’s no baby yet, right. At the end of the day, it is still just a little cell.

In many cases, participants’ narratives displayed several adjoining positions simultaneously. The following citation comes from a couple in whose narratives the whole range of possible positions was found, although in the course of the interview they moved more towards the end of the continuum where they see the embryos as children.

Sandara: Ok, they are not really your babies, it’s just little cells and you do realize that. But still, somewhere you think of it already as . . . a baby, as your child. You know, it is something. It is alive you know . . .
Patrick: As a possible child.
Sandara: Ah yes . . . Because I still remember clearly, the second time we did IVF . . . We have done three attempts, and the second time we had ten in the freezer. And I had something like . . . Whoa, ten little children! . . . Try to imagine that they all would . . . you know . . .
Patrick: Mmm yes.
Sandara: . . . stay alive, then that would be ten little children. Whoa.
Interviewer: Yes yes, so in the beginning you saw them as little children?
Sandara: Yes yes, now still!
Patrick: Now still.

One participant referred to the moment of conception, when sperm and oocyte merge to form a zygote, as an important marker of the moral value of the embryo. A major difference from the citations above, which (also) referred to the relational theme, is that this woman, when asked why she did not object to the fact that it is
allowed to donate oocytes for science when she did object to the use of embryos for scientific research, did not talk about the specific combination of genes or the gamete providers.

Emily: Yes, just because it has not been fertilized together that I don’t make a big deal out of it. But if it is fertilized, I find that something . . . . You know . . . .
Interviewer: Than it is something else?
Emily: Yes, I really think that is . . . already . . . No, an embryo is a child, I think. When it develops, it is a child. So I find that very personal. No problem with eggs or sperm, both apart. But together, no.

When participants described their embryos as things, descriptions that fitted the medical-technical theme were found more often. Furthermore, they also mentioned more frequently the need of emotional distance and the fear of getting too emotionally attached to their embryos, while participants who described their embryos mostly as children more often expressed positive feelings towards them.

Instrumental value. In addition to the moral status, embryos were also described as objects with a high instrumental value. Two aspects were brought up by the participants when explaining this instrumental value. The first relates to the creation of the embryo, and more specifically to the investment or energy put into the creation of the embryo both by the patients themselves and by the members of the medical team. The second aspect was participants’ awareness of the existence of potential beneficiaries of donated embryos (both infertile couples and scientific research) and their needs. One participant even compared embryos with organs, as entities with an important level of usability to the receivers.

Attaching the moral status of personhood to an embryo did not preclude attaching instrumental value to it. When the choice was between donating the embryos for science or destroying them, Peggy, who said earlier in the interview that embryos deserved the status of a person, recognized the instrumental value of the embryo. She hoped that people, who did not want to give their embryos a chance to live, would at least let them be used for science.

Interviewer: And why exactly, you say?
Peggy: When people do not want to give it to other couples, or use it themselves . . . . I would hope . . . that they would . . . . No, but in that case I really think that they should let science have some tests . . . . So they can help people.

In case of donation to others, there can be a partial overlap of two reasons to donate: the embryo is seen as a person who deserves to live (donation for the sake of the embryo), and it is of high value to others in creating a family (donation for the sake of the recipients).

Disposition preferences: a two-stage decision sequence

Three couples had been confronted with an invitation to renew their initial EDD or to make one for the first time. For all three of them, this confrontation resulted in a decision to resume treatment, using their stored embryos.

When participants were asked to place the cards with the disposition options in order of preference, 13 participants began the task by positioning the card with the option ‘donation to another couple’. Three participants said that the cards coincidently lay in order of preference when displayed. Only two participants began by positioning the card ‘destroying’. In 12 of the 13 interviews where participants first placed the card ‘donation to another couple’, this option also was the first thing they talked about in discussing their task, even when this option was placed at the same level as another option in the final order of preference.

Participants talked with great emotion about the topic of donation to others and in most cases also took a clear stand when they considered this option. Twelve participants placed it resolutely at either the top or the bottom of the line up.

Furthermore, in clarifying their choices (mostly unsolicited and while still at the task), participants most often began by discussing the position of the card ‘donation to other couples’, whether that card was placed at the top or the bottom of their ranking. All participants in whose narratives the themes ‘genetic link’ and ‘symbolic meaning’ emerged placed the ‘donation to other couples’ card at the bottom and also referred to that theme to explain their choice.

Emma: The fact that you know that there is a child of yours out there . . .
You know, and I mean, from the two of you, I think that’s even worse . . .
Giving an embryo, compared to just an egg . . .
Interviewer: Because it is from the two of you?
Emma: Then that is really of the two of you. Knowing that it is somewhere out there . . . . No, I would not . . . . But I myself would not want it either, from someone else. You see, that also was a decision that we’ve made.

As shown in the quote above, some participants who did not want to donate to others also spontaneously talked about their reluctance to receive embryos from others.

Besides the importance of genetic lineage and the symbolic representation of their partnerships, participants referred to other elements when they did not want to donate left-over embryos to others. Some participants talked about feelings of responsibility for the potential offspring and the wish to protect the welfare and interests of these children. The fact that they could not control this factor was one of the reasons not to donate. One man, when presupposing that the welfare of the offspring might be jeopardized, described feelings of anticipated regret about donating his embryo. Other reasons for not donating were participants’ fear that they would not be able to stop wondering about the possible offspring and fear of being confronted with the offspring in the future.

Patrick: That it will always be on your mind, for instance after 30 odd years, suppose that you did that, all of a sudden someone rings your doorbell ‘Ah daddy, or mummy’ . . .
Sandra: Now suppose that you did that and when that child is 18 years old, it is there and . . . . it has had a very bad childhood . . .
Patrick: Or bad experiences with those people . . .
Sandra: Then that would be quite painful, wouldn’t it.

For participants who were positive about the donation option, one of the main motives was helping others. But also participants who did not want to donate had taken this aspect into consideration as one of the points in favour.

Hannah: I can imagine if you really can’t get children, that that just becomes an obsession . . . . An urge to: it has to be, you know. And you hear about couples who break up, that relationships break up because they can’t have kids. That they go and try their luck with someone else. So give those people a chance, right.
Tessa: On the other hand: the feeling is double. You would want to help someone, but you have to make sure that you don’t regret that for the rest of your life.
Participants were asked whether their decision to donate or not donate to other couples would change if they could choose to limit the donation to (or exclude) specific types of patients or couples. Only two people who did not want to donate would consider donation if they could select couples with specific characteristics. Caroline would choose couples who lived far away. Two participants who were already willing to donate, would prefer to have their wishes taken into account in the selection of the receiving couple: Marco would exclude unemployed people and Hannah would direct her embryos exclusively to healthy couples. Three other participants who already considered donating to other couples did not want to specify the conditions or select couples based on anonymous descriptors. Two of them very clearly stated that they considered all possible recipients to have an equal right to their embryos.

With respect to anonymity and identifiability, participants were asked whether they would change their minds about their willingness or reluctance to donate to others if donation was either anonymous or non-anonymous. None of the participants, who did not want to donate, would change their mind if they could choose either anonymous or non-anonymous donation. Most of them clearly stated that they would not want to be identifiable. Only Hannah, who considered donating, indicated that she would like to meet the child in the future, although she had doubts about the effect this would have on the child. She also preferred the idea of identifiability in both directions in case there would be a medical problem and either one would need the other.

Participants, who attributed the moral status of personhood to the embryo, were positive about the donation option only when the themes ‘genetic link’ and ‘symbolic meaning’ were absent from their narratives. From the three participants who described their embryos mostly as children, only one was prepared to donate her embryos. In her narratives, the themes ‘genetic link’ and ‘symbolic meaning’ were not found. The other two participants were not prepared to donate their embryos. For these participants, the fact that they saw their embryos as children (‘it’s already a child of us’) because of the specific combination of gametes was one of the reasons to be reluctant about donation, despite the fact that this meant that their ‘children’ would be destroyed.

In addition to the high moral status of the embryo as a reason to donate embryos (to give them ‘a chance to live’), four participants considered donation to other couples mainly because of the instrumental value of the embryo. By donating they would ‘make other people happy’.

When participants had reached a decision about whether or not to donate to other couples and had their card laid out in the ranking, they spontaneously went to stage two of the decision sequence, in which they considered whether or not to donate for science. This unsolicited sequence in considering the various options was found for all participants.

Only four participants planned the option to donate for science lower than the option to destroy the embryos. All four pointed at a lack of confidence in medical science as the most important reason not to donate. Among these participants were the only two who did not start the task of placing the option cards in the order of preference by positioning the card ‘donation to couples’ (this card was placed at the end of the queue for both of them). These two participants started by positioning the card ‘destroying’.

Two participants who preferred destruction over donation for science were afraid that the embryos would be allowed to grow in the laboratory or would be transferred into a woman’s uterus as part of a scientific project.

Variations on these thoughts were mentioned by another two participants, who would consider donation for science. The fact that they expressed these deep worries did, however, not indicate an overall negative view of science. Some participants who did not want to donate for science mentioned their appreciation of the progress in scientific knowledge thanks to studies using embryos. They said they were well aware that this was of great value, also to their own
treatment. Nevertheless, they could not see themselves giving their own embryos in order to help increase the scientific knowledge.

Emily: Just for me personally, I wouldn’t be able to. I do know, science has to go forward and without those studies it would probably never have existed. But me personally, I would have a big problem with it. But I think it is ok that it happens, because otherwise they cannot get any further, can they? Otherwise it would probably never exist, IVF, if that wouldn’t happen. I do not have a problem with that. But not with my embryos! This might be selfish, but anyway...

Although the lack of confidence in medical science was negatively correlated with the donation for science, the idea that the embryo is an entity with a high instrumental value was positively linked with donation for science. Participants who considered donating for science saw the usefulness of embryos mainly in terms of learning something from them. Most of these participants also talked about the possibility to help others indirectly by helping science to increase knowledge about embryos and fertility. Moreover, some thought that destroying embryos would be a waste in the light of this usefulness and the efforts that had gone into creating the embryos.

Karen: And just to let it die or to destroy. I would think that is such a waste of... of all that effort. And then I think, perhaps it will be of some use for science and maybe they can find something that might help couples in the future. So that really was... it was important to us. Yes. Just to have it destroyed, I think that’s a waste.

Hannah: And destroying? I think that’s completely unacceptable. You know, you just don’t do that. It is the same with... You are in a coma you can’t get out. And they know they can use your liver, lungs, or whatever, for someone else. And you say, as a family member: no, let that other person die too. That’s completely unacceptable.

Two participants placed both the cards ‘donation to couples’ and ‘donation for science’ at the top of their order of preference. When they talked about their reasons to attach equal value to these options, they referred to the instrumental value of the embryo. Both participants thought that it was important that their embryos were used to attempt to help others. It did not seem to matter to them whether this was through donation to others so they could have a child or through the use of embryos for scientific research so infertility patients could benefit from the progress of science. The different outcome for the embryo itself (certain destruction versus a chance for life) was not discussed in weighing these disposition options.

Anne: Yes [Places both cards on the same level]. I think at one point euh, this can also be placed on the same line. Destroying would really be the last option.

Interviewer: And why exactly?

Anne: Well, in the end, when you have got this far, why would you not have someone else share your good fortune? Or when science can do something... Destroying is like... No, definitely not!

Olivia: I would say that this [card ‘donation to couples’] is definitely equal to... [card ‘science’]... You know, this is what I am thinking now. But I’ve really never thought about that. [laughs] Euhm, yes, I would say that it really is of equal value...

Interviewer: Donation to other couples and to science?

Olivia: Yes.

Interviewer: And these are placed higher than destroying?

Olivia: Yes, if possible. You see, destroying is really when nobody could use it anymore. I mean, when you have something that they can use, then I definitely would not have it destroyed.

For Anne and Olivia, discarding would be the final option. Some participants even expressed the idea that it was not a (morally) acceptable option. When asked whether there were destinations for embryos which she would find morally unacceptable (a question addressed to all participants), Joanna literally said that the option to destroy was one of these things, an option she called immoral.

Regarding the decision-making sequence, discarding appeared to be the final option considered. Furthermore, it often appeared to be a negative choice: it was only seriously considered when other options were ruled out.

Four of the themes in the participants’ narratives played a role in the decision-making sequence: genetic link to oneself and/or one’s partner; symbolic meaning; moral status and instrumental value (see Fig. 1). The themes ‘medical-technical perspective’ and ‘feelings’ were not found to be directly relevant to the disposition decision.

Almost all participants described themselves as Roman Catholics, when asked about their life stance or religion. However, they did not think the views of the Roman Catholic Church (that destruction of the embryo represents destruction of human life) were relevant to their decision-making. Furthermore, no participant spontaneously referred to religious considerations when discussing their beliefs about their embryos and their disposition preferences.

Olivia: Euh, now if, for instance, we would be very religious and, and they would say, you may not do this and you may not do that, I wouldn’t really give that [religious restrictions] much consideration, no. I don’t think another person should decide about my... You know, at least not on such a basis.

Discussion

Instead of focusing on one topic in the domain of patients’ EDDs, such as their intentions or their moral considerations, this study was designed to obtain a broad picture of the way patients speak about their embryos in general. Furthermore, analyses of the data collected when patients ranked EDD options in order of preference increased our understanding of the process of deliberation.

A limitation of this study is the fact that the process of decision-making was analysed in an artificial task situation and not at the time of the actual decision. However, the task of ranking disposition options provided a firm basis to collect data on the process of decision-making. This study also included patients and couples who never had embryos in storage at the time of the interview and who based their decision-making on a hypothetical scenario. Nevertheless, since July 2007 all Belgian patients are obliged to make their EDDs prior to their first treatment, thus on a hypothetical basis. The Belgian law stipulates that these advance directives need to be followed even in cases where one of the partners later objects to it and cannot reach an agreement with the other partner (Pennings, 2007). In this case, the advance directive is given more weight than the actual refusal of one partner based on an actual situation.

Participants spontaneously followed a two-stage decision sequence in ranking the disposition options. At the first stage of this sequence, the presence of the themes ‘genetic link’ or ‘symbolic meaning’ was linked with a clear reluctance to donate to other infertile patients. This genetic link between the embryo and the gamete providers

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has been described as a reason for patients not to donate to others (Laruelle and Englert, 1995; Sehnert and Chetkowski, 1998; McMahon et al., 2000; de Lacey, 2005, 2007). In addition to this genetic link, patients may have feelings of parental responsibility or may feel an obligation to protect the welfare and the interests of the potential offspring (Laruelle and Englert, 1995; de Lacey, 2005; Nachtigall et al., 2005; Fuscaldo et al., 2007). In this study, the genetic link and the feelings of responsibility were part of the participants’ explanations of their reluctance to donate. In addition, participants in whose narratives the theme ‘symbolic meaning’ was found felt that their embryo had a high symbolic value based on the fact that it resulted from the combination of gametes of two people who have a unique and highly appreciated relationship. Because of this symbolic meaning, participants explained, they could not pass their embryo on to others. This theme clearly differs from a refusal to donate based on the idea that the genetic link between parents and child is more important than the social and psychological upbringing (Laruelle and Englert, 1995). For half of the participants in this study, the embryo was perceived as a symbol of the relationship between both partners and was very highly valued even though they knew it would probably or definitely not lead to a child. This theme has not been identified elsewhere.

All main positions regarding the moral status of the embryo (child, potential child, living entity and thing) were found and in many cases participants’ narratives displayed several adjoining positions simultaneously. Other studies have found widely divergent views between participants (Nachtigall et al., 2005; Lyerly et al., 2006; de Lacey, 2007; Fuscaldo et al., 2007). However, there have been no accounts about different adjoining statuses in the narratives of one participant. This finding shows the risks of imposing concepts held by ethicists.
on data gathered among patients, for instance, by using questions that ask respondents to choose only one of a series of pre-labelled moral statuses to describe how they think about their embryos.

Another interesting finding is that the moral status of the embryo was hardly ever mentioned in our participants’ explanations of why they felt they could, should or should not donate to others. The idea that the embryo deserved the moral status of personhood was positively linked to the donation option only when the themes ‘genetic link’ or ‘symbolic meaning’ were absent from the participants’ narratives. In other words, the moral status of the embryo appeared to be less important to the decision-making process than relational considerations. Lyerly et al. (2006) already advised research to move away from narrow assertions about the moral status of the embryo because they found that other considerations regarding the personal situation of patients were more relevant. Laruelle and Englert (1995) also suggested that the patients’ opinions on the respective importance of genetic lineage (and education) were more important in their disposition decision than their opinions on the moral status. What is more, they found that couples despite viewing their embryo as a child, decided to discard it. In this study, couples who saw the embryo as a (potential) child and as a symbol of their relationship decided against donation to others in favour of the disposition options that result in the destruction of the embryo.

Participants in a study of de Lacey (2007) explained that discarding embryos while attaching high moral status to them can sometimes be viewed as a sort of ‘reproductive waste’ comparable with spontaneous pregnancy termination. One man in our study also compared this with ‘an accident of fate’ (alternatively labelled as nature). Conversely, he admitted that there was one point of difference: the discarding of the embryo was not beyond his control, which is the core characteristic of fate. The use of this metaphor may be part of a way to rationalize his decision. Also in the study of de Lacey (2007) that focused on retrospective arguments, this metaphor might show a way to cope with a choice rather than a way to deliberate between options. The decision itself possibly has been made on an emotional basis (e.g. feeling uncomfortable with passing on a very private and unique symbol) rather than rational basis (e.g. the moral status or the instrumental value of an embryo).

At the second stage of the decision sequence, two aspects were relevant to the decision whether or not to donate for science. First, a lack of confidence in medical science was linked with a clear reluctance to donate (McMahon et al., 2003; Parry, 2006; Fuscaldo et al., 2007). Secondly, the idea that the embryo is an entity with a high instrumental value was positively linked with donation for science and to donation to other couples. Two participants even saw both types of donation as equally valuable alternatives. Some authors have described this as an altruistic desire to help other patients (McMahon et al., 2000; de Lacey, 2005; Hammarberg and Tinney, 2006; Parry, 2006). However, we would not describe this as altruism because participants often did not formulate this in positive terms but in terms of embryos that would not have the chance to live up to their utility potential. Moreover, they often expressed the idea that discarding was a waste and therefore not an (morally) acceptable option. For all but two participants, discarding was a negative choice considered after rejecting the other options. This confirms findings in other studies that decisions may be less altruistic and more based on the least uncomfortable alternative (the lesser of evils) (Laruelle and Englert, 1995; de Lacey, 2007). Thoughts of not wanting to waste embryos or the effort invested in creating them have been widely described (McMahon et al., 2003; Hammarberg and Tinney, 2006; Parry, 2006; de Lacey, 2007; Fuscaldo et al., 2007). This is different from concerns about discarding a form of life or an entity with a right to life (Skoog Svanberg et al., 2001).

Furthermore, in contrast to findings of Robertson (1995), ‘willingness to help others’ was not identified as a key factor in this study. It was easily overruled by either seeing the embryo as a symbol of the relationship or importance of the genetic link (for the decision to donate to others) or by confidence in medical science (for the decision to donate for research).

Almost all participants in this study described the embryo using a medical-technical vocabulary. Parry (2006) showed that patients describe embryos in terms of chances and quality, indicating that the medical judgement regarding the chances of success is of particular relevance to them and that some of the perceptions patients have are compounded by what medical staff had said. The widespread occurrence of the medical-technical theme in this study indeed suggests that patients’ narratives are influenced by the terminology used by medical staff. Furthermore, it shows patients’ principal focus on their treatment, seeing their embryos mainly as a means to an end: a healthy baby. This way of describing embryos was related to positive feelings, such as hope for a successful outcome, but a number of patients also used this medical-technical perspective to create an emotional distance towards their embryos as a protective (anticipating) coping strategy. However, these patients were not interested in counselling or discussing this issue with the medical team, which suggests that this emotional issue would go unnoticed by professionals.

Religious considerations did not play a significant role for our patients. Regarding the influence of religious factors, two studies had found that religious factors were sometimes related to difficulties with decision-making or the level of concern about the decision as well as to the choice itself (Choudhary et al., 2004; Fuscaldo et al., 2007).

In conclusion, four of the emergent embryo themes in this study were linked with the patients’ preferences regarding (future) EDDs: the genetic link to oneself and/or one’s partner; the symbolic meaning of the relationship between partners; the moral status of the embryo and its instrumental value.

The finding of a two-stage decision sequence and the relevance of the themes ‘symbol of the relationship’ and ‘instrumental value of the embryo’ provides new insights to the way patients reach an EDD. Based on these findings, it can be concluded that patients’ conceptualization of their embryos plays an important role in the decision-making regarding supernumerary embryos. However, this study shows a rather limited influence of the moral status they attribute to their embryos (as part of that conceptualization) on the specific choice they make.

**Declaration of authors’ roles**

All authors take full responsibility for the reported research. We warrant that all authors have participated in the concept and design; analysis and interpretation of data; drafting or revising of the manuscript and that they have approved of the manuscript as submitted.
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