Decisional and Psycho-Social Aspects of the Embryo Disposition Context

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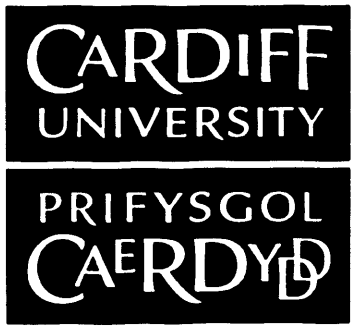

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I dedicate this thesis to

my family

Tobias & Lennox

my parents

Helga & Walther

and my parents in law

Annegret & Willi

who all gave me strength in their own way

DECLARATION

This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.

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Thesis Summary

Embryos in cryo-storage accumulate worldwide with conservative estimates suggesting that over 180,000 embryos are currently in storage in the United Kingdom. Couples keep their embryos in storage despite having satisfied their family building needs and evidence suggests that a proportion of couples will need decisional support in resolving the embryo disposition decision. The aim of the studies presented in this thesis was to better understand the embryo disposition decision context, establish factors associated with the decision (facilitators and impediments) and identify targets for decision support to improve patient experiences.

The work presented in this thesis demonstrates that the embryo disposition decision is embedded in a complex and distressing decision context that makes it difficult for couples to choose a disposition option. The complexity and difficulty of the decision context emerges from couples' affective forecasting, their representation of embryos, their treatment experience, reproductive life stage and personality characteristics.

An affective and cognitive embryo representation measure was developed allowing a multifaceted assessment of how couples feel and think about their embryos. It was suggested that the difficulty and complexity of the decision context emerges because in order to make a disposition decision couples need to achieve integration of their embryo representations with their disposition intentions. Embryo representations as well as embryo disposition preferences may change as a function of treatment experience, especially treatment success which makes the integration process even more difficult. The new measures offer the opportunity to integrate findings from cross-cultural settings, and are hoped to be used to support patients during treatment.

Publications

Paper

Chapter 3:

Stiel, M., McMahon, C. A., Elwyn, G., and Boivin, J. (2010). Pre-birth characteristics and 5-year follow-up of women with cryopreserved embryos after successful in vitro fertilisation treatment. *Journal of Psychosomatic Obstetrics and Gynecology, 31*(1): 32-39: doi: 10.3109/01674820903537081.

Talk

Stiel, M., Durand, M.-A., Boivin, J., Elwyn, G. (2008). Theory-based design of decision support technologies: guidelines for the real world. In: Oral programme of the International Conference on Communication in Healthcare. September 2008. Oslo, Norway.

Posters

Chapter 3:

Stiel, M., Boivin, J., and McMahon, C.A. (2007). Characteristics of patients who postpone decision-making in embryo disposition. In: Conferences Book of the 4th International Shared Decision Making conference. May 2007. Freiburg, Germany.

Chapter 4:

Stiel, M., Elwyn, G., Boivin, J. (2010). Embryo disposition : who finds the decision most difficult and why ? In Program and Abstracts of the 26th Annual Meeting of the European Society for Human Reproduction and Embryology. June 2010. Rome, Italy: Human Reproduction, 24 (Supplement 1), i282: doi: 10.1093/humrep/de.25.s1.425

Table of Content

Index of Tables

Index of Figures

Glossary of Abbreviations

AREA	Attend React Explain Adapt
ART	Assisted Reproductive Technologies
CAER	Cardiff Affective Embryo Representation
C-C	Cohort-Comparison
CCER	Cardiff Cognitive Embryo Representation
CEP	Cardiff Embryo Perception
CPS	Choice Predisposition Scale
DCS	Decisional Conflict Scale
DEQ	Depressive Experiences Questionnaire
DRK	Daily Record Keeping
ED	Embryo Disposition
EDA	Embryo Disposition Apprehension
EDS	Embryo Disposition Survey
EFA	Exploratory Factor Analysis
E-S	Embryo-Storage
ESES	Embryo Scale Evaluation Survey
HFEA	Human Fertilisation and Embryology Authority
HLM	Hierarchical Linear Model
ICSI	Intracytoplasmic Sperm Injection
IVF	In Vitro Fertilisation
LCB	Locus of Control of Behaviour
NHS	National Health Service
NPU	No Personal-Use

PCA	Principal Component Analysis
PCOS	Polycystic Ovary Syndrome
PES	Past Embryo Storage
PU	Personal-Use
SET	Single Embryo Transfer
SPSS	Statistical Package for the Social Sciences
STAI	State-Trait Anxiety Inventory
T1	Time 1
T2	Time 2
TAI	Trait Anxiety Inventory

Chapter 1: General Introduction and Thesis Overview

Introduction

Since 1978 when the first child was conceived with in vitro fertilization (IVF) (Steptoe & Edwards, 1978) the use of IVF and other assisted reproductive technologies (ART) have increased dramatically with the result that in the UK alone about 12,000 babies are born from treatment each year (Human Fertilisation & Embryology Authority, 2010). The term *in vitro* fertilisation stems from the Latin root meaning *in glass* fertilisation referring to fertilisation of the oocyte outside the women's body which is commonly carried out in glass containers such as petri dishes (Gardner, Weissman, & Shoham, 2004). Similarly, Intracytoplasmic Sperm Injection (ICSI) also involves fertilisation outside the women's body for which a sperm head is manually injected into the oocyte (Gardner et al., 2004). ICSI is commonly chosen for over IVF when severe male factor infertility is present because the technique allows low quality sperm to fertilise an oocyte (Devroey & Van Steirteghem, 2004). In order to collect oocytes for IVF or ICSI treatment fertility drugs are administered that stimulate the development and maturation of multiple follicles (see Table 1.1 for an illustration of the sequence of a stimulated cycle).

Once fertilisation has taken place four distinct embryo development stages are to follow (see Figure 1.1). The term *embryo* has a Greek root meaning *that which grows* where growth is achieved by means of mitosis and cytokinesis, two processes that allow a eukaryotic cell to divide into two cells containing equal shares of the cellular components (Gardner et al., 2004). Viable embryos are transferred back to the women's body on day two, three, or five of embryo development. Similarly, embryos are commonly frozen on day two, three or five after insemination (Gardner et al., 2004).

Table 1.1

Ovarian hyperstimulation protocol for IVF/ ICSI

Medical/ physiological target	Treatment
Suppressing the natural monthly hormone cycle	A drug is administered for about 2 weeks to suppress the women's natural cycle.
Ovarian stimulation & oocyte retrieval	Typically started on the 3rd day of menstruation consisting of a regimen of fertility medications for about 12 days to stimulate the development and maturation of multiple follicles in the ovaries. After maturation occurred about 10 oocytes are retrieved using a transvaginal technique involving an ultrasound-guided needle piercing the vaginal wall to reach the ovaries. Through this needle follicles can be aspirated, and the follicular fluid is handed to the IVF laboratory to identify oocytes.
Fertilisation	For IVF the collected ooytes and partner's or the donor's sperm are incubated together at a ratio of about 75,000:1 in a culture media for about 16-20 hours until the fertilised oocyte shows two pronuclei. For ICSI a single sperm may be injected directly into the oocyte. The fertilised oocyte is passed to a special growth medium for further development.
Embryo transfer	The embryo(s) that achieved the best grading based on its number of cells, evenness of growth and degree of fragmentation is transferred to the patient's uterus through a thin, plastic catheter, which goes through her vagina and cervix. Any remaining embryos may be frozen for future embryo transfers.

All information based on Gardner (2004) and the HFEA (2009c)

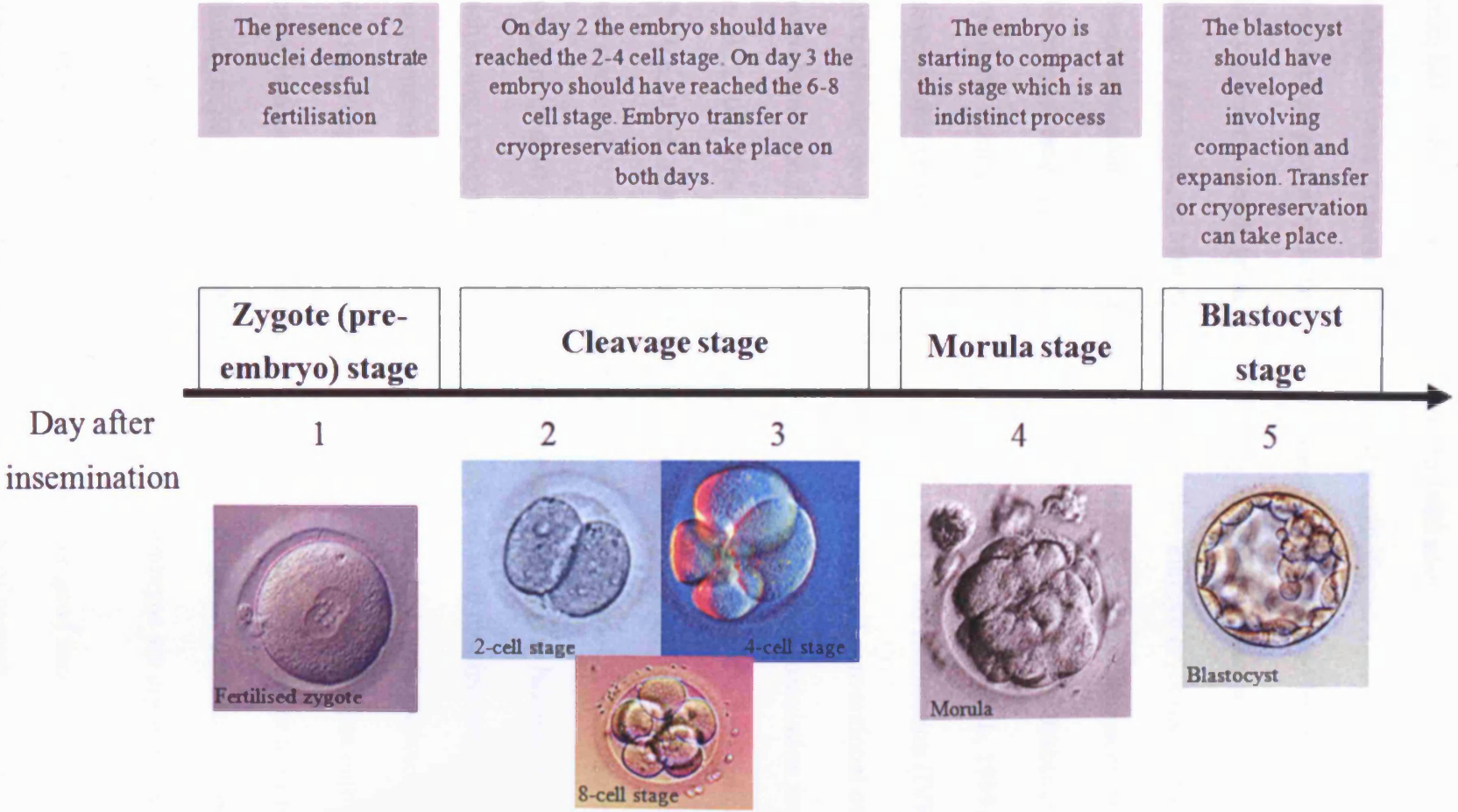

Figure 1.1: Embryo development stages as a function of day after insemination[1]

[1] Pictures are a courtesy of Lyndon Miles, consultant embryologist at the Centre for Reproductive Medicine Wales. Information is based on *Embryo development: a patients' guide* (Cook Medical, 2007)

Under certain circumstances, in particular when embryo freezing is prohibited by law, pre-embryos at zygote stage are frozen that is before the pronuclei of the woman and man have merged (e.g., Brewe, 2006). In 1983 another break-through in ART was achieved when Trounson and Mohr first accomplished a pregnancy from a cryopreserved embryo (Trounson & Mohr, 1983), followed by the first life birth from a cryopreserved embryo accomplished by Zeilmaker in the same year (Gianaroli, Magli, Ferraretti, & Munné, 1999). Thereafter, embryo cryopreservation quickly became standard practice in ART programmes. By further advancement of freezing techniques researchers were able to increase the number of utilizable embryos resulting from each cycle of ovarian stimulation (Gianaroli et al., 1999). On average seven viable embryos are created by means of in vitro fertilisation (IVF) or intra cytoplasmic sperm injection (ICSI) in any one cycle of conventional ovarian stimulation and five embryos as a result of mild ovarian stimulation protocols (Baart et al., 2007). The clinical guidelines of the National Institute for Clinical Excellence (NICE, 2004) state that no more than two embryos should be transferred during any one cycle of IVF/ ICSI treatment, whereas the transfer of three embryos is limited to women aged 40 years or older. This approach, adopted to balance the likelihood of achieving a pregnancy with the risks associated with multiple pregnancies, leads to extra embryos that will not be transferred in the initial cycle (Newton, McBridge, Feyles, Tekpetey & Power, 2006). In order to be able to use extra embryos at a later point in time, for example after a fresh embryo transfer failed or to satisfy further family building needs without having to go through the demanding process of ovarian stimulation and oocyte collection again, extra embryos are cryopreserved.

Treatments such as IVF have been shown to have good success rates, with the majority of couples (69.4%) achieving their goal of parenthood by means of an

average of 3.5 treatment cycles with half of the couples (52.1%) having two or more children within five years (Pinborg, Hougaard, Nyboe Andersen, Molbo, & Schmidt, 2009).

Given the number of embryos created using conventional stimulation, couples will have many *extra* embryos that may ultimately not all be required to fulfil couples' family building needs. This means the couple (or individual) will eventually have to make a decision about the fate of so called *surplus* embryos, which is referred to as the embryo disposition (ED) decision. Patients can commonly choose between up to four ED options that include 1) Continuation of storage, 2) Donation of the embryo to research, 3) Donation to another infertile couple, and 4) Disposal as medical waste. The availability of specific disposition options is dependent upon the country and clinic where embryos are stored.

The aim of this thesis is to explore the factors associated with the ED decision to investigate the ED context that is the nature of the decision-making process, the factors that facilitate or hinder decision-making, and individual differences in how the decision process is approached. The following sections present an overview of the aspects examined in the present thesis.

Thesis Overview

Chapter 2: The empirical evidence: A comprehensive literature review of embryo disposition studies

Research on the ED decision has increased substantially since 1995 when a statutory storage period for embryos in the UK was introduced and first reports were published on the potential dilemma that stored embryos may cause (Brinsden, Avery, Marcus, &

MacNamee, 1995; Cooper, 1995). Research since then has been concerned with the accumulation of embryos and its respective storage costs, the availability of embryos for donation (either to another infertile couple or human embryonic stem cell research) and the factors associated with choosing between specific disposition options.

The aim of Chapter 2 was to conduct a comprehensive literature review, to describe the guidelines and statute laws in regards to embryo storage across countries, to illustrate the number of cryopreserved embryos across countries and to critically appraise the findings to date on factors associated with the ED decision-making process.

Chapter 3: Pre-birth characteristics and 5-year follow-up of women with cryopreserved embryos after successful in vitro fertilisation treatment

In Chapter 3 data from a longitudinal study were employed to identify individual differences at an early treatment phase (demographic, social, family, personality and relational variables) predictive of having embryos in storage five years later.

Studies to date investigating factors associated with ED choices have found inconsistent results showing that age and prior treatment success are negatively linked to decision-making and responding to clinic letters (Newton, McDermid, Tekpetey, & Tummon, 2003), whereas others found no relationship (Burton & Sanders, 2004). Personality traits such as dispositional anxiety and an external locus of control have been associated with avoidant decision-making and a low preference for active involvement in the decision-making process in related health context (Hashimoto & Fukuhara, 2004; Schneider et al., 2006). Relational variables have received little attention in the ED decision context even though research suggests that couples'

disagreement about the most superior disposition options makes the decision process more difficult (de Lacey, 2005; Hammarberg & Tinney, 2006).

The aim of Chapter 3 was to compare psychosocial factors assessed at the initiation of treatment (time 1, T1) in women who still had cryopreserved embryos five years after treatment (time 2, T2) to a cohort control group in order to identify predictors of long-term embryo storage.

Chapter 4: Correlates of decisional conflict and foundational research for an embryo representation scale

Decisional difficulty refers to the difficulty of choosing between options and their potentially undesired consequences (O'Connor, 1995). Decisional conflict is theoretically linked to decision avoidance as described in the Rational-Emotional Model of decision avoidance (Anderson, 2003), which postulates that action (decision-making) is avoided or deferred when people experience or anticipate negative emotions (e.g., anxiety, regret) when contemplating a decision. Evidence suggests that couples experience difficulty when making a decision about *surplus* embryos (e.g., Lyerly et al., 2006; Nachtigall, Becker, Friese, Butler, & MacDougall, 2005) but little is known about the extent of the difficulty and the associated factors.

The first aim of Chapter 4 was to assess the extent of decisional conflict in the ED population by comparing those women who intended to use their extra embryos for further treatment to those who did not intend to use their embryos because they had finished treatment. Further, the association between demographic, fertility and decision-making factors and decisional conflict was investigated.

The second aim of Chapter 4 was to collect an extensive account of women and men's views and emotions towards their embryos. These two goals were approached by

means of a mixed-methods online survey including both validated scales and closed-ended questions for quantitative data collection and open-ended questions to collect qualitative information.

Chapter 5: Embryo scale evaluation

The aim of Chapter 5 was to generate an embryo representation scale from the comprehensive literature review described in Chapter 2, international expert consultations, and the results from the mixed-methods survey described in Chapter 4. The resulting Cardiff Affective Embryo Representation (CAER) and Cardiff Cognitive Embryo Representation (CCER) scales were submitted to an empirical acceptability and psychometric evaluation survey comprising 421 individuals in five countries. The results showed that these measurement tools provide a reliable and sensitive way of measuring affective and cognitive representations of embryos. These evaluations showed high coherence and reliability among subscale items and concurrent validity.

Chapter 6: Affective and cognitive embryo representations and their change as a function of treatment experience

The aim of Chapter 6 was to use the CAER and CCER scales to investigate affective and cognitive representations of embryos in a longitudinal study from before oocyte collection (time 1, T1) to embryo transfer (time 2, T2). During this treatment phase couples experienced a range of meaningful events such as the retrieval and fertilisation of oocytes and the transfer of their embryos. It is examined to what extent embryo representations change between treatment phases and how affective and cognitive embryo representations relate. It is also examined whether spouses differ in

their embryo representations and what role gender plays in the relation between affective and cognitive representations.

Chapter 7: General discussion and conclusions

The chapter presents the overall aims of the thesis and the main findings for the studies conducted. Further, the clinical implications of such findings and future research goals are discussed.

Chapter 2: The Empirical Evidence: A Comprehensive Literature Review of Embryo Disposition Studies

In the present chapter the guidelines, regulations and empirical evidence regarding ED decision-making across nations will be reviewed.

Surplus Embryos Worldwide

The number of embryos in storage differs worldwide. In 1991 the HFEA in the United Kingdom (UK) released an Act that regulated the statutory storage period of embryos to a maximum of five years in order to avoid embryo accumulation (Human Fertilisation and Embryology Authority, 1996). The Act was amended in 2008 in response to technological developments in ART and changes in society extending embryo storage to 10 years (Human Fertilisation & Embryology Authority, 2008), and enabling clinics to dispose of any unclaimed extra embryos thereafter.

In the UK the HFEA estimated the number of stored embryos in 1996 to be 52,000 of which 9,000 had reached their maximum storage time leaving 43,000 embryos in storage (Boulton, 1996). Thereafter, little is known about the number of embryos for the years 1997-2001. Since 2002, as shown in Figure 2.1, on average ~ 45,000 embryos were put into storage annually and ~ 29,000 were annually used in reproductive treatment cycles leaving ~ 16,000 extra embryos in storage every year (R. Martin, 05/08/09; personal communication with the HFEA). Thus, given the legislation of 2008, in any 10 year period up to 160,000 embryos (10 x 16,000) could have accumulated in storage. Given the relative stability of used and stored embryos (see Figure 2.1) it can be assumed that if this trend continued after 2007 3200 couples are facing the disposition of their extra embryos annually (based on the HFEA estimate of five stored embryos per treatment cycle, 16,000 / 5 = 3,200).

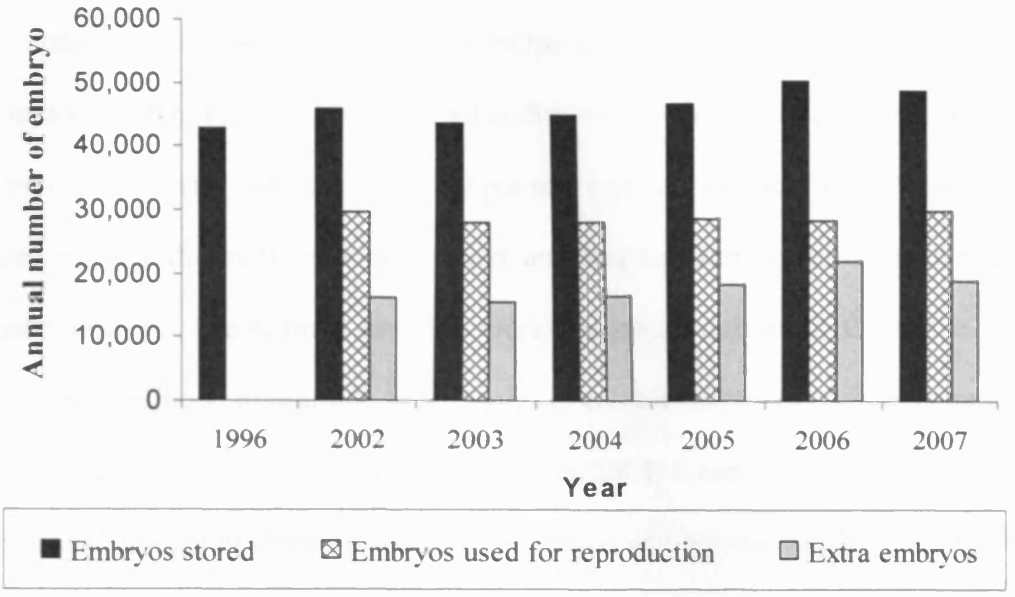

Figure 2.1: Number of stored and thawed embryos in the UK per year[2].

[2] Numbers of stored embryos and embryos used for reproduction were provided by the HFEA (R. Martin, 05/08/2009; personal communication with the HFEA)

In a trend analysis on embryo transfers by the Centers for Disease Control and Prevention in the USA similar results were found. Between the years 1996 and 2002 about a third (range 29.9 - 34.4%) of all embryos were extra after couples' initial embryo transfer and were subsequently put into cryo-storage (Reynolds & Schieve, 2006). Further, during the reported period, and despite efforts towards single embryo transfers (SETs), two or more embryos were commonly transferred. Given the increased likelihood of multiple pregnancies in combination with couples commonly desired family size of two children (Berrington, 2004) it can be concluded that a substantial amount of those 30% of extra embryos will become surplus to couples building needs.

In other English-speaking countries the number of stored embryos varies with a range of 396,000 surplus embryos in the United States to 15,615 in Canada. However, when the ratio between the population and number of stored embryos of a given country is considered Australia and New Zealand had the highest number of stored embryos per citizen (7.8 / 1000) whereas Canada (0.5/1000) showed the lowest ratio (see Table 2.1). The variation in the number of stored embryos worldwide may be due to the maximum storage limit that is among the highest in Australia and New Zealand UK (see Table 2.1), where the storage limit can be as long as 15 years (depending on state). Thus, one reason for accumulation of embryos might be a less restrictive legislation in statutory storage periods. A second reason for the high numbers of embryos in storage worldwide is that conventional hormonal stimulation produces on average seven viable embryos (Baart et al., 2007). A third reason is the current trend towards SET because of the health risks associated with multiple pregnancies (HFEA, 2009a).

Table 2.1

Number of stored embryos in English-speaking countries

Country	Number of cryopreserved embryos	Year	Population	Cryopreserved embryos / 1000 citizens	Source
Australia & New Zealand*	22,280	1994	11,621,000	1.9	Bryant, Sullivan & Dean (2004)
	92,541	2002	11,873,000	7.8	
Canada	15,615	2003	32,307,000	0.5	Baylis et al.
United States	396,000	2003	302,741,000	1.3	Hoffman et al.

Note. Number of cryopreserved embryos is based on provided citations. Population estimates are based on the population prospect of the United Nations (2008).

* For Australia and New Zealand data provided for 1994 and 2002.

This may lead to even more extra embryos for patients that typically produce more oocytes in response to stimulation (e.g., young women, women with Polycystic Ovary Syndrome (PCOS)). Given the overall success rates of treatment (32.8% for a fresh embryo transfer and 21.8% for a frozen embryo transfer; HFEA 2009b) many patients will not utilise all their embryos and this also contributes to embryo accumulation.

Extra embryos remaining in storage pose a problem for ART clinics due to maintenance costs and limited storage space (Klock, Sheinin, & Kazer, 2001), and most importantly, in cases where patients do not reply to clinic letters, legislation requires in many countries storage institutes to destroy unclaimed embryos which has been shown to cause ethical dilemmas and legal battles between couples and health professionals (Edwards & Beard, 1997).

Embryo Disposition Guidelines and Legislations

Countries differ in regard to their ED regulations. Some countries (e.g., Italy, Germany) prohibit cryopreservation of embryos altogether whereas others (e.g., United States, South Africa) have no legal storage limit for stored embryos (see Table 2.2). In countries where cryopreservation of embryos is prohibited (e.g., Italy, Germany, Switzerland) all generated embryos must be used in the concurrent cycle (Weil, 2006) and only if medical circumstances prevent a fresh embryo transfer can embryos be cryopreserved. In Austria, Germany and Switzerland, however, cryopreservation is allowed for pre-embryos (fertilised zygotes, see Figure 1.1, page 4) that are defined as fertilised oocytes at zygote stage which is before sperm and ovum join to form an embryo (Brewe, 2006).

Table 2.2

Embryo cryopreservation variation across countries

Country	Year	Legislation	Source
English-speaking countries			
Australia (Victoria)	1995	**Storage limit:** Five year limit **Storage extension**: Possible **After storage:** Embryos can be destroyed if patients cannot be traced	Infertility Treatment Act (Kovacs, Breheny, & Dear, 2003)
Australia (South, Northern Territory and other states)	1988	**Storage limit:** 10 year limit **Storage extension**: No provision **After storage**: No information provided	Reproductive Technology Act (Kovacs et al., 2003), (National Health and Medical Research Council, 1996a) and (Reproductive Technology Accreditation Committee, 2002)
Australia (Western)	1991	**Storage limit:** 15 years **Storage extension**: Consent for storage is to be renewed every three years **After storage:** No information provided	Human Reproductive Technology Act (Kovacs et al., 2003)
Canada	2005	**Storage limit:** Five years **Storage extension**: No information **After storage:** No information provided	The Royal Commission on New Reproductive Technologies (Government of Canada, 2004)

Table 2.2 continued

Country	Year	Legislation	Source
English-speaking countries			
Great Britain	1995	**Storage limit:** 10 years **Storage extension**: For patients who are prematurely infertile storage can be extended by anothers 10 years until a maximum storage period of 55 years has been reached. **At the end of storage:** Embryos can be destroyed if patients cannot be traced	(Human Fertilisation and Embryology Authority, 1996)
Ireland	2005	**Storage limit:** Five years (recommended) **Storage extension**: Storage length varies between clinics **At the end of storage:** No information	(The Commission on Assisted Human Reproduction, 2005)
New Zealand	2007	**Storage limit:** 10 years **Storage extension**: Possibility for extension upon application to an ethics committee **At the end of storage:** No information	Human Assisted Reproductive Technology Act (New Zealand Government, 2004)
South Africa	2007	**No storage limit**	(Human Tissue Amendment Act, 1989)
United States	2002	**Storage limit:** End of reproductive life **Storage extension**: No information **At the end of storage:** The disposal of abandoned embryos is ethically acceptable	(American Society of Reproductive Medicine, 1998)

Table 2.2 continued

Non English-speaking countries

Country	Year	Legislation	Source
Austria	1992	Embryos can only be cryopreserved when a fresh embryo transfer is unfeasible. Fertilised oocytes at zygote stage (see Figure 1.1, page 4) can be cryopreserved **Storage limit:** One year **Storage extension**: No information **At the end of storage**: Fertilised oocytes can be destroyed	The reproductive medicine legislation: new legal responsibilities for the Austrian gynaecologist (Bernat, 1993)
Belgium		**Storage limit:** Five years **Storage extension**: Storage can be extended under exceptional circumstances **At the end of storage**: Embryos can be destroyed	Law on Medically Assisted Reproduction and the Disposition of Supernumerary Embryos and Gametes (Pennings, 2007)
Brazil	1992	**No storage limit**	The Brazilian Federal Medical Council (Franco, 1995)
Denmark	2003	**Storage limit:** Five years **Storage extension**: No information **At the end of storage:** No information	Act on artificial fertilisation (Nordic Council of Ministers, 2006)
Finland	1990	**Storage limit:** No information **Storage extension**: No information **At the end of storage:** No information	No specific legislation (Nordic Council of Ministers, 2006)

Table 2.2 continued

Non English-speaking countries

Country	Year	Legislation	Source
France	1994	**Storage limit:** Five years **Storage extension**: No information **At the end of storage:** Embryos can be destroyed	The French bioethic law (Cohen, 1995)
Germany	1990	Embryos can only be cryopreserved when the fresh embryo transfer is unfeasible. Fertilised oocytes at zygote stage (see Figure 1.1, page 4) can be cryopreserved **Storage limit:** No information **Storage extension**: No information **At the end of storage:** No information	Embryo Protection Law (Brewe, 2006)
Iceland	1996	**Storage limit:** Five years **Storage extension**: No information **At the end of storage**: No information	Act on artificial fertilisation and Regulation on artificial fertilisation (Nordic Council of Ministers, 2006)
Italy	2004	Embryo cryopreservation is allowed only under exceptional circumstances such as unforeseeable health conditions of the woman, making transfer of embryo(s) impossible. **Storage limit**: Embryos must be cryopreserved for the shortest time possible	Law on assisted reproductive technology (Boggio, 2005; Fineschi, Neri, & Turillazzi, 2004)

Table 2.2 continued

Non English-speaking countries

Country	Year	Legislation	Source
Norway	2004	**Storage limit:** Five years **Storage extension**: No information **At the end of storage**: No information	Act on the medical use of biotechnology(Nordic Council of Ministers, 2006)
Spain	1988	**Storage limit:** Five years **Storage extension**: No information **At the end of storage**: No information	Spanish law governing assisted reproduction techniques (Peinado & Russell, 1990)
Sweden	1988	**Storage limit:** Throughout the women's reproductive life **Storage extension**: No information **At the end of storage**: No information	Act 14/2006 on human assisted reproduction techniques (Luna et al., 2009; Vidal Martínez, 2006)
Switzerland	1990	Embryos can only be cryopreserved when the fresh embryo transfer is unfeasible. Fertilised oocytes at zygote stage (see Figure 1.1, page 4) can be cryopreserved **Storage limit:** Five years **Storage extension**: No information **At the end of storage:** No information	Swiss International Survey Laws on Assisted Procreation (Max-Planck-Institut für ausländisches und internationles Strafrecht, 2003)

Table 2.2 shows clearly that there is little consensus when it comes to storage length where storage limits range between one year and indefinite storage. It has been reported that cryopreserved embryos can be stored for over a decade and still result in healthy babies (Parker, 2006; Revel et al., 2004). Given the advances in ART and reports of successful long-term storage it has been argued that there is no scientific basis for any storage limit at all (Brinsden et al., 1995; Edwards & Beard, 1997; Machtinger et al., 2002; Revel et al., 2004).

Once extra embryos are cryopreserved the frequency of contact between patient and clinic decreases considerably. If patients are not in treatment they are commonly contacted by the ART clinic via letter once a year requesting an up-date on storage instructions. Here, patients can choose between up to four ED options that include 1) Continuation of storage, 2) Donation of embryo to research, 3) Donation to another infertile couple, and 4) Disposal as medical waste. The availability of specific disposition options is dependent upon the country and clinic where embryos are stored. Research facilities or couple donation programmes do not exist at every clinic and in some countries options are prohibited by law (e.g., Brazil: donation to research is prohibited; Germany: donation to other couples is illegal). In the UK, patients are requested by the HFEA to sign a legal document to consent to the creation and storage of their embryos (see Appendix 1 for the female version of the HFEA consent form). This form also specifies the storage length, and asks patients whether they consent to their embryos being used in research projects and what they would want the clinic to do with their embryos in case of mental incapacity or death. Thus, ownership rights for embryos lie with the couple who created the embryos.

In summary, ART procedures often produce more embryos than are needed by patients resulting in many embryos remaining in cryo-storage. Regulations in the form of guidelines and statute laws exist in some countries that mandate the statutory maximum storage period (e.g., 10 years in the UK), and some also determine the availability of disposition options. Ultimately, however, the decision of what to do with extra embryos lies with the couple to whom the embryos belong.

Embryo Disposition Options

In order to understand why embryos accumulate in some parts of the world and what the 3,200 couples do with their 16,000 extra embryos in the UK every year, it is important to gain insight into how people chose between the ED options available to them and their reasons for their choice. In the following section, factors associated with choosing ED options will be described by contrasting those factors that have been shown to facilitate decision-making from those that hinder the decision.

A PubMed search was conducted to establish factors associated with the embryo disposition decision. Firstly, the term Embryo Disposition [MeSH] was searched, resulting in 427 records that were scanned for relevance. Secondly, records were excluded if their title referred to guidelines and policies, stem cell technology, oocyte cryopreservation, pregnancy outcome (miscarriage, abortion), multifetal pregnancy reduction, therapeutic cloning, embryo scoring (quality), embryo dignity, genetic technologies (preimplantation genetic diagnosis), assisted hatching, religious views (theological debate), and children's needs. This resulted in a total of 100 abstracts that were examined for relevance. Full reports were obtained as necessary and other citations were identified in the reference lists of the relevant citations. 48 relevant publications were extracted and included in the current review.

Disposition intention versus decisions

It is important to note that research to date concerns couples' disposition preferences (intentions) before or during treatment or their actual disposition choices after finishing treatment. Table 2.3a shows results of cross-sectional studies investigating disposition preferences, whereas Table 2.3b shows results of cross-sectional and longitudinal studies investigating actual disposition decisions at the end of treatment. Table 2.3a & b also show the disposition option to continue storage for the samples. Storage continuation can be chosen for two reasons, that is, either because couples wish to use their embryos for their own treatment in the future, or couples are undecided as to which disposition option to choose or whether to postpone the decision. As shown in Table 2.3a & b when actual disposition decisions are compared to couples' disposition preferences almost double the amount of patients choose to discard their extra embryos (32%) than intend to (18%) and fewer patients choose to continue storage (22%) than intend to (40%). These findings are to be expected given that couples do not need their extra embryos anymore after successful treatment. Moreover, more couples donate their surplus embryos to research (36%) than intend to (21%), and similarly, more couples donate their surplus embryos to another couple (18%) than intend to (12%). These numbers suggest that when initiating treatment, couples do not anticipate any leftover embryos, but assume they will need and use all their embryos for their own family building.

Table 2.3a

Percentage of couples intending to choose a specific embryo disposition option

Disposition intention

Storage Continuation							
Research	Couple	Disposal	Own use	Undecided	Source	Country	Comments
-	9%	2%	51%*	43%*	(Brzyski, 1998)	USA	Quantitative cross-sectional design. 38% replied (n = 136); 43% intended to use after 1 year of storage; 12% returned as undeliverable
10%	12%	34%	44%	-	(Van Voorhis et al., 1999)	USA	Quantitative cross-sectional design. 99% replied (n = 360), intended use after > 2 years storage
-	2%	21%	4%	50%	(Cattoli et al., 2000)	ITA	Quantitative cross-sectional design. 76% replied with embryos in storage between 4-8 years
26%	20%	-	53%		(Moutel et al., 2002)	FRA	Quantitative and qualitative cross-sectional design. 49% replied (n = 404), after 4-12 years years of storage
30%	15%	-	-	-	(Burton & Sanders, 2004)	USA	Quantitative cross-sectional design. 57% replied (n = 126), only willingness to donate to research or couple were assessed
2%	6%	24%	39%	-	(Cattoli et al., 2004)	ITA	Quantitative cross-sectional design. 72% replied (n = 612), after > 2 years of storage
39%	28%	8%	-	34%	(Lyerly et al., 2006)	USA	Qualitative cross-sectional design. Interviews (n = 34), answers not mutually exclusive
21%	-	-	54%	-	(Lyerly et al., 2010)	USA	Quantitative cross-sectional design
-	4%	-	22%	-	(McMahon & Saunders, 2009)	AUS	Quantitative and qualitative cross-sectional design. 29% replied, 23% were eligible (n = 133), embryos were stored for > 3 years, only donation to couple and own use were assessed
Average 21%	12%	18%	40%				

Note. Dashes indicate that the option was not available at the clinic

* Answers are not mutually exclusive

Table 2.3b

Percentage of couples choosing a specific embryo disposition option

Disposition decision

				Storage Continuation				
	Research	Couple	Disposal	Own use	Undecided	Source		Comments
	21%	12%	29%	38%	-	(Oghoetuoma et al., 2000)	UK	Quantitative cross-sectional design. Disposition decisions between 1988 – 1994. 51% replied (n = 182) after 5 years of storage
	19%	5%	30%	46%		(Elford, et al., 2004)	CAN	Quantitative cross-sectional design. Disposition decisions between 1991 - 2001
	60%	29%	-	-		(Bangsboll et al., 2004)	DNK	Quantitative cross-sectional design. 74% replied (n = 210)
	42%	16%	30%	5%	7%	(Hammarberg & Tinney, 2006)	AUS	Quantitative cross-sectional design. 40% response rate (n = 123), disposition decisions between 2002 - 2003
	33%	13%	44%	10%		(Newton et al., 2007)	CAN	Quantitative longitudinal design. 62% response rate (n = 144), disposition choice > 5 years of storage was compared to disposition intention at time of cryopreservation
	36%	28%	17%	8%	11%	(Luna et al., 2009)	ESP	Quantitative cross-sectional design. 39% response rate (n = 786), clinic letters sent after >10 years of storage
	59%	3%	38%	-	-	(Lanzendorf et al., 2010)	USA	Quantitative cross-sectional design. N = 149 disposition decisions between 2002 - 2007
	14%	34%	39%	-	-	(Lornage et al., 1995)	FRA	Quantitative cross-sectional design. 87% response rate (n = 62),
Average	36%	18%	32%		22%			

Note. Dashes indicate that the option was not available at the clinic

* Answers are not mutually exclusive

Surprisingly, over 20% of couples keep their embryos in storage even after finishing treatment when they have no intention to use them for their own reproductive purposes anymore. In addition, results show between 25 to 62% of couples did not even respond to clinic letters requesting a final disposition choice, which in many clinics also meant that embryos were destroyed.

In summary, research to date shows that ED decisions can change as couples progress from the initiation of treatment to the end of treatment. Many couples keep embryos in storage though they are not required for further treatment and actual decisions are often made passively (i.e., by non-response to clinic letters). In the following section evidence for the dynamic nature of the ED decision will be outlined.

The dynamic nature of the ED decision

It has been reported that between 28% – 71% of couples change their disposition intentions as they go through treatment (Ferling et al., 2004; Hounshell & Chetkowski, 1996; Klock et al., 2001; Lornage et al., 1995; Newton, Fisher et al., 2007). Although Table 2.3a & b suggest that donation to another couple is a somewhat stable disposition preference, the few longitudinal studies on this subject suggest that couples who initially opted to donate to another couple chose an alternative disposition option once treatment was finished (Cooper, 1995; de Lacey, 2005; Ferling et al., 2004; Hounshell & Chetkowski, 1996; Lornage et al., 1995). This was in particular the case after couples were counselled to explore their feelings and conceptualisation of their embryos (79% changed their mind; Saunders, Bowman, Grierson, & Garner, 1995). Since this tendency is not reflected in the relative stability of average numbers for donation to another couple as shown in Table 2.3a & b, it can

be assumed that the opposite trend must also occur, for example, couples change their disposition preference towards donation to another couple after finishing treatment.

Several explanations could account for a difference between initial preference and actual choice. First, it has been speculated that when couples indicate their disposition choice at the initiation of treatment, their perception of their embryos is somewhat abstract (Cooper, 1995). For example, embryos may be perceived as a chance to become pregnant (de Lacey, 2005) or as cells with potential (Lyerly et al., 2006). In contrast, after couples' became parents, reports of embryo perception are often dramatically different owing to the experience of parenthood. The difference in perspective can be illustrated by the following quote from a research participant:

> "*After having a daughter who was a frozen embryo it has made it more difficult to think of embryos as some scientific thing when we look at her and remember what she looked like at three cells. All of our embryos are now humanised for us. Before she was born we were much more detached.*" (McMahon et al., 2003, p. 875).

In studies showing that embryos are viewed as virtual children and biological siblings to existing children, embryo donation to another couple was regarded as child relinquishment (Cooper, 1995; de Lacey, 2005; Elford et al., 2004). The difference in perception of the embryo may change the nature of the embryo decision to be made and consequently lead to the observed difference between intentions and actual disposition decisions. However, as all studies investigating embryo perception are retrospective accounts, causal inferences as to the direction of change cannot be made.

From a theoretical perspective, the change in couples' disposition preference may be due to a bias in perception of events that are temporarily distant (Pennings, 2002).

That is, at the time of initiating treatment, couples simply cannot imagine how they will feel and think about their embryos if they eventually no longer need them. This phenomenon, referred to as a cold – hot empathy gap, occurs when people make a decision (e.g., disposition preference) while being in an affectively cold state, that is, when people are not affectively aroused (Loewenstein, 2005). This is illustrated in a quote by a woman stating:

> *"The decision had been very easy when we completed the hypothetical questionnaire [consent form] at the commencement of the IVF process. In reality it was very difficult and it took us two years of discussing it to make it. If finances had permitted, I would probably still be paying the storage fees and putting off thinking about it!"* (Hammarberg & Tinney, 2006, p. 90).

It was reported that at the time of treatment initiation many patients have never thought about embryos and their moral status, and many may not have believed (or fully realised) there could be remaining embryos at the end of their treatment (de Lacey, 2005; Lyerly, Brelsford, Bankowski, Faden, & Wallach, 2004; Lyerly et al., 2006). The strong desire for a child may lead couples to focus on achieving their goal of a family, with cryopreservation being a necessary means that patients did not anticipate could become a problematic issue in the future (Nachtigall et al., 2005). In line with this, couples' initial decision-making has been described as an ideal plan (de Lacey, 2005), where embryo donation to another couple might be regarded as an altruistic act (Cooper, 1995) rather than a purposeful decision (de Lacey, 2005).

Conceptualisations of embryos

Couples have been shown to conceptualise their embryos in many different ways that will be described in the following section.

Human perspective

Several authors made the observation that couples conceptualise their extra embryos as life or living entities (Melamed et al., 2009; Nachtigall et al., 2005), as human beings (Lyerly et al., 2006; Provoost et al., 2009), as real people (Lyerly et al., 2006; McMahon, Gibson, Cohen, Leslie, & Tennant, 2000), as unborn, virtual or potential children (de Lacey, 2005; Elford et al., 2004; Fuscaldo, 2005; Karpel, Frydman, Frydman, Flis-Treves, & Fanchin, 2007; Laruelle & Englert, 1995; Lee & Yap, 2003; Melamed et al., 2009; Nachtigall et al., 2005; Nachtigall et al., 2009; Söderström-Anttila, Foudila, Ripatti, & Siegberg, 2001), as siblings to existing children (Hammarberg & Tinney, 2006; Karpel et al., 2007; McMahon et al., 2000; Nachtigall et al., 2005), or as part of their family (de Lacey, 2005; Nachtigall et al., 2005). Therefore it is not surprising that some of the couples who think of their extra embryos as human beings also ascribe them a moral status (Lyerly et al., 2010; Provoost et al., 2009) with interests that need protection (Lyerly et al., 2006; Nachtigall et al., 2005).

Medical perspective

Another common conceptualisation of extra embryos is as a medical entity, clusters of cells (de Lacey, 2007; Fuscaldo, Russell, & Gillam, 2007; Lyerly et al., 2006) or biological material (Melamed et al., 2009) without uniquely human moral rights or interests (Lyerly et al., 2006). According to this perspective, embryo donation is

regarded to be similar to organ or blood donation (Zweifel, Christianson, Jaeger, Olive, & Lindheim, 2007).

Other perspectives

In addition, several other views on extra embryos have been reported that did not fit the human – medical distinction. For example, some couples emphasised the value of their extra embryos in that they represented a lot of effort (Provoost et al., 2009), a chance to become pregnant (de Lacey, 2005), but also a genetic or psychological insurance and security blanket that provided prolonged fertility (Lyerly et al., 2006) or medical treatment in the future (e.g., source of stem cells; Nachtigall et al., 2005). Couples have also emphasised the importance of their genetic link to their extra embryos (Fuscaldo, 2005; Provoost et al., 2009), their emotional attachment and feelings towards them (Provoost et al., 2009) or referred to extra embryos as a symbolic reminder of their past infertility and the struggle they went through (Nachtigall et al., 2005).

Consent at the initiation of treatment

The legal aspect of the disposition decision was investigated in regards to couples' attitudes toward the decision in case of death of one or both partners, separation or divorce (Styer, Cekleniak, Legedza, Mutter, & Hornstein, 2003). A prominent legal case in the UK was that of Evans against Johnston where Miss Evans who suffered from cancer that resulted in the removal of both her ovaries created embryos with her oocytes and sperm of her then partner Mr Johnston in order to preserve her chances of reproduction. About a year after the creation of the embryos, the couple ended their relationship with the result that Mr Johnston withdrew his consent to use the embryos

in any future pregnancy attempts. The subsequent legal battle caused media attention in the UK for the following 6 years because Miss Evans took her case to the British High Court, Court of Appeal, and the European Court of Human Rights in Strasbourg where she eventually lost her case. That is based on the HFEA Act (1990) Mr Johnston successfully pursued his right to withdraw consent to the use and storage of extra embryos. Similarly, a case report stemming from a court in Massachusetts (USA) disregarded the informed consent because of "unenforceab[ility] due to change in circumstances" four years after the original agreement based on the assumption that the "husband's interest in avoiding procreation outweighed the wife's interest in having (additional) children" (Styer et al., 2003, p. 589). Based on the possibility that one or both partners could change their mind at a later point it has been argued that the validity of pre-treatment consent is questionable altogether, and therefore, no contracts or advance directives should be required for situations in which the couple remains competent (Pennings, 2002). When couples are asked to indicate their choice in case of death, separation or divorce it was shown that only 3.6% were unable to choose among disposition options (Styer et al., 2003). This finding provides support for the claim that pre-treatment consent lacks validity because the ED decision seemed to be unproblematic pre-treatment, whereas about a third of couples do not come to a final disposition choice post-treatment (see Table 2.3b, page 26). Moreover, regarding the choices couples made before initiating treatment it is noteworthy that patients were shown to be more likely to dispose of the embryos in case of death of the female (41%) than the male partner (15%) (Styer et al., 2003). This finding suggests that women may be more willing than men to use their embryos without their partner, which might be linked to the women's ability to carry and deliver the resulting child, whereas men would need to find a surrogate to become fathers. In

related areas, women are also given preference, for example, despite the beginning of equalisation of parental rights women are still more likely to be granted custody (Derdeyn, 1976). However, due to a lack of studies investigating gender differences in ED, to date there is little evidence to support this assumption.

In summary, it is questionable whether informed consent at the initiation of treatment can effectively prevent ART clinics from legal claims in the future because many couples can simply not imagine how they will feel and think about their embryos at the initiation of treatment. Additionally, couples may experience a change in value as they go through ART treatment and subsequently change their disposition preference.

Factors associated with specific disposition preferences

In the following section, couples' reasons for discontinuing cryopreservation and their rationale for and against choosing any of the ED options (donation to research, donation to another infertile couple, disposal or continuation of storage) are outlined. In this section, it will become clear that the same rationale can motivate opposite disposition choices.

Reasons for not intending to use embryos in the future

Couples' desire for more children is the crossroads for embryo disposition, with couples who have not fulfilled their family building needs continuing with treatment and those who have fulfilled their family building needs facing the disposition decision (Lyerly et al., 2006). Hence, the most commonly reported reason for not using extra embryos for own family building was satisfaction with family size (Bangsbøll et al., 2004; Hammarberg & Tinney, 2006; Newton et al., 2003). Other reasons for not using embryos have included not being able to have more children

because of personal circumstances (e.g., age, finances, separation) (Bangsbøll et al., 2004; Hammarberg & Tinney, 2006; McMahon et al., 2000), a too short storage period and therefore insufficient time for further family building (Bangsbøll et al., 2004) and a perceived inability to cope with the stress of further treatment (Hammarberg & Tinney, 2006; Lyerly et al., 2006; McMahon et al., 2000; Newton et al., 2003) and simultaneous child care demands (Newton et al., 2003). Couples' understanding of the treatment procedures and view of their embryos has also been shown to be important in that couples who believe that cryopreservation may result in increased malformations in the foetus are less likely to use cryopreserved embryos for further treatment (Provoost et al., 2010; Skoog Svanberg, Boivin, & Bergh, 2001), whereas couples who ascribe their extra embryos a high moral status have been shown to be more likely to use them (Lyerly et al., 2010).

Donation to research

As shown in Table 2.3b, page 26 donation to research is chosen by an average of 32% of couples. A multifaceted picture is drawn of the reasons for choosing this disposition option. That is, the decision has been linked to how couples view their embryos with those who ascribe a lower moral status being more likely to donate them to research (than to another infertile couple). Similarly, those couples for whom embryo destruction (including research) was not an option were more likely to see their embryos as life (n = 20/38 (53%); Hammarberg & Tinney, 2006), to have religious beliefs (Bangsbøll et al., 2004; Burton & Sanders, 2004), and to expressed concerns about a perceived lack of control over the type of research to be carried out (Lyerly et al., 2006; McMahon et al., 2003). Other reasons that led to donation to research were feelings of altruism (Lyerly et al., 2010) and the wish to give something

back to the clinic or science in general and not to waste the embryos (Elford et al., 2004; Fuscaldo, 2005; Hammarberg & Tinney, 2006; Lyerly et al., 2006; McMahon et al., 2000; McMahon et al., 2003) which was portrayed by one women as:

> *"I feel that medical research has allowed me to fall pregnant and I would hope that by donating the embryos for further research other couples may also be helped"* (McMahon et al., 2003, p. 874).

However, couples also had concerns regarding embryo research in that they feared a misapplication of the technology (Lyerly et al., 2006; McMahon et al., 2000; McMahon et al., 2003), frequently expressed the need for more information on specific research projects (McMahon et al., 2000), and showed a general need for outside help for making the disposition decision (Burton & Sanders, 2004).

There is mixed evidence as to how prior treatment success is linked to donation to research in that some couples were more likely to donate to research if they had a live birth from treatment (Bangsbøll et al., 2004) whereas others found no relationship (Burton and Saunders, 2004).

Donation to another couple

Donation of surplus embryos to another infertile couple is the least favoured disposition option with only 16% making this choice. There is mixed evidence regarding couples' reasons for choosing this option. Some reports have shown that couples choose this option because they would like to give the embryos a chance at life (Hammarberg & Tinney, 2006) and want to help another couple (Hammarberg & Tinney, 2006; Lyerly et al., 2010). Another important factor is how couples view their embryos, in that thinking of them as unborn children (Elford et al., 2004), or ascribing

the embryo a high moral status (Lyerly et al., 2010) was linked to donating to another couple. There have also been reports that experiencing a birth makes couples view their embryos as more human (McMahon et al., 2003, p. 875) and accordingly it was shown that having realised a live birth from an embryo was linked to donating to another couple (Bangsbøll et al., 2004; Lanzendorf et al., 2010). However, others either found no relationship between live birth and donation to another couple (Laruelle & Englert, 1995) or reported conflicting findings. That is, couples who thought of their surplus embryos as their (already existing) children, who had a sense of ownership and responsibility for their well-being (Lyerly et al., 2006), or who emphasised the genetic link between them and their surplus embryos (de Lacey, 2005) were less likely to donate them to another couple because they did not want to put their genetic children in an unknown situation where they would be raised by another family (McMahon et al., 2000; McMahon & Saunders, 2009). One woman (age 44) said:

> *"...I just feel that I have a responsibility towards this embryo and I don't have the right to put it in an unknown situation"* (Lyerly et al., 2006, p. 1627)

and another woman said that any resulting child would be:

> *"[...] me and you, that is us. (I) just couldn't bear the thought (in considering donation) that it was ours", "it had everything about us in it"* (de Lacey, 2005, p. 1665).

Accordingly, some couples expressed fear that their children might meet and fall in love some day without knowing they were genetic brothers and sisters (McMahon et al., 2000; McMahon & Saunders, 2009). The uncertainty of not knowing whether

another child existed and the fear of that child seeking contact some day was too distressing (McMahon et al., 2000). However, reluctance to donate to another couple also came at the price of feelings of guilt because couples empathised with others' inability to have children (McMahon & Saunders, 2009).

Discarding the embryos

Disposal of surplus embryos is chosen by 32% of all patients (see Table 2.3b, page 26). The reasons for choosing this disposition option are particularly diverse and contradictory. Disposal was chosen when couples did not want a sibling to their existing children to be born because of concern about his/her future (de Lacey, 2005; Hammarberg & Tinney, 2006; Lyerly et al., 2010), when concerns about misuse of embryos in research were expressed (Melamed et al., 2009), when couples ascribed their embryos a low moral status (Lyerly et al., 2010), or, in contrast, when couples experienced a live birth (Bangsbøll et al., 2004; Newton, Fisher et al., 2007), whereas others found no relationship between live birth and disposal (Lanzendorf et al., 2010). Reluctance to dispose embryos has been linked to their human status (Elford et al., 2004; McMahon et al., 2000), and perceiving disposal as a waste of resources (Lyerly et al., 2010).

Continuation of storage

Keeping embryos cryopreserved is in most cases chosen because couples have not fulfilled their family building needs and would like to use their extra embryo in subsequent cycles. However, on average a fourth of all couples that have completed treatment nevertheless choose to continue storage of their surplus embryos (see Table 2.3b, page 26). One factor that was associated with keeping embryos in storage

is duration of storage. When couples were asked how likely they were to choose any of the disposition options, those couples who had embryos in storage for five years or more were unlikely to ever use them for future pregnancy attempts and more likely to discard or store them indefinitely (Lyerly et al., 2010). Reasons for keeping embryos in storage were finding the disposition decision difficult (Hammarberg & Tinney, 2006), and considering continued storage as an insurance policy in case something happens to already existing children (McMahon et al., 2000). Accordingly, patients that achieved a pregnancy have been shown to be more likely to continue storage (Lieberman, Buck, & Hazledine, 1996; Oghoetuoma et al., 2000). Continuation of storage was also associated with how couples view their embryos: Couples who perceived their embryos as life or children were less likely to choose their destruction (disposal or research; Hammarberg & Tinney, 2006; Lee & Yap, 2003; Lyerly et al., 2006; McMahon et al., 2003) or donate them to another couple (de Lacey, 2005; Lyerly et al., 2006). Additionally, reports suggested that averse circumstances such as health issues and relationship problems as well as fear of (further) treatment failure may lead couples to keep their embryos in storage (Lieberman et al., 1996).

Alternative disposition options

Although routinely only four disposition options are made available to couples, there have been reports of clinics offering additional disposition options on request because between 15 to 40% of patients express dissatisfaction with the available option set and ask for alternative options (Lyerly et al., 2006; Lyerly et al., 2010; McMahon et al., 2000). Among the few alternative disposition options that have been described are a disposal ceremony at the time of thawing the embryos or conducting a compassionate

transfer that takes place at a time when pregnancy is unlikely (Lyerly et al., 2010). One woman (aged 35) said:

> *"You could go into a hospital chapel...with them in a little box and half an hour later, go out...just something where you could have a quiet few minutes to think about it...kind of mourn for those children that will not exist"* (Lyerly et al., 2006, p. 1627),

and another women (aged 33) commented:

> *"The ultimate thing would be [to] have them put into your body when you are not ovulating for your body to dissolve naturally...I think if you ask ten women in my situation they probably would tell you the same thing: they don't want them flushed down the toilet... If you think about it where would you want them? So I just think that would be the most humane natural thing to do. Let your body absorb them"* (Lyerly et al., 2006, p. 1628).

Results from qualitative and quantitative studies have shown that couples request alternative disposition options because they feel responsible and concerned about the embryo, foetus, or future children that may result from the embryos (Lyerly et al., 2006; Lyerly et al., 2010). It has been argued that if patients feel obliged to make a choice about their surplus embryos without agreeing with any of the available disposition options, they might be dissatisfied throughout the decision process and beyond (McMahon et al., 2000). In contrast, providing alternative choices may help couples satisfy their need for closure in a personalised way (Lyerly et al., 2006). However, despite couples' appreciation of alternative disposition options such as

disposal ceremonies, few clinics offer them. This may reflect reluctance to enter discussion on how ***human*** embryos are and how ***human*** they ought to be treated.

As the current review shows some factors (e.g., human conceptualisation of the embryo) can motivate opposite disposition decisions (e.g., to donate to another couple or to dispose the embryos). Thus, in summary, there is no clear picture as to the reasons underlying the choice of specific disposition options. In the following sections couples' reasons for not choosing any of the available disposition option will be explored further.

No response to clinic letters

In addition to the conundrum posed by keeping embryos in storage without plans for their future use, couples' response rate to clinic letters requesting a disposition decision is very low. As shown in Table 2.3b, page 26 39-62% of couples respond to clinic letters, which means for the non-responding couples that their embryos are either destroyed or kept in storage indefinitely (depending on country/ legislation). Since it is very difficult to investigate couples that do not reply to clinic letters, little evidence is available as to those couples' characteristics and reasons for non-response. It was reported that non-responders were older, had fewer embryos in storage, and had stored their embryos for longer (Brzyski, 1998). Older age has been previously associated with having finalised treatment (McMahon et al., 2000), and long embryo storage has been linked to the difficulty of the decision with couples who stored their extra embryos for longer having more difficulty making the choice (McMahon et al., 2003). Thus, it might be that couples who are finished with treatment and who therefore are facing a final disposition decision avoid the decision by not responding to clinic letters (Skoog Svanberg, Boivin, & Bergh, 2001).

There is mixed evidence as to whether success with treatment has an influence on responding to clinic letters with some findings showing that successful couples were more likely to respond to clinic letters (Newton, Fisher et al., 2007) whereas others found no relationship (Brzyski, 1998). It has been argued that embryos may have greater meaning for couples achieving pregnancy and therefore couples are more inclined to respond, whereas further communication with the clinic might be too distressing for couples who ended treatment despite not having achieved a pregnancy (Newton, Fisher et al., 2007). By keeping embryos frozen couples may have hoped to procrastinate (Pennings, 2000) or postpone the decision indefinitely (de Lacey, 2005; Nachtigall et al., 2005) with the result of avoiding it altogether. That is, by not responding to clinic letters, there is no need to face the unsettling prospect of contemplating the ED decision (Nachtigall et al., 2009), nor is it necessary to take responsibility for this irreversible decision (Nachtigall et al., 2005; Skoog Svanberg, Boivin, & Bergh, 2001). In retrospective, some couples commented that they would have preferred to have used up all their embryos, and without storage fees they would have kept the embryos stored indefinitely because they felt ambivalent and indecisive about the decision (Nachtigall et al., 2009) or were in disagreement with their partner (Hammarberg & Tinney, 2006; Nachtigall et al., 2009).

Embryo dilemma

It is somewhat paradoxical that couples describe their extra embryos as highly valuable (de Lacey, 2009; Fuscaldo, 2005; Provoost et al., 2009) with great physical, emotional and financial effort being invested in their creation (Hammarberg & Tinney, 2006; McMahon et al., 2003; Provoost et al., 2009), but simultaneously couples leave their embryos in storage for years without claiming them.

Difficulty associated with the ED decision

A possible explanation for this paradox is that the embryo disposition decision has been described as emotionally (Duke et al., 2009; Fuscaldo, 2005; Fuscaldo et al., 2007) as well as morally difficult (Lyerly & Faden, 2007), and distressing (Fuscaldo, 2005; Hammarberg & Tinney, 2006; McMahon et al., 2000), with the result that couples postpone it when financially viable to do so (Duke et al., 2009). Various negative emotions experienced at the time of ED decision-making have been associated with the decision such as guilt and regret (Fuscaldo, 2005), anguish and agony (de Lacey, 2005) as well as anxiety and sorrow (McMahon et al., 2000; Skoog Svanberg, Boivin, & Bergh, 2001). When talking about their extra embryos, some couples became so emotional that they started crying when they described their state of indecision and their final decision-making (de Lacey, 2005; McMahon et al., 2000). Negative emotions have also been reported post-decisional when couples agonised about their choice (McMahon et al., 2000), regretted their decision (de Lacey, 2005; McMahon et al., 2000), and grieved their loss (Skoog Svanberg, Boivin, & Bergh, 2001) years after making the decision. When asked about their choice (to discard their embryos), some couples reported that the topic of their extra embryos was still a sensitive one and memories still felt "raw" (de Lacey, 2005, p. 1668). One woman said:

> *"It was a very difficult decision which took us over 7 years to make. In the end we were forced to decide due to my medical condition, however it was something which caused us a great deal of anxiety and always will"* (Hammarberg & Tinney, 2006, p. 90).

Others reported mixed emotions in that they experienced sadness and relief after making the decision (McMahon et al., 2000).

There is contradictory evidence, however, about the degree of difficulty associated with the decision. One study reported that about half of couples found the decision easy or rather easy, whereas the other half found it quite difficult or very distressing (Hammarberg & Tinney, 2006). Elsewhere 57% of couples rated the decision as moderately difficult (Klock et al., 2001), whereas another report stated that couples described the decision as one of the most difficult decisions they ever had to make (McMahon et al., 2000).

The factors associated with the difficulty of the decision are also unclear. Some studies found that successful treatment was associated with more difficulty when making the decision (Fuscaldo, 2005), whereas others found no relationship (Hammarberg & Tinney, 2006). The occurrence of negative emotions has been linked to couples' emotional attachment and responsibility towards their embryos, in particular when embryos were perceived as children (Fuscaldo, 2005). Conceptualisation of the embryo has also been linked to the difficulty of the decision, especially when couples hold a deeply personalised view of their embryos that has been shown to be associated with ambivalence, uncertainty and difficulty when making the decision (Nachtigall et al., 2005). For some couples, decision-making included the challenging task of reconceptualising their embryos as something other than potential children (Nachtigall et al., 2009). Finally, the duration of storage was associated with the degree of difficulty of the decision, where couples who stored their extra embryos for longer had more difficulty making the choice (McMahon et al., 2003). There are two plausible interpretation for this, it either may be that the

longer embryos are stored the more pressing the need for an ED decision becomes (McMahon et al., 2003), or the more difficult the decision is the longer couples keep their embryos in storage in the hopes of avoiding responsibility by having the decision being made for them (Skoog Svanberg, Boivin, & Bergh, 2001).

Methodological issues

In the following section, the literature will be critically appraised in regards to its methodological strengths and limitations in order to investigate the trustworthiness of its findings.

In total 48 articles were included in the current literature review concerning embryo disposition preference, disposition choice, and the difficulty of the ED decision. There were 42 original articles, one review article, three articles on ethical and legal aspects, one theory article, and one comment to the editor. Of the 42 original articles, 5 were longitudinal designs (two qualitative, three quantitative) and 37 were cross-sectional designs (21 quantitative, 12 qualitative, and four mixed-method designs).

Although the literature on ED portrays a rich account for factors associated with the decision, findings as to why couples chose a particular disposition option and the difficulty of the decision are contradictory at times. This may be due to differences between studies such as 1) Time of assessment and sampling, 2) Disposition options, 3) Disposition context (e.g., legislation, cost of storage) 4) Type of assessment.

Time of assessment

The time of assessment has been shown to range from before initiating treatment (e.g., at the time of consenting to treatment and cryopreservation) (e.g., Newton, Fisher et

al., 2007) to a variety of points during treatment (after 2-4 years, 5-10 years, > 10 years; e.g., Luna et al., 2009) to years after ending treatment (McMahon et al., 2000). At the initiation of treatment and during treatment, couples' disposition preferences and intentions are assessed, whereas couples actual disposition choice is assessed after ending treatment. It can be argued that the decision context differs between before, during and after treatment in that couples' embryo knowledge and experience changes as part of their fertility treatment. Thus, couples who are assessed before initiating treatment (e.g., Newton, Fisher et al., 2007) have commonly little or no experience with embryos. Therefore, the decision context they are facing is hypothetical (i.e., in case of death, divorce, or when embryos are no longer needed) which has been described as an *ideal plan* (de Lacey, 2005). In contrast, during or after treatment the disposition context is no longer hypothetical as couples will have had embryos stored for a variety of periods of time (e.g., for 2-10 years (Luna et al., 2009); 4-8 years (Cattoli et al., 2000), 4-12 years (Moutel et al., 2002), and some will have experienced what an embryo can become by achieving a live birth.

Couples with embryos in storage may be further differentiated into those who have fulfilled their family buildings needs and those who have not. Since embryos are commonly cryopreserved to be used for future treatment, it can be argued that there is no need for those who are still in treatment to make a disposition decision because they intend to use their embryos for themselves. Accordingly, the decision context differs between those who aim to increase their family size and those who have all the children they desire (Nachtigall et al., 2009). Nevertheless, in some studies the term *surplus* is used to refer to *any* cryopreserved embryos created at the time of treatment regardless of whether the couple eventually personally use them in subsequent transfers (e.g., Luna et al., 2009; Lyerly et al., 2010; Newton, Fisher et al., 2007), and

only few studies differentiate between true *surplus* embryos (not needed for own family building, e.g., Lanzendorf et al., 2010) and *extra* embryos (intended for future treatment, e.g., Hammarberg & Tinney, 2006; Porz, Bürkli, Barazzetti, Leach Scully, & Rehmann-Sutter, 2008). No study to date, however, has investigated the disparity of these decision contexts (embryos still intended for personal use versus not intended for personal use) which may yield different results to those investigating combined groups.

Disposition options

The diversity of findings in regards to couples' reasons for choosing a particular disposition option may also be linked to differences within the available option set. Although, commonly four disposition options are described (donation to another infertile couple, donation to research, disposal, continuation of cryo-storage) some studies report on a subset of the available disposition options due to legislative limitations (e.g., Cattoli et al., 2000), or research question (e.g., Bangsbøll et al., 2004; Burton & Sanders, 2004; McMahon et al., 2003). In contrast, clinics occasionally provide additional disposition options (e.g., compassionate transfer when pregnancy is unlikely, disposal ceremony, Lyerly et al., 2010) or differentiate between different types of the same disposition options (e.g., donation to research, where research is further distinguished in stem cell research or infertility and training research; Bangsbøll et al., 2004).

Embryo storage

As described in Table 2.2, pages 17-21 storage length can vary substantially between countries (e.g., two year storage limit in Denmark at the time of conducting the study,

(Bangsbøll et al., 2004) versus ten years in parts of Australia (McMahon et al., 2003)). Additionally, there have been differences in storage length within studies (e.g., Luna et al., 2009; Oghoetuoma et al., 2000). It has been argued that, where storage limits are imposed by legislation, couples may not have finished their family building in the given time period (Bangsbøll et al., 2004) and therefore, disposition requests may be forced upon. Similarly, studies that report couples' reasons for preferring a particular disposition option across a variety of storage lengths are difficult to interpret because couples' personal situation remains unknown (e.g., have those with embryos stored for longer finished treatment?).

Storage costs may also account for differences between couples' reasons for choosing particular disposition options in that introduction of storage fees has been shown to result in more couples making a disposition decision who may have otherwise left their embryos in storage for longer (Duke et al., 2009). Similarly, it can be assumed that the amount of storage costs (e.g., 100$, 200$ or more, Brzyski, Binkley, David Pierce, & Eddy, 2000; Newton, Fisher et al., 2007) may motivate couples in their decision-making.

Type of assessment

Research findings have been benefitted from the use of qualitative and quantitative methods that have been argued to complement one another in investigating phenomena (Pope & Mays, 1995). In particular, couples' attitudes towards their embryos and/ or reasons for choosing certain disposition options have been assessed using qualitative data collection methods such as interviews and focus groups as well as quantitative methods such as questionnaires (e.g., de Lacey, 2009; Lyerly et al., 2010). There is also little agreement, however, on the types of questions asked

regarding couples' attitudes/ reasons for choosing a specific disposition option, e.g.`, "we have got one child and do not want more children" (Bangsbøll et al., 2004, p. 2416), or "not wanting to donate to another couple as a resulting child would be a sibling to own children", "discarding is not an issue of moral or religious concern because embryos are not fully human"`, or "to help advance science" (Hammarberg & Tinney, 2006, p. 87). Interview questions underlying qualitative methods have also been shown to be diverse focussing on the experience of having *extra* embryos (e.g., "what was it like to have embryos frozen?"; de Lacey, 2005, p. 1663), couples' disposition decision (e.g., "what was it like to make a decision about their outcome?", de Lacey, 2005, p. 1663; or "have you decided what to do with them?", Nachtigall et al., 2005, p. 432), and their emotional reaction towards the decision (e.g., "how do you feel about your decision/ consideration at this point in time?", Nachtigall, 2005, p. 432).

Moreover, various question and answer formats have been used. Qualitative assessment has varied by employing open-ended questions (de Lacey, 2005; Nachtigall, 2005), hypothetical scenarios (de Lacey, 2005; Kufner, Tonne, & Barth, 2009), a disposition ranking task during which couples' were encouraged to think-aloud about their attitude towards the disposition options (Provoost et al., 2009), or free-text boxes as part of questionnaires (McMahon & Saunders, 2009). Quantitative response scales also varied from two-point scales (e.g., yes or no, Bangsbøll et al., 2004; Hammarberg & Tinney, 2006) to seven-point scales (e.g., "no moral status" - "maximum moral status", Lyerly et al., 2010) including various statements.

Thus, although there is agreement about the importance of measuring couples' attitudes in the ED decision-context, there has been little consistency on how attitudes ought to be measured, and to date, no validated ED attitude tool exists.

In summary, there is need to acknowledge that couples' knowledge and experience in regard to embryos changes as part of their treatment experience. Therefore, samples need to be distinguished into those with *extra* and those with *surplus* embryos. Additionally, disposition preferences might change over time but few studies have employed longitudinal designs assessing couples' attitudes throughout the ED context. Measurement of ED attitudes has benefitted from employing mixed methods designs but has been unsystematic because no validated ED tool exists. In the current thesis these limitations will be addressed by differentiating decision contexts, employing longitudinal designs and developing and evaluating an embryo attitude measure.

Summary

Evidence across countries shows that embryos are accumulating and it seems that many more embryos are produced than required for couples' personal treatment needs. Couples have been shown to conceptualise their embryos diversely with a seemingly clear distinction between a medical concept (e.g., a bunch of cells) and a human perspective (e.g., a baby, sibling), while emphasising the value and symbolic meaning of embryos. It seems that couples' views of their embryos are neither pre-defined at the initiation of treatment nor stable across different treatment stages. Accordingly, couples' disposition preferences seem to change as a function of their treatment experience, which may call into question the validity of pre-treatment consent. There might be one particular sensitive phase (e.g., when patients become

parents) when a change in disposition preference is most likely. However, more longitudinal evidence is needed to confirm this proposal.

Much research has focussed on exploring couples' reasons for choosing a specific disposition option. However, little is known about what keeps some couples' from making a decision altogether. Some couples appear to find the disposition decision difficult with feelings of uncertainty causing a need to avoid a potentially unsettling deliberation process and an irreversible decision. Negative emotions also play a crucial role in that some couples feel distressed during and beyond the decision-making process. By remaining passive (e.g., not responding to clinic letters, actively choosing continued storage) couples may feel they can avoid responsibility for the decision. In order to support couples in making the disposition decision, it is crucial to know who is at risk of experiencing difficulty with the decision and to understand couples' reasons for remaining passive.

Methodological issues have highlighted the importance of differentiating those with *extra* embryos from those with *surplus* embryos, and the need for a validated ED attitude measures.

The aim of the present thesis is to further investigate the factors associated with the difficulty of the decision by employing longitudinal as well as cross-sectional designs that include both quantitative as well as qualitative methods. Special emphasis will be given to patient characteristics, emotional aspects of the decision, couples' emotional response to and conceptualisation of their embryos while investigating potentially sensitive phases in the decision-making process. An embryo attitude measure will be developed and evaluated to systematically investigate this construct and differentiate groups accordingly.

Chapter 3: Pre-birth Characteristics and 5-year Follow-up of Women with Cryopreserved Embryos after Successful In Vitro Fertilisation Treatment

Introduction

Long-term embryo storage has been considered problematic because embryos that are kept in storage without any apparent plan for their future take-up resources (e.g., storage space, costs and energy) and may represent couples' difficulty with the decision (Hammarberg & Tinney, 2006; McMahon et al., 2003). Reasons for not using embryos for further family building have included satisfaction with family size (Bangsbøll et al., 2004; Hammarberg & Tinney, 2006; Newton et al., 2003), personal circumstances (e.g., age, finances, separation; Bangsbøll et al., 2004; Hammarberg & Tinney, 2006; McMahon et al., 2000), and a perceived inability to cope with the stress of further treatment (Cattoli et al., 2004; Hammarberg & Tinney, 2006; Lyerly et al., 2006; McMahon et al., 2000; Newton et al., 2003). It has been argued that couples keep embryos in storage long-term to procrastinate the decision (Pennings, 2000) or postpone it indefinitely (de Lacey, 2005; Nachtigall et al., 2005).

Overall, the ED decision has been described as emotionally (Duke et al., 2009; Fuscaldo, 2005; Fuscaldo et al., 2007) and morally difficult (Lyerly & Faden, 2007) as well as distressing (Fuscaldo, 2005; Hammarberg & Tinney, 2006; McMahon et al., 2000). Negative emotions occur at the time of decision-making (e.g., McMahon et al., 2000; Skoog Svanberg, Boivin, & Bergh, 2001) as well as post-decisional (e.g., de Lacey, 2005; McMahon et al., 2000; Skoog Svanberg, Boivin, & Bergh, 2001).

Many factors have been linked to decision-making though associations are not always consistent. In some studies (Burton & Sanders, 2004) age was positively related to decision-making, but others report no relationship (Burton & Sanders, 2004; Newton et al., 2003); prior treatment success has been linked to a greater response to clinic letters (Bangsbøll et al., 2004; Burton & Sanders, 2004; Oghoetuoma et al., 2000), or

lower likelihood of claiming *surplus* embryos (Newton et al., 2003). Beliefs about the embryos have been reported to influence decision-making in that embryos were frequently described as human beings (Lyerly et al., 2006; McMahon & Gibson, 2002; Nachtigall et al., 2005) that should either not be destroyed (Lyerly et al., 2006) or had to be destroyed in order to avoid dilemmas associated with donation to other couples (de Lacey, 2005; Hammarberg & Tinney, 2006).

While overall this research provides some evidence for the difficulty of the embryo decision-making context, two important aspects have received little attention. First, personality variables identified as relevant to decision-making have not yet been investigated in the embryo decision-making context. In other decision contexts, personality traits, for example, dispositional anxiety has been associated with risk avoidant decision-making (Maner et al., 2007) and low self-efficacy, which incorporates fear of being unable to make a good decision (Blais, 2001). An external locus of control has also been associated with lower preference for active involvement in decision-making processes (Hashimoto & Fukuhara, 2004; Schneider et al., 2006). Further, highly dependent individuals that are generally reliant on interpersonal relationships have been shown to be prone to feelings of helplessness, concerns about loss (Blatt, Zohar, Quinlan, Zuroff, & Mongrain, 1995), and feelings of guilt (Zuroff, Moskowitz, & Wielgus, 1983) when making a decision.

Second, studies have mainly used a cross-sectional design making it impossible to identify whether the psychosocial variables under investigation were predictors of longer storage times, a consequence of delayed decision-making, or both. Personality factors such as locus of control, dependency and anxiety have been shown to be constructs stable over time (Gatz & Karel, 1993; Lenzenweger, 1999; Lovibond,

1998; Smith & Dechter, 1991; Zuroff, Moskowitz, & Wielgus, 1983). The stability of these constructs is particularly important for the purpose of the current study where it was aimed to identify such characteristics early on in treatment, that is, during women's first IVF pregnancy, in order to predict who might need decision support five years later.

In the current chapter, the association between psychosocial factors and long-term embryo storage is investigated by comparing personality and relational variables assessed during women's first IVF pregnancy (time 1, T1) in women who still had embryos five years later (time 2, T2) to a cohort who had achieved a pregnancy through IVF at the same time, but who did not have embryos at T2. The analyses presented were carried out on data collected for a project on the transition to parenthood in women who had used fertility treatment to conceive. The original study was the first to follow IVF couples prospectively from pregnancy (see McMahon, Tennant, Ungerer, & Saunders, 1999; 1997). At a 12 month follow-up, unanticipated stress emerged among some parents regarding their stored frozen embryos and it was decided to further examine decision making and concerns regarding embryos at child age five years.

Method

Participants and recruitment

The final sample consisted of 66 women who were participants in a larger longitudinal Australian study of couples conceiving by IVF. All women had embryos created as part of their IVF treatment. Women were assigned to one of two groups according to their embryo status at T2, that is group Embryo-Storage (E-S) consisted

of women who had embryos in storage five years after their first pregnancy with IVF (n = 26, 39.4%). The remaining women either originally had embryos in storage, but had used them (n = 19; 28.8%) or did not report that they had ever stored any of their embryos (n = 21; 31.8%). There were no differences between the latter two groups on any study variables and they were therefore collapsed and assigned to the Cohort-Comparison group ('C-C' group: n = 40, 60.6%).

Women were recruited over a period of 18 months from an IVF unit. At the time of assessment women were 28 weeks pregnant (T1). Women in both groups met the following inclusion criteria: primiparous, singleton or twin pregnancy, 28 years or older, living with the father of the child, and English-language skills sufficient to complete the questionnaires. Additionally, both parents had to be genetically related to the child. The response rate was 80% (n = 70) of those invited into the study. Women were assessed again at child age five years (T2, N = 66; 94.3% of original sample).

The demographic and infertility characteristics of the final sample are shown in Table 3.1. The majority were White and from Australia or New Zealand, and at T1 women were in their mid thirties (range 28 - 42) and had been married for more than seven years (M = 7.45, SD = 5.35). The majority were educated to diploma or college/ university level. It took the majority of women over five years to have their first live birth through IVF, of which the majority were singletons. At T2, women had on average two children.

Table 3.1

Descriptive statistics for demographic variables and family history (N = 66)

Variables	
Demographics (T1)	
Age (M ± SD)	33.85 ± 3.03
Country of origin (% (n))	
Australia & New Zealand	63.6 (42)
United Kingdom	15.2 (10)
Europe (without UK)	13.6 (9)
Asia	7.6 (5)
Education (% (n))	
University/ College	38.5 (25)
Diploma/ Professional Certificate	30.8 (20)
5 – 6 years of Secondary School	12.3 (8)
3 – 4 years of Secondary School	18.5 (12)
Family and fertility history (T2)	
Number of years married (M ± SD)	7.45 ± 5.35
Number of children[1] (M ± SD)	1.86 ± 0.82
Time to first child (% (n))	
< 6 months	1.5 (1)
6 – 12 months	3.0 (2)
1 - 2 years	18.2 (12)
2 - 4 years	34.8 (23)
> 5 years	42.4 (28)
Singleton	78.8 (52)
Twins	18.2 (12)

Note. N varies between variables

[1] All women had at least one child

Materials

The study materials included information from medical records (T1), validated anxiety and personality scales, and a semi-structured face-to-face interview that was designed specifically for this study to assess aspects of the ED decision (see Appendix 2 for these materials).

Personality scales

Trait Anxiety Inventory (TAI: Spielberger, Gorsuch, & Luschene, 1970). Trait anxiety was measured using the 20-item Trait Anxiety Inventory that assesses feelings of tension, nervousness, worry and apprehension measured on a 4-point Likert-type scale (i.e., 1 = not at all, 2 = somewhat, 3 = moderately, 4 = very much) with total summed scores pro-rated to range from 20-80 where higher scores indicate more anxiety. The manual reports good test–retest reliability of the Trait anxiety scale ($r = 0.77$), and low test–retest reliability for the State scale ($r = 0.33$). However, the latter coefficient is expected given the transitory nature of state anxiety. The manual also provides evidence for construct validity of both scales.

Locus of Control of Behaviour scale (LCB: Craig, Franklin, & Andrews, 1984). The 17-item Locus of Control of Behaviour Scale was used to measure the extent to which individuals perceive events as being a consequence of their own behaviour and therefore being under their personal control, where high scores indicate an external locus of control. The 17-items are rated on a 6-point Likert scale (i.e., 0 = strongly disagree, 1 = generally disagree, 2 = somewhat disagree, 3 = somewhat agree, 4 = generally agree, 5 = strongly agree) with total summed scores pro-rated to range from 0-100 where higher scores indicate an external locus of control. The scale was

shown to have satisfactory internal reliability and construct validity, correlating substantially with Rotter's I-E General Expectancy Scale (r = 0.67) (Lovibond, 1998). The scale has been shown to have satisfactory internal reliability, construct validity, not to be related to sex, age or social desirability and to be stable over time.

Dependency and Relatedness (Blatt et al., 1995). The 10-item Dependency and Relatedness subscale of the Depressive Experiences Questionnaire (DEQ; Blatt, D'Afflitti, & Quinlan, 1976) measured the extent to which individuals are dependent on their interpersonal relationships on a 7-point Likert-type scale (i.e., 1 = strongly disagree, 7 = strongly agree) with total summed scores pro-rated to range from 20-80 where higher scores indicate more dependency. Items addressed concerns about abandonment, feeling helpless, a need to be close to and dependent upon others, and a fear of separation, loss and rejection (Blatt et al., 1995). The internal reliabilities of the DEQ have been reported to be adequate, with a coefficients ranging from 0.78 to 0.86 for the two main factors (Viglione, Clemmey, & Camenzuli, 1990). Construct validity was demonstrated to have test– retest correlations of 0.89 and 0.81 for dependency (Zuroff, Moskowitz, Wielgus, Powers, & Franko, 1983). These scales are widely used and have been shown to have content, criterion-related, and construct validity and internal reliability (Cronbach's $\alpha = 0.96$).

Interview

At T2 women were interviewed by a member of the research team when they attended the laboratory for a 5-year follow up appointment. Women were asked about their reproductive experiences between T1 and T2, details of further treatment (e.g., number of treatment cycles), subsequent pregnancies and births (naturally or with IVF), current family composition, satisfaction with family size and future

childbearing intentions. Interviews were audio-taped and transcribed, and all scoring of responses was done from the transcripts. A semi-structured interview was used because of the exploratory nature of the study and the personally and emotionally sensitive topic. In addition, semi-structured interviews provide the flexibility and sensitivity necessary to capture the range of possible responses. Women were also asked if they viewed their cryopreserved embryos as a sibling to an existing child, and how frequently they thought about their embryos with response options 'not at all', 'occasionally', and 'preoccupied'. Women indicated the likelihood of various disposition options (donate to research or other couples, use themselves or discard), and whether they would postpone the embryo disposition decision with options including 'no postponement', 'will decide soon', and 'postpone as long as possible'.

Procedure

At T1 questionnaires were mailed to the mothers and collected at the time of a laboratory visit. At T2 women were given the questionnaires as part of a face-to-face semi-structured interview. At T1 and T2 women completed independent batteries of questionnaires. At the time of assessment the Australian legislation allowed storage for a maximum of 10 years (National Health and Medical Research Council, 1996b; Reproductive Technology Accreditation Committee, 2002). Couples received a letter after 3 years, asking them to make a decision and annual reminders thereafter. An annual storage fee was paid for continued embryo storage. The study received ethical review and approval from the Human Research Ethics Committee at Royal North Shore Hospital, St Leonards, New South Wales (Australia).

Data analysis

Data were analysed using univariate and multivariate analyses. At a univariate level non-parametric categorical and nominal variables were examined using Chi-square tests (using Fisher's exact probability where appropriate), whereas parametric interval data was examined using t-tests. In light of the multiple tests, two approaches were used to minimise the risk of alpha inflation. First multivariate analyses of variance (MANOVA) were carried out on related sets of variables (i.e., demographic characteristics, relational variables, personality variables) and univariate tests were only examined when the multivariate test was significant according to the method of Tabachnik & Fidell (1997). Second, where MANOVA was inappropriate Bonferroni adjusted probability values were used. A standard discriminant analysis was then computed using those predictor variables that showed univariate significance or marginally significant differences between the E-S and C-C groups. The subject to variable ratio in the discriminant analysis was 10:1 which is acceptable for this type of analysis (Tabachnik & Fidell, 1997). Discriminant analysis summarises the pattern of intercorrelations among predictor variables by extracting independent dimensions that maximally differentiate between the groups. In the case of two groups only one dimension can be extracted and loadings on this dimension are an indication of the strength of association between an individual predictor and the dimension that differentiates the group after controlling for all other factors. As such the loadings act as effect size measures and loadings above 0.30 are considered significant (Tabachnik & Fidell, 1997). The level of significance was $p < .05$.

Results

Demographics

Table 3.2 shows the demographic characteristics of the E-S and C-C groups. The MANOVA was significant (multivariate F (2, 63) = 7.4, $p < .001$; Wilks $\lambda = .81$).

Follow-up univariate F-tests showed that women in the E-S group were significantly younger (F (2, 63) = 12.4, $p < .001$; Wilks $\lambda = .81$) and had been married for fewer years (F (2, 63) = 3.85, $p < .05$, Wilks $\lambda = .81$) than the C-C group.

In the E-S group one woman was more than 37 years old, whereas 32.5% (n = 13) in the C-C group were in this age group. Groups differed on education, $\chi 2$ (3) = 7.93, p = .047, with more women in the E-S group having a diploma or university degree (76%). Groups did not differ on country of origin, $\chi 2$ (11) = 11.47, p = .41, with the majority being born in either Australia or Great Britain (78.8%).

Reproductive and treatment experiences

The groups did not differ on time trying to get pregnant with their first IVF child which took the majority more than five years (E-S: 45.5% (n = 18); C-C: 38.5% (n = 10)). The MANOVA on reproductive and treatment variables showed a significant result (multivariate F (4, 56) = 2.84, p = .032; Wilks $\lambda = .84$). Follow-up univariate F-tests showed that women in the E-S group had significantly more children at T2 than the C-C group (F (2, 56) = 7.99, p = .006; Wilks $\lambda = .84$). Groups did not differ significantly on number of treatment cycles or percentage of singletons (81.8%) versus twins (18.2%) (χ^2 (1) = 2.20, p = .14) (see Table 3.2).

Table 3.2

Demographics (T1), reproductive and treatment experiences (T2) according to group E-S and C-C (N = 66)

Variables	Embryos Storage E-S (n = 26)	Cohort Control C-C (n = 40)	t / χ^2
Demographics (T1)			
Age (M ± SD)	32.35 ± 2.04	34.82 ± 3.19	3.52**
Country of origin (% (n))			11.47
Australia & New Zealand	65.4 (17)	62.5 (25)	
United Kingdom	15.4 (4)	15.0 (6)	
Europe (without UK)	19.1 (5)	10.0 (4)	
Asia	-	12.5 (5)	
Education (% (n))			7.93*
University/ College	28.0 (7)	45.0 (18)	
Diploma/ Professional Certificate	48.0 (12)	20.0 (8)	
5 – 6 years of Secondary School	16.0 (4)	10.0 (4)	
3 – 4 years of Secondary School	8.0 (2)	25.0 (10)	
Years married (M ± SD)	5.89 ± 2.89	8.47 ± 6.3	1.96*
Reproductive and treatment experiences (T2)			
Number of children (M ± SD)	2.15 ± 0.88	1.65 ± 0.73	2.46*
Total number of pregnancies (M ± SD)	2.12 ± 1.03	1.73 ± 1.45	1.17
Total number of treatment cycles (T1–T2)[1] (M ± SD)	4.96 ± 5.29	5.18 ± 4.68	0.17
Number of currently frozen embryos (M ± SD)	5.27+3.16	-	-

Note. * $P < 0.05$. ** $P < 0.001$.
[1] Treatment cycles include only IVF (using fresh and frozen embryos).

More women in the C-C than E-S group expressed dissatisfaction with their family size (46% versus 27%, respectively) in that they would like to have more children, but the difference was not significant (χ^2 (1) = 5.30, p = .15). The E-S group had an average of 5.27 (SD = 3.16, range = 1–13) embryos currently in storage.

The majority of E-S women reported thinking about their embryos occasionally (61.5%, n = 16) and 34.6% reported being preoccupied with their embryos (n = 9). Almost all women in this group, 88.5% (n = 23), considered the embryos as potential siblings to existing children. Overall 42.3% (n = 11) of E-S women indicated that it was possible or probable that they would donate to research, and 26.9% (n = 7) considered donation to other couples. A total of 42.3% (n = 11) planned to use embryos in subsequent treatment and 30.8% (n = 8) wanted to discard the embryos (multiple answers were possible). Only 34.6% (n = 9) of women in the E-S group indicated they would make a final disposition shortly, with 65.4% (n = 17) reporting they would postpone the decision as long as possible.

Personality traits (T1)

Table 3.3 shows descriptive and inferential tests for personality traits. A MANOVA was computed on personality characteristics and was marginally significant (F (3,51) = 2.31, p = .087; Wilks λ = .88) with women in the E-S group showing a more externally oriented locus of control compared to the C-C group. The E-S group also showed higher dependency scores on the Blatt et al. (1995) questionnaire. The groups were similar on trait anxiety.

Table 3.3

Mean and standard deviation for personality characteristics according to group E-S and C-C (N = 66)

Variables	Embryo Storage E-S (n = 26)	Cohort Control C-C (n = 40)	t-test (df = 53)
Locus of control of behaviour (LCB)	29.8 ± 7.39	25.28 ± 9.01	2.07*
Trait anxiety (TAI)	37.0 ± 9.74	34.52 ± 8.79	1.05
Dependency (DEQ)	36.08 ± 5.79	32.94 ± 4.26	2.42*

Note. * $P < 0.05$

Factors differentiating E-S and C-C groups

Discriminant analysis was used to investigate to what extent the T1 variables that differentiated the E-S and C-C groups represented unique or overlapping features differentiating the groups (see Table 3.4). Based on the significant univariate results the variables entered into the discriminant analysis were: female age, years married, number of children at T2, locus of control and dependency (variables showing significant or marginally significant between-group differences). Table 3.4 shows the pooled within-groups correlations (i.e., loadings) for the significant discriminant function (χ^2 (5) = 15.51, p = .017). As shown, all variables remained significant when considered as a group, and together explained 27% of the between-group variance.

Group centroids showed that the E-S group scored significantly higher (centroid = .722) on the discriminant function than did the C-C group (centroid = -.497). The loadings showed that a higher score on the function that discriminated the groups was associated with younger age, fewer years living together, more children at T2, a more external locus of control and higher dependency.

Table 3.4

Pooled within-groups correlations coefficients (loadings) (N = 66)

Variables	
Demographic	Loadings
Age	-.72*
Years married	-.43*
Number of children (T2)	.46*
Psychological	
Locus of control of behaviour (LCB)	.50*
Dependency (DEQ)	.47*

Only loadings > .30 were considered significant (Tabachnik & Fidell, 1997)

Discussion

Five years after a successful IVF treatment cycle, 58% of women still had embryos in storage and a significant proportion of these women were preoccupied with their embryos and wanted to further postpone decision-making about their fate. The secondary analysis of the prospective data demonstrated that retaining embryos could be indicative of decisional avoidance, which in turn, could be ascertained from demographic factors and personality traits assessed at the start of treatment. The results demonstrated a need for decisional support in women undergoing IVF.

The exploratory analyses showed that those women who had embryos in storage five years after conceiving their first IVF child had a different demographic and psychological profile. This group of women were at an earlier reproductive life stage in that they were on average 2.5 years younger, they had been married for fewer years than the control group, and they had been more successful with IVF treatment in that they had more children than the control group. As such women may have been more hesitant to make decisions about embryos that they could (in theory) use for further family building even if they did not necessarily want more children (i.e., more children and less family-size dissatisfaction than C-C group).

Women who still had embryos in storage also showed a more externally oriented personality profile. People with an external locus of control indicated by high scores on the Locus of Control Behaviour Scale perceive themselves as having little control over their behaviour, for example they tend to think they cannot control their problems (Craig et al., 1984). Thus it may be that women in the E-S group generally relied more on external support provided by physicians, family and friends when

coping with a health decision, and this tendency would extend to the disposition decision context. Together the findings suggested that the ED decision is not just dependent on identifying the best disposition option but also dependent on reproductive life stage and personality traits.

Reproductive life stage and personality traits were shown to independently differentiate the E-S group from the remaining women who started treatment at the same time and these factors may influence decision-making about cryopreserved embryos via different pathways. Younger couples may not yet have achieved their desired family size, and their age would allow them to extend their family further. Family size was also found to be an important determinant in other studies with patients who had a successful delivery (Bangsbøll et al., 2004) or who had completed their family (Newton et al., 2003) being more likely to not claim their cryopreserved embryos. However, in the current sample E-S women were good *responders*, that is, they responded well to IVF treatment resulting in an average of two children which satisfied their family building needs. Nevertheless, 40% stated they would consider using their cryopreserved embryos in further treatment. This juxtaposition of good response to IVF treatment and concurrent satisfactory family composition at an earlier reproductive life stage in the E-S group may make the decision to use (or relinquish) embryos particularly difficult because it would require women to close off the possibility of having more children when it was still biologically possible, though not necessarily desired. In addition, the burden of continued fertility options may have been lesser in the C-C group where 30% of women were more than 37 years old.

Personality traits may exert their influence through factors that have the potential to influence any life decision. People who experience decisional conflict in other

contexts, for example whether or not to use contraception (Hendricks & Fulliove, 1983; McDonald, 1970; Plotnick, 1992) or deciding to seek fertility treatment when problems arise (White, McQuillan, Greil, & Johnson, 2006) have been shown to share similar characteristics to the profile found in the E-S group. For example, it was found that people with an external locus of control are less likely to use contraceptives (Hendricks & Fulliove, 1983), whereas those with an internal locus of control are less likely to seek fertility treatment when problems arise (White et al., 2006). The current findings would concur with these general observations in that those who still had embryos many years after treatment were more externally oriented. Results from the two personality scales are suggestive of individual differences in autonomy and assertiveness.

Items on the dependency measure, for example, assess the extent to which individuals are concerned about abandonment, and inclined to feel helpless and want to be dependent upon others for their well-being (Blatt et al., 1995). Similarly, an external locus of control indicates a tendency to view events as controlled by external rather than internal causes. Autonomy and assertiveness may facilitate decision-making in challenging situations so that individuals who are less autonomous and assertive may be more inclined to postpone decision-making, and be in greater need of external guidance and support. In the current sample age and dependency [$r(60) = -0.318$, $p = 0.013$] were negatively correlated so that maturational factors may also play a part.

Another factor that may influence decision-making is attitude towards the embryo. The current results were consistent with previous studies demonstrating that people conceptualise their embryos as siblings to their already existing children (de Lacey,

2005; Elford et al., 2004; Hammarberg & Tinney, 2006). This type of conceptualisation was evident in the E-S group where 88.5% of patients referred to their embryos as real persons. This human conceptualisation of the embryo has been associated with discarding or freezing the embryos indefinitely (Lyerly et al., 2010) and with making the decision-making process more difficult (Lyerly et al., 2006). Although it cannot be ascertained from the design of this study whether such factors were pivotal in decision making, the results were consistent with previous studies showing that conceptualisation of the embryo as a potential child or sibling is associated with long storage duration (Lyerly et al., 2006; Nachtigall et al., 2005).

The strengths of this study included the prospective design with personality variables measured prior to the birth of the first child. The participation rate was high (80%) and the attrition rate over the 5-year follow-up period was relatively low (20%) so that the final sample can be considered representative of the cohort of women conceiving with IVF. The multifactorial assessment battery included both reliable and valid questionnaires and face-to-face interviews. A further strength was the homogeneity of the sample with respect to parity, education, and time to conceive the first child.

There were several substantial limitations. First the small sample size, which meant less than ideal power to detect group differences. A second important limitation was the composition of the cohort comparison group. This group included women who had started treatment at the same time as the E-S group and that comprised of women who had previously made an embryo disposition decision and women who had never had cryopreserved embryos. These groups were combined because they did not show marked differences on target variables and because pooling increased power for group comparisons and the participant-to-variable ratio for the multivariate analysis. More

fine-grained comparisons with the individual groups could allow for stronger conclusions to be drawn and therefore, the current approach can only allow general statements to be made about women who still had embryos many years after the initiation of fertility treatment. However, the prospective data in this exploratory study provided a useful starting point for future studies on the ED context and for informing decision support.

Conclusion

In conclusion, women who still have embryos many years after fertility treatment may have a psychosocial profile suggestive of decisional avoidance, where the most crucial differentiating factors are reproductive life stage, autonomy and assertiveness and to a lesser extent, conceptualisation of the embryo. Thus, women who have already satisfied their family building needs, have dependent personality traits and who conceptualise their embryos as siblings to their children may have a more difficult time making the embryo disposition decision. Consequently, this group may be in greater need of external support. In the context of embryo disposition, external support is commonly provided within the infertility clinic by health professionals (consultants, embryologists, infertility nurses). By identifying characteristics that are unique to patients who retain embryos many years after treatment an important step has been made towards tailoring patient support o the specific needs of patients in the ED context.

Chapter 4: Correlates of Decisional Conflict and Foundational Research for an Embryo Representation Scale

General Introduction

Past research has shown that many couples are able to make the embryo disposition decision, but a substantial number either leave their embryos in storage with no apparent plans for future treatment, often beyond the statutory storage limit (Brzyski, 1998) or do not reply to clinic letters requesting a disposition decision (between 39 - 62%; see Table 2.3a & b, page 25-26). The lack of directive from couples leads in many cases to the destruction of embryos. Recent figures indicate that the number of embryos in storage in the UK might still be growing with about 16,000 more embryos being stored annually than thawed (see Figure 2.1, page 13) (R. Martin, personal communication with the Human Fertilisation and Embryology Authority, UK March 16, 2009). In such cases, clinics are confronted with the dilemma of what to do with unclaimed *surplus* embryos.

The term *surplus* has been used to refer to a heterogeneous group of cryopreserved embryos. In some studies, the term *surplus* is used to refer to *any* cryopreserved embryos created at the time of treatment regardless of whether the couple eventually personally use them in subsequent transfers (Newton, Fisher et al., 2007). In other studies, *surplus* refers only to embryos that are no longer required for personal use typically because the couple has achieved their desired family size (Hammarberg & Tinney, 2006; Porz et al., 2008). Although in both situations couples have *extra* embryos, it has been argued that the disposition decision context is not the same when couples personally use *extra* embryos than when they need to decide on another disposition option (e.g., discard, donate, continue storage; Nachtigall et al., 2009). However, existing studies have not differentiated these decision contexts when investigating factors associated with embryo disposition (Lyerly et al., 2010; Newton,

McBride, Feyles, Tekpetey, & Power, 2007; Provoost et al., 2009; Zweifel et al., 2007). In the present study decisional factors were examined in groups that intended or did not intend to use cryopreserved embryos for personal use.

The lack of action on the part of individuals having *extra* embryos has been taken to reflect the difficulty of the embryo disposition decision (Fuscaldo et al., 2007; Hammarberg & Tinney, 2006; Nachtigall et al., 2005; Nachtigall et al., 2009) with the degree of difficulty described as ranging from *rather easy* to *extremely difficult* (Fuscaldo et al., 2007; Hammarberg & Tinney, 2006; Hug, 2008; Nachtigall et al., 2009). Factors that have been associated with the difficulty of the ED decision have included having experienced a live birth from treatment (Fuscaldo, 2005), a deeply personalised conceptualisation of the embryo (Nachtigall et al., 2005; Nachtigall et al., 2009), long embryo storage (McMahon et al., 2003), lack of trust in the clinic, a perceived lack of adequate information, support and/ or acceptable disposition options (Lyerly et al., 2004; Lyerly et al., 2006).

Decisional difficulty is manifested in the construct of decisional conflict, a state of uncertainty about the most superior course of action, and refers to the difficulty of choosing between options and their potentially undesired consequences (O'Connor, 1995). People are most likely to experience decisional conflict when making choices including risk or uncertainty about outcomes, especially when potentially high gains and losses are at stake and anticipated regret over rejected options is experienced (O'Connor, 1995). Decisional conflict is theoretically linked to decision avoidance as described in the Rational-Emotional Model of decision avoidance (Anderson, 2003). This model postulates that action (decision-making) is avoided or deferred when people experience or anticipate negative emotions (e.g., anxiety, regret) when

selecting the most superior option. Similarly, decision makers who experience high decisional conflict delay decision-making and experience feelings of uncertainty about decision implementation (O'Connor, 1993). According to Anderson (2003), this is especially the case when the decision is irreversible because active decision-making is associated with being responsible for the decision outcome.

The aim of the present study was to better understand the nature of the disposition decision context by investigating the association between demographic, fertility and decision-making factors and decisional conflict in women who intended to use their *extra* embryos versus those who had *surplus* embryos that were not intended for personal use. This aim was achieved using a mixed method design that included a cross-sectional survey with validated scales and closed-ended questions for quantitative data collection and open-ended questions to collect qualitative data.

This 'triangulation design' was employed because of the nature of the research questions which was to quantify the occurrence of decisional conflict in the ED decision-context and its correlates as well as explore in greater depth couples' cognitive embryo representations (e.g., their thoughts, beliefs, and perceptions of embryos) and affective embryo representations (e.g., their feelings towards embryos). Triangulation is the method of combining different kinds of research data (here, qualitative and quantitative) in order to ascertain whether they corroborate one another (Silverman, 2006). It has been argued that this approach increases the validity and reliability of findings in that the strength of one methodology can overcome the weakness of the other and vice versa (Cunningham, Young, & Lee, 2000). The methods and results from the two parts of the study are reported sequentially with the

quantitative data being presented first (Chapter 4 Part I) followed by the qualitative data (Chapter 4 Part II).

One difficulty in embryo disposition research is the recruitment of participants because regular contact between clinic and patients with/ without embryos does not necessarily exist especially when patients have no intention for further treatment. Therefore, participants were recruited via the internet. One advantage of research via the internet is that it extends researcher's access to people who are geographically distant and/ or hard to reach (Mann & Stewart, 2001). Over the last decade or so the internet has increasingly become a platform for people searching for health information, health care services and support when faced with a medical issue (Bauerle Bass, 2003; Eysenbach, 2000) including infertility treatment and its outcomes (Bunting & Boivin, 2007). Couples from all socioeconomic backgrounds have been shown to use the internet for fertility-related issues and decision-making (Weissman, Gotlieb, Ward, Greenblatt, & Casper, 2000) with women being more active users than men (Haagen et al., 2003). For the current study this search activity was used to recruit two groups of women: those who had *surplus* embryos because they did not intend to use their embryos for personal use and those who had *extra* embryos that were intended for their own treatment. Participants completed an online Embryo Disposition Survey (EDS) and decision and anxiety scales to assess the disposition decision context, embryo representations, decisional conflict and mood.

Part I: Factors Associated with Decisional Conflict (Quantitative Analysis)

Introduction

The empirical literature on decision-making in embryo disposition supports the theoretical assumptions underlying decisional conflict and decisional avoidance. First, embryos are perceived as highly valuable (de Lacey, 2009; Provoost et al., 2009) and their disposition accompanied by uncertainty about the most superior disposition option (Lyerly et al., 2004; Nachtigall et al., 2005) as well as regret at the time of decision-making and beyond (de Lacey, 2005; McMahon et al., 2000; Provoost et al., 2009). Second, couples who experience strong negative emotions when choosing the best disposition option have been shown to experience more difficulty making a decision (McMahon et al., 2000; Nachtigall et al., 2005). As a consequence of difficulty people may be indecisive, postpone the decision and experience emotional distress as they attempt to solve the decision problem, resulting in high decisional conflict (O'Connor, 1999). Third, feelings of strong responsibility towards the embryos can also cause emotional distress and hinder the decision-making process (Cattoli et al., 2004; Lyerly et al., 2006; Nachtigall et al., 2005). The desire to avoid taking responsibility has been shown to result in patients not responding to disposition requests made by the clinic with the consequence that clinics had to make the decision for the couple (Dawson, 1997).

In part I of the present chapter, participants were differentiated as to whether they intended to use their embryos for further treatment or not in order to investigate group differences on factors associated with the ED decision (e.g., demographic and fertility characteristics, ED context variables, and factors associated with the ED decision).

The Decision Conflict Scale (O'Connor, 1993) was adapted to examine this construct in people deciding about the fate of their embryos by investigating the extent of decisional conflict according to group and its association with psychological and emotional variables.

It was hypothesised that women who had *surplus* embryos that were not intended for personal use would experience more decisional conflict and negative emotions and would be in greater need of emotional and decisional support than those who had *extra* embryos that were intended for their personal needs.

Method

Participants and recruitment

The final sample consisted of 159 women who currently had stored cryopreserved embryos as a result of infertility treatment.

Respondents were assigned to one of two groups according to their intended plans for ED. The "Personal-use" group (n=115, PU) comprised women who had *extra* embryos that were not surplus to personal needs because participants intended to use them for their own treatment. The "No Personal-use" group (n=32, NPU) included women who had *surplus* embryos because they had no intention to use them in a future embryo transfer.

Women were recruited online via websites for people with fertility problems. Over a 24-week period, from February 2008 through July 2008, the study was posted online. The exclusion criteria were (1) women who no longer had embryos in storage (n=33) and (2) men were excluded because they were too few to be analysed (n=10). Women

who were undecided as to whether they intended to use their embryos for future pregnancy attempts (n=12) were excluded from the quantitative part of the analysis because they could not be assigned to one of the decision groups.

The demographic and infertility characteristics of the final sample are shown in Table 4.1. The majority were White and from North America. Women were in their mid thirties (range 22-55), the majority were in a partnership (n = 144; 90.6%) and had been living with their partner for about 10 years (M = 10.29, SD = 4.6). The majority were educated to college or university level and had on average one child (including adopted and step-children).

About a third of women (n = 57; 39.9 %) had difficulty getting pregnant because of female factor infertility, 36 (25.2 %) male factor infertility, 29 (20.3 %) combined male and female factor infertility and 21 (14.7 %) had unexplained infertility. Forty-two (26.4 %) women had primary infertility, that is, they had never experienced a pregnancy. Women had been trying to conceive for 4.4 years (SD = 2.89, range < one to 17 years), and their last cycle that resulted in cryopreserved embryos was 1.47 years ago (SD = 1.82). About a third of the sample said they were currently in treatment (37.3%, n = 59).

Table 4.1

Descriptive statistics for demographic variables and family history (N = 159)

Variables	
Demographics	
Age (M ± SD)	35.95 ± 6.0
Ethnicity (% (n))	
White	88.7 (141)
Asian	3.8 (6)
Latin-American	3.1 (5)
Black	1.9 (3)
Other	2.5 (4)
Country of origin (% (n))	
United States	58.2 (82)
United Kingdom	13.5 (19)
Australia	13.5 (19)
Canada	12.1 (17)
Other	2.8 (4)
Education (% (n))	
University	69.8 (111)
Post-Secondary/College	22.6 (36)
Secondary School	4.4 (7)
Primary School	3.1 (5)
Family history	
Number of years living with partner (M ± SD)	10.29 ± 4.6
Women who have children (% (n))	60.4 (96)
Number of children (M ± SD)	1.73 ± 0.81
Discrepancy between number of children wished for and current number of children (includes women without children)	1.49 ± 1.01

Note. N varies between variables

Materials

The study materials included the Embryo Disposition Survey (EDS) that was designed specifically for this study to assess aspects of the ED decision and decisional factors. Participants also completed validated decision and anxiety scales to assess decisional conflict and to assess mood during survey completion (State-Trait Anxiety Inventory, Marteau & Bekker, 1992; Decisional Conflict Scale, O'Connor, 1993; Choice Predisposition Scale, O'Connor, 1996; see Appendix 3 for these materials).

The study materials were transferred online using Survey Tracker®, a software that allows the design of web-based questionnaires as well as the recording and storing of participant data.

Embryo Disposition Survey

The quantitative part of the EDS addressed issues relevant to decision-making in the context of ED as identified in theoretical work and the empirical literature. For the purpose of this study, only questions asked of women who still had cryopreserved embryos are described. Pilot work that informed the content of the EDS was carried out including stakeholder consultation (embryologists and consultants in obstetrics and gynaecology) in an assisted reproduction unit. The EDS comprised 91 questions in four sections: 1) Demographic and fertility characteristics, 2) Issues related to cryopreserved embryos, 3) ED decision context, and 4) Factors contributing to ED decision-making.

Demographics and fertility history

Demographic characteristics included current country of residence, age, highest educational qualification (i.e., primary school, secondary school, post-secondary school/college or university), number of years living with partner, parity (have delivered, yes or no), and number of children from previous relationships (including adopted and step-children).

Number of years trying to conceive was recorded as well as number of live births, pregnancy failures (i.e., miscarriage, ectopic pregnancy, abortion) and adoptions. Further, past outcomes of treatment using fresh or cryopreserved embryos was recorded, the number of children wished for and the duration of fertility treatment were assessed. In addition, the reasons(s) for the fertility problem (i.e., normal or unexplained infertility, endometriosis, no ovulation, other hormonal problem, blocked tubes, problems with sperm, tubal sterilisation, vasectomy, age, social reasons, or other) were reported.

Issues related to cryopreserved embryos

The number of cycles with cryopreserved embryos and the number of cryopreserved embryos was recorded. Further, the point in time of storage initiation and storage end was asked (months, years), and frequency of receiving and replying to clinic letters regarding stored embryos was assessed (once every six months, once a year, less often than once a year, I don't know).

Conceptualisation of the embryo was assessed using eight items developed specifically for this study that inquired to what extent participants' perceived the embryo as a human being (e.g., my frozen embryos are: like a child, a bunch of cells,

part of my family etc.). Responses were assessed on a five-point Likert scale ranging from 1=strongly agree to 5= strongly disagree. Scores were averaged and two were reversed so that higher scores indicated stronger human conceptualisation.

Finally, frequency of thinking about the cryopreserved embryos was determined using a 4-point Likert-type response scale (1 = never, 2 = sometimes, 3 = often, 4 = all the time).

Embryo disposition decision context

The timing of the ED decision relative to the treatment process was reported. The response options were: at consent, when embryos were created, after transfer, when the clinic got in contact, when the storage period ended or when treatment was finished. Moreover, the type of disposition options available to the participant was ascertained using a structured checklist of seven options (e.g., donation to research, donation to another couple, thawing/discarding, continued storage etc.), where multiple answers were possible. Scores were averaged and ranged between zero and six-with higher scores indicating more disposition options available. Further, a final open-ended question was used to identify participants' most superior disposition option and the reason for this choice.

Women rated their preferred role in the decision making process (e.g., I would like to make the decision myself or with my partner) using a five point agreement scale. Agreement was also rated for a set of 15 apprehensions regarding decision-making generated for the present study based on concerns identified from the empirical literature and stakeholder consultations (e.g., I am uncertain about which option to chose, I am not sure if I want to try for more children, I feel worried that I might

regret the decision later) using a 5-point Likert scale (1 = strongly agree to 5 = strongly disagree). Responses were averaged across items and reversed so that scores would range from one to five with higher scores indicating more decision apprehension.

Factors contributing to ED decision-making

The importance of four independent factors contributing to decision-making that were identified in the empirical literature (financial situation, size of family, personal values, and conceptualisation of the embryos) was rated on a series of 15-point Likert-type response scales ranging from 1 = not at all important to 15 = very important.

The type of information and support that women received or would have wanted to receive was assessed via four items on information (e.g., information on procedures involved in each option) and four items on support (e.g., discussion with family). The response scale was "I have received/done it already" or "I would like to receive/do it". A total score was calculated across the items by reversing scores and computing an average so that scores would range from zero to one with higher scores indicating more need for information and support. Helpfulness of the information/support was rated on a 5-point Likert-type response scale (1 = not at all, 2 = a little, 3 = moderately, 4 = very much, 5 = extremely). Responses were averaged across items on information and items on support separately where scores would range from one to five. Further, a list of five items on the type of support that would help decision-making (advice from a doctor, counselling, talking to others in the same situation, talking to my partner, talking to my family/friends) was assessed (yes or no).

Decision and anxiety scales

Choice Predisposition Scale (CPS: O'Connor, 1996): The CPS was adapted to the ED context and was used to assess what O'Connor (1998) refers to as *leaning towards* any of the four most common disposition options (e.g., donation to research, donation to another couple, thawing and disposal, and continuation of storage) at the time of their participation. The response scale for the CPS is a 15-point Likert-type response scale ranging from 1 = no, I don't want to (in this study: donate, thaw/dispose, or continue storage) to 15 = yes, I want to (donate, thaw/dispose, or continue storage). In past research the CPS showed good test-retest reliability (coefficients >0.90), and correlated moderately with the related construct of value congruency, which is to what extent the selected option is in line with the values of the decision-maker (r=0.4-0.56) (O'Connor et al., 1998).

Decisional Conflict Scale (DCS: O'Connor, 1993): The DCS was adapted to the ED context in order to assess decisional conflict. Four of the five subscales of the DCS comprising a total of 16 items were used in this study. These assessed 1) uncertainty in choosing options (e.g., I feel sure about what to chose), 2) feeling uninformed (e.g., I know which options are available to me), 3) feeling unclear about personal values (e.g., I am clear about which benefits matter most to me), and 4) feeling unsupported in decision-making (e.g., I have enough support from others to make a choice. Subscale five was not used because it covers post-decisional processes and was therefore not applicable to the study population. Responses were rated on a five-point Likert scale ranging from 0 = strongly agree to 4 = strongly disagree. Responses were averaged across items and multiplied by 25 so that scores could range from 0 to 100, with higher scores indicating more decisional conflict. In past work a score less than

25 was associated with implementing decisions, whereas a score exceeding 37.5 was associated with decision delay and feeling unsure about implementation (O'Connor, 1993). The DCS has shown good test-retest reliability (coefficient = 0.81), internal consistency (coefficients 0.78 - 0.92) and construct validity in regard to related constructs of knowledge, regret and discontinuance (O'Connor, 2005). The scale appears to have predictive validity in that for every unit increase in the DCS, people are 59 times more likely to change their mind and 23 times more likely to delay their decision (Sun, 2005). Effect sizes range between 0.4 – 0.8 for discrimination between those who make and those who delay decisions (O'Connor, 2005).

Short form of the state scale of the State-Trait Anxiety Inventory (STAI: Marteau & Bekker, 1992). The short form of the STAI was administered at the beginning and end of the survey to assess state anxiety. It consists of 6 items (e.g., I feel tense) assessed on a 4-point Likert-type response scale (i.e., 1 = not at all, 2 = somewhat, 3 = moderately, 4 = very much) with total summed scores pro-rated to range from 20-80 where higher scores indicate more anxiety. The six-items STAI short form has shown good reliability ($\alpha = 0.82$) and good consistency between the mean scores obtained from the original (20 items) and the short-form of the STAI (Marteau & Bekker, 1992). In the present study reliability was $r = .87$ prior to and after survey completion. External validity was tested by comparing the results of the current study with those of women receiving an abnormal pregnancy screening result showing no differences, $t(169) = 0.68$, $p > .05$.

Procedure

Webmasters at eight websites targeting people with fertility problems were contacted via email to ask whether they would post the study on their site. The study was placed

on the six sites that replied (www.theafa.org, www.icsi.ws, www.infertilitynetworkuk.com, www.iaac.ca, www.access.org.au, www.resolve.org) and in one forum concerning infertility support (the Infertility Support Group on Facebook). A link to the survey was either posted on the website or was sent to members via a newsletter. Clicking on the link took participants to a consent form and description of the content of the questionnaire. Questions were presented in sections and took about 15-20 minutes to complete. Throughout the questionnaire participants had the option to click out and close the window with no data being submitted. The Ethics committee of the School of Psychology, Cardiff University approved this research. The survey was anonymous. The study was posted for a 15-week period.

Data analysis

Preliminary data screening produced ten participants who were excluded from the analysis due to incomplete (> 50% of data missing) or invalid data

Data were examined to determine suitability for univariate and multivariate analyses. Outliers (number of currently stored embryos, n = 3; years since last frozen cycle, n = 2) were set to one unit greater than the next highest value in the distribution for their group (i.e., winsorised).

Raw values are presented in tables, but for analytic purposes extreme skewness (≥ 2.58) was reduced using square-root, logarithmic or inverse transformations depending on the relative skewness of the variable (Tabachnik & Fidell, 1997). For this purpose square-root transformation was used in a) number of children (among entire sample), b) number of embryos ever cryopreserved, c) leaning towards donation to another couple, and d) decisional conflict that improved normality (improved

skewness to a) 2.05, b) 1.52, c) 1.72, d) 1.77). Further logarithmic transformations were used to reduce skewness for a) number of children (among those who have children only), b) number of years in treatment, c) number of currently cryopreserved embryos, d) number of years since last frozen cycle, and e) number of years to storage end. Skweness was improved to a) 1.31, b) 1.66, c) 0.93, d) 1.26, and e) 1.79. Inverse transformation was used to reduce skewness for a) number of live births, b) number of cycles with frozen embryos, c) leaning towards thawing/discarding the embryos with skewness being reduced to a) 1.0, b) 5.68, and c) 4.0. The combination of differently transformed variables in multivariate analyses is commonly used in order to ensure that each variable is re-expression (transformed) in a way that is most likely to achieve linear relationships with the dependent variable according to the method of Tabachnik and Fidell (1997).

Two factor analyses were carried out to combine interrelated items. The first factor analysis was computed on the list of eight items concerned with embryo conceptualisation, and the second factor analysis was computed on the 15 apprehensions regarding ED decision-making. For both factor analyses, varimax orthogonal rotation was used. Loadings above .30 were considered significant as per Tabachnik & Fidell (1997).

Ethnicity, country of origin, and education were categorical variables with more than two levels. In order to analyse them in a regression, they were meaningfully reduced to two levels. This resulted in white versus other for ethnicity, US versus other for country of origin, University versus other for education, every 6 months versus less often for frequency of clinic letters, and self versus other for women's preferred role in the decision-making process.

At the univariate level, group differences were examined using chi-square tests (for non-parametric categorical and nominal variables) and t-tests (for parametric interval data). In order to minimize alpha inflation, multivariate analyses of variance were carried out on related sets of variables (i.e., factors contributing to decision-making) with follow-up t-tests carried out only when the multivariate test was significant according to the method of Tabachnik and Fidell (1997).

Zero-order correlations were carried out to examine the relationship between decisional conflict and all other variables.

Multiple regression was computed to assess main and interaction (moderator) effects of the predictor variables on the dependent variable decisional conflict using the method of Baron and Kenny (1986). According to this method, moderation exists when the strength or direction of the association between predictor and dependent variable differs significantly between groups. That is, the interaction of the grouping variable and any of the predictor variables has a unique contribution to the overall variance after controlling for the variance explained by its main effects. Thus, on the first step of the regression, those variables that showed significant or marginally significant correlations or group differences with the dependent measure in univariate analyses were entered as predictors into the standard multiple regression. The only exceptions were significant variables excluded from multivariate analysis due to a low participation rate. As a result, the individual effects of 14 predictors and moderators were assessed and any additional joint effect of predictor and moderator were subsequently assessed on the second step of the analysis. Interactions were computed by multiplying all main effect variables by the grouping variable "intention for

personal use" (groups PU versus NPU). This resulted in 14 interactions that were entered on a second step in the standard multiple regression model.

A probability value of $p < 0.05$ was regarded as statistically significant. Bonferroni adjustment according to the method of Keppel (Keppel, 1991) was performed when multiple comparisons among sets of related variables were conducted. Analyses were performed with the software Statistical Package for the Social Sciences (SPSS) 16.

Results

Group comparisons

Fertility and embryo history

The majority of women had embryos created because they had difficulty getting pregnant (n = 154; 98.7%), one women (0.6%) was single and one was in reproductive treatment because of cancer (0.6%).

As shown in Table 4.2, on average women in both groups had had about one ART cycle where embryos were created resulting in a total of about six embryos per woman with a range of one to ten embryos for 84.6% of women and 11-19 embryos for the remaining 15.4%. There was no difference between the groups on the number of embryos in storage at the time of assessment.

The time interval since the last cycle that resulted in cryopreserved embryos was significantly longer for NPU than the PU group. A significantly higher percentage of women in the NPU group still had all their embryos stored, whereas significantly more women in the PU group still had some of their embryos stored.

Table 4.2

Mean (SD) and t-test results for fertility and embryo history (N = 147)[a]

Variables	Intention		t / χ^2
	Personal-use (n = 115)	No Personal-use (n = 32)	
Number of cycles with cryopreserved embryos (M ± SD)	1.43 ± .91	1.39 ± .62	.09
Total number of cryopreserved embryos (M ± SD)	6.52 ± 4.40	5.76 ± 3.65	-.85
Number of embryos currently in storage (M ± SD)	4.94 ± 3.44	5.29 ± 3.28	.62
Embryos currently in storage (as % of total cryopreserved embryos)	82.68 ± 27.39	92.7 ± 20.35	1.83
% of women having all embryos in storage	64.8 (68)	86.2 (25)	4.92*
% of women having only some embryos in storage	35.2 (37)	13.8 (4)	
Years since last cryopreserved cycle (M ± SD)	1.2 ± 1.71	1.9 ± 1.91	1.96*
Overall live birth with IVF/ICSI (n (% yes))	38.1 (43)	71.9 (23)	11.50***
Live birth with fresh embryo transfer	29.2 (33)	65.6 (21)	3.93***
Live birth with frozen embryo transfer	11.5 (13)	12.5 (4)	.024
Women who have children (% (n))	51.3 (59)	78.1 (25)	7.35**
Number of children (M ± SD)	1.52 ± 0.71	2.04 ± 0.79	2.98**
Discrepancy between number of children wished for and current number of children (includes women without children)	1.75 ± 1.01	0.81 ± 1.09	-4.58***

* $p < .05$, ** $< .01$, *** $< .001$
[a] n varies between variables

In both groups, about 12% of the participants had been successful with treatment using cryopreserved embryos. The NPU group however, had been more successful overall, that is, significantly more had achieved a live birth (65.6%, n = 21 versus 29.2%, n = 33 in the PU group). Thus, significantly more women in group NPU had children and had more of them in comparison to the PU group. Further, for women in the NPU group the discrepancy between number of children wished for and current number of children was significantly smaller than for women in group PU.

Clinic context

As shown in Table 4.3, significantly more women in the PU (versus the NPU group) reported not being given any disposition options, though for both groups this was the case for few women (< 15%). There was no difference between groups on time until storage period ended, number of women who received clinic letters, frequency of clinic letters, response rate to clinic letters, and number of disposition options offered.

Factors contributing to decision-making

Table 4.4 shows the factor analysis on items concerned with the conceptualisation of the embryo. Intercorrelations among the eight items ranged from .01 to .80, however, the Kaiser-Meyer-Olkin index was .88 showing a "meritorious" degree of common variance (Zwick & Velicer, 1986).

Inspection of the scree plot showed that a one-factor solution fitted the data best accounting for 51.15% of the variance (eigenvalue 4.09). Six of the eight items loaded strongly on the first factor (>.76) and only weakly on the second factor (<. 16). The remaining two items loaded highly on the second factor and were deleted as two items was too few to form a meaningful subscale.

Table 4.3

Descriptive statistics, t-test and Qui-square results for ART clinic context (N = 147)[a]

Variables	Intention		t / χ^2
	Personal-use	No Personal-use	
Women who were not presented with any disposition options (% (n))	3.5 (4)	12.5 (4)	3.96*
Remaining years until storage period ends (M ± SD)	2.34 ± 2.47	1.39 ± 1.60	-.97
Women who received clinic letters (% (n))	47.8 (55)	62.5 (20)	2.16
Frequency of clinic letters (% (n))			.23
once every 6 months	38.6 (17)	33.3 (6)	
once a year	54.5 (24)	61.1 (11)	
less often than once a year	6.8 (3)	5.6 (1)	
Response rate for clinic letters (% (n) replied)	62.0 (31)	73.7 (14)	.83
Number of ED options offered (M ± SD)	3.97 ± 1.64	3.88 ± 1.85	-.27

[1] Multiple answers possible
* $p < .05$, ** $p < .01$, *** $p < .001$
n varies between variables

Table 4.4

Factor loadings of eight items about conceptualisation of the embryo

Item	Component	
My frozen embryos are:	1	2
like a child	.911	
a human being	.876	
part of my family	.839	
completely different from children	-.782	
a bunch of cells	-.766	
like a brother/sister to my existing children	.764	
cells that could replace a child if something happens		-.879
a symbol of my infertility		-.431

Note. Extraction method was Principal Component Analysis.

Only loadings >.30 are shown

The remaining six items were averaged to create a Human Concept score (items 'a bunch of cells' and 'completely different from children' were reversed before averaging). Internal reliability coefficient for the six item scale was Chronbach alpha=.85. As shown in Table 4.5, there was no difference between groups on their Human Concept mean scores.

Moreover, Table 4.5 shows that there was no difference between groups on their rating of the importance of four different aspects (financial situation, family size, personal values, view of the embryos) with all four aspects showing high importance when making a disposition decision (scores above mid-point seven). Significantly more women in the PU than NPU group wanted to make the decision themselves or with their partner. Significantly more women in the PU group (versus the NPU group) indicated they had made a disposition decision at the time of consent, whereas significantly more women in group NPU than PU said they made a decision when they had finished with treatment. Women in group NPU thought about their embryos less frequently than in group PU.

Groups did not differ on their intended disposition choice where the most frequent disposition choice in both groups was continuation of storage, which was chosen by about 90% of women in group PU and 70% of women in group NPU.

A MANOVA was conducted in order to examine group differences on leaning towards any of the disposition options and showed a significant multivariate group effect ($F(3, 140) = 4.83$, $p = .001$; Wilks $\lambda = .88$). Post hoc independent t-tests revealed that leaning towards continuation of storage was significantly stronger in group PU than NPU. There was no difference between groups on any of the other disposition options.

Table 4.5

Mean (SD), t-test and qui-square results for factors contributing to decision-making (N = 147)[a]

Variables	Intention		F / t / χ2
	Personal-use (n = 115)	No Personal-use (n = 32)	
Human Concept scale (M ± SD)	3.52 ± 0.99	3.15 ± 1.08	1.85[t]
Extent of importance of aspects when making a disposition decision (M ± SD)			.29
Financial situation	10.61 ± 4.52	10.75 ± 5.04	
Size of family	11.23 ± 4.03	11.84 ± 2.56	
Personal values	9.96 ± 4.75	10.22 ± 4.52	
View of embryos	12.66 ± 2.83	12.23 ± 3.16	
Preferred role in decision-making process (% (n))			
Make the decision myself or with partner	99.1 (114)	90.6 (29)	6.84**
Would like clinic to make the decision	0.9 (1)	3.1 (1)	.95
Fate or God should make the decision	7.8 (9)	9.4 (3)	.08
Point in time when disposition decision was made (% (n))[1]			
Time of consent	58.3 (67)	21.9 (7)	13.26***
Initiation of treatment (embryo creation)	14.8 (17)	9.4 (3)	0.81
After embryo transfer	7.0 (8)	--	2.35
When the clinic contacted us	4.3 (5)	12.5 (4)	2.9
When finished with treatment	1.7 (2)	9.4 (3)	4.44*
At the end of statutory storage period	0.9 (1)	6.2 (2)	3.63
Frequency of thinking about the embryos (M ± SD)	2.7 ± 0.74	2.28 ± 1.52	-2.85**
Intended disposition choice (% (n)			5.29
donation to research	6.5 (7)	14.8 (4)	
donation to another couple	4.6 (5)	11.1 (3)	
thawing and discarding	0.9 (1)	3.7 (1)	
continue storage	88.0 (95)	70.4 (19)	
Leaning towards the disposition option (M ± SD)			4.83***
donation to research	6.47 ± 5.51[bd]	8.56 ± 5.30[bd]	3.57[t]
donation to another couple	5.68 ± 5.21[bd]	5.97 ± 5.60[bd]	.19
thawing and discarding	2.97 ± 3.72[bc]	4.71 ± 4.53[bc]	6.37*
continuation of storage	14.27 ± 2.49[a]	11.72 ± 4.59[a]	13.90***
Women who are undecided about their embryos (% (n))	31.3 (36)	43.8 (14)	1.73

[t] p < .10, * p < .05, ** p < .01, *** p < .001
For all factors higher scores mean more of the attribute (e.g., greater importance, frequency, need)
Note: Different superscripts indicate significant differences between means within groups

When differences between leaning towards the disposition options were examined within groups, continuation of storage was found to be more preferred than every other options (thawing/disposal, donation to couple, donation to research) in both groups. Further in group NPU donation to research was preferred to thawing/ disposal. Similarly, continuation of storage was preferred to any of the other options in the PU group. Additionally, donation to research and donation to another couple was preferred to thawing/disposal of the embryos.

There was no difference between groups on percentage of women being undecided about their cryopreserved embryos.

Cognitive and emotional aspects of ED context

The factor analysis on apprehensions regarding decision-making showed intercorrelation among the 15 items that ranged from .06 to .79, however, the Kaiser-Meyer-Olkin index was .90 representing a "marvellous" degree of common variance (Zwick & Velicer, 1986). Three factors emerged with an eigenvalue of >1. Inspection of the scree plot, however, showed that a one-factor solution fit the data best accounting for 48.12% of the variance (eigenvalue 7.22).

Ten of the 15 items loaded strongly on the first factor (>.58) and only weakly on the second and third factor (<.30) (see highlighted items in Table 4.6). The remaining five items loaded highly on the second or third factor or to some degree on two factors and were deleted from further analyses because these did not form meaningful subscales. The ten items loading on the first factor were subsequently reversed and averaged to create an Embryo Disposition Apprehension (EDA) scale with higher scores indicating greater apprehension regarding ED decision-making.

Table 4.6

Factor loadings of 15 items on apprehensions concerning ED

	Factors		
Item	1	2	3
I find it difficult to choose the best option	.864		
I dread the decision	.840		
I am too anxious to make a decision	.823		
I feel too worried	.823		
I am afraid that I might regret the decision later	.819		
I feel too fearful to make a decision	.812		
I am uncertain about which option to choose	.799		
I am afraid of self-blame	.785		
I think a better option might become available	.612		
I am afraid that my partner or someone important will blame me	.595		.502
I am not sure if I want more children	.577		
I wish to avoid an irreversible decision	.559	.640	
My partner and I do not agree	.517		.597
I am afraid to lose the embryo	.351	.426	
I prefer to keep the situation as it was		.642	-.491

Extraction method: Principal Component Analysis.

Only loadings >.30 are shown.

The internal reliability coefficient for the group of items, was Chronbach alpha=.93. As shown in Table 4.7, groups differed significantly on the EDA scale with women in the NPU group having significantly higher scores than group PU (i.e., more decision apprehensions).

A mixed factor 2 (Group) x 2 (time) ANOVA was conducted in order to examine group differences between pre and post anxiety scores on the STAI short form. The Group x Time interaction was significant ($F(1, 145) = 5.57$, $p = .02$) (see Figure 4.1). Post hoc dependent t-tests revealed significant differences between pre- and post questionnaire assessment in group PU but not NPU with women in the PU group having significantly less anxiety after filling in the questionnaire. Assessment of decisional conflict (DCS) showed significant differences between groups with group NPU showing significantly more decisional conflict on the overall DCS scale (see Table 4.7).

A MANOVA was conducted in order to examine group differences on the four DCS subscales. The analysis revealed a significant multivariate group effect ($F(3, 141) = 6.74$, $p < .001$; Wilks $\lambda = .838$). Follow-up F-tests showed groups differed significantly on the uncertainty subscale ($F(143, 1) = 19.27$, $p < .001$) and on the support subscale ($F(143, 1) = 3.80$, $p < .05$) with group NPU having higher uncertainty scores and being less supported.

Chi-square tests showed that significantly more women in the NPU group had a score exceeding 37.5, the threshold for decision delay, on the the uncertainty subscale of the DSC, and to a lesser degree on the overall DCS and the support subscale of the DCS (O'Connor, 1993).

Table 4.7

Mean (SD), t-test and MANOVA results for psychological variables (N = 147)[a]

Variables	Intention for Personal-use (n = 115)	Intention for No Personal-use (n = 32)	F / t / χ^2
Psychological variables			
Embryo Disposition Apprehension (EDA) scale	2.29 ± 0.96	3.03 ± 1.06	3.75***
STAI short form			5.57*
Pre EDS completion	49.32 ± 15.58[a]	41.28 ± 15.1	
Post EDS completion	46.08 ± 13.31[b]	43.65 ± 16.64	
Total of Decision Conflict Scale (DCS)[1]	14.62 ± 17.89	22.56 ± 16.90	2.53*
Uncertainty subscore DCS	21.49 ± 27.76	47.92 ± 34.2	4.56**
[Un-] Informed subscore DCS	11.38 ± 18.68	11.98 ± 15.83	.17
[Lack of] Values clarity subscore DCS	10.58 ± 18.58	8.07 ± 14.59	-.71
[Lack of] Support subscore DCS	15.07 ± 19.62	22.14 ± 20.48	1.78*
Women having scores > 37.5 (% (n) on			
Total DCS	9.6 (11)	21.9 (7)	3.53[t]
Uncertainty subscore DCS	25.4 (29)	53.1 (17)	8.88**
[Un-] Informed subscore DCS	7.0 (8)	9.3 (4)	.21
[Lack of] Values clarity subscore DCS	7.8 (9)	6.2 (2)	.09
[Lack of] Support subscore DCS	10.4 (12)	21.9 (7)	2.91[t]

t p < .10, * p < .05, ** p < .01, *** p < .001
n varies between variables
Note: Different superscripts indicate significant differences between means within groups

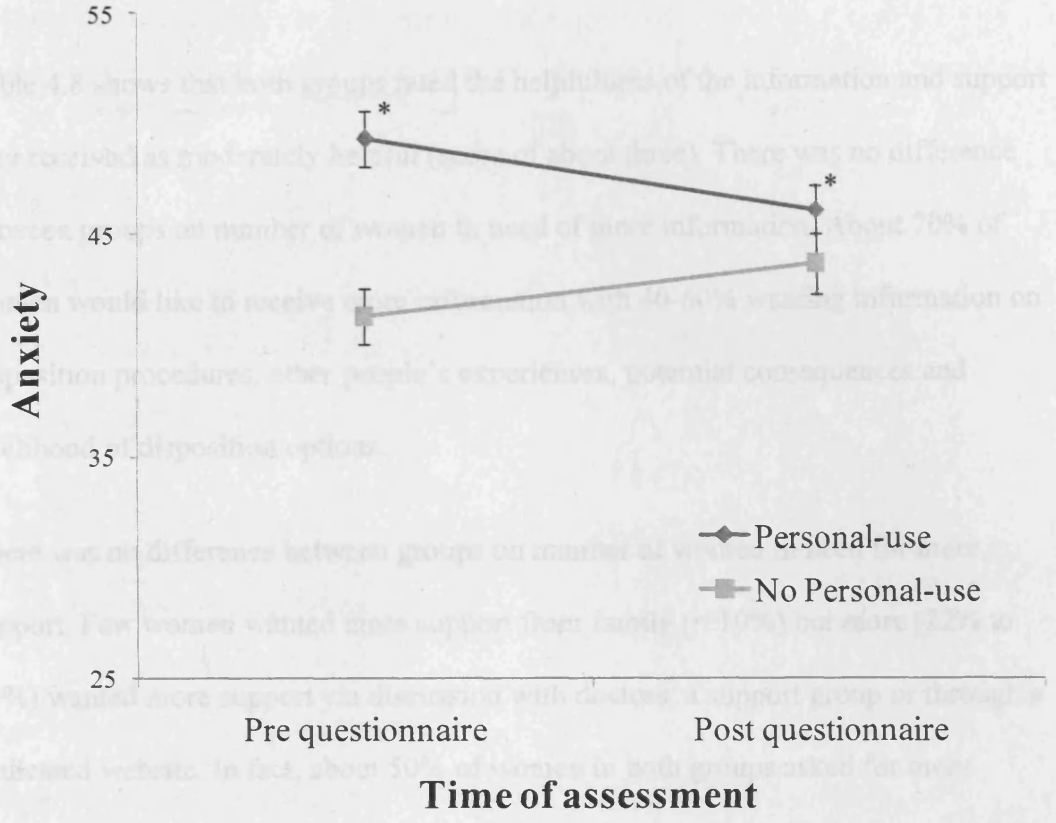

Figure 4.1: Anxiety as a function of administration time (pre or post survey completion) in group PU versus NPU.

* $p < .05$.

Information and support

Table 4.8 shows that both groups rated the helpfulness of the information and support they received as moderately helpful (score of about three). There was no difference between groups on number of women in need of more information. About 70% of women would like to receive more information with 40-60% wanting information on disposition procedures, other people's experiences, potential consequences and likelihood of disposition options.

There was no difference between groups on number of women in need for more support. Few women wanted more support from family (< 10%) but more (22% to 43%) wanted more support via discussion with doctors, a support group or through a dedicated website. In fact, about 50% of women in both groups asked for more support in general and 78.1% of women in the NPU group asked for more information.

Correlates of decisional conflict

Table 4.9 shows summary statistics for main and interaction effects in a regression on correlates of decisional conflict. In total 62.3% of variance in decisional conflict was accounted for by the set of predictors with an adjusted r square of 0.576, $F(13,117) = 13.23$, $p < .001$.

Higher decisional conflict was significantly associated with having had prior success with cryopreserved embryos, greater decision apprehension, higher need for information and support, and higher frequency of thinking about the embryos.

Table 4.8

Mean (SD), t-test results for information and support (N = 147)[a]

Variables	Intention		t / χ^2
	Personal-use (n = 115)	No Personal-use (n = 32)	
Information			
Helpfulness of received information	3.2 ± 0.87	3.08 ± 1.24	-.49
Number of women in need of information on (% (n))			
Procedures	47.8 (55)	50.0 (16)	.25
Potential consequences of options	44.3 (51)	40.6 (13)	.01
Likelihood involved in each option	47.8 (55)	40.6 (13)	.02
Other people's experience	53.0 (61)	62.5 (20)	.91
Support			
Helpfulness of received support	3.22 ± 0.98	3.12 ± 1.13	-.38
Number of women in need of support by (% (n))			
Discussion with family	9.6 (11)	9.4 (3)	.13
Discussion with doctor	29.6 (34)	28.1 (9)	.08
Discussion in support group	33.9 (39)	43.8 (14)	1.61
Using a website	22.8 (33)	37.5 (12)	.94
Number of women who would like to receive more (% (n))			
information	67.8 (78)	78.1 (25)	1.61
support	53.0 (61)	50.0 (16)	.025

* $p < .05$, ** $p < .01$, *** $p < .001$

Table 4.9

Summary statistics for main and interaction effects in moderated regression analysis on correlates of decisional conflict (n=118)

Predictors	Beta	SE B	sr^2 (%)	t
Block 1 Main effects				
Number of live births	.09	.18	.40	1.04
Discrepancy between number of children wished for and current number of children	.04	.21	.10	.57
Number of currently stored embryos	-.09	.14	.70	-1.43
Years since last cycle with frozen embryos	-.03	.16	.10	-.45
Live birth as result of previous frozen transfer	.20	.45	1.60	2.86**
Human concept scale	-.05	.15	.20	-.71
Frequency of thinking about embryos	-.13	.14	1.40	-1.97*
Intention for further transfer	.06	.37	.20	.80
Embryo Disposition Apprehension scale	.64	.16	27.40	8.68***
Point in time when decision was made: at the time of consent	-.07	.30	.40	-1.06
Point in time when decision was made: when finished with treatment	-.06	.76	.40	-1.00
Need for information and support	.22	.16	3.50	3.12**
Discrepancy between STAI short form post and pre questionnaire assessment	-.01	.14	.0	-.10
Block 2: Interaction effects [a]				
Human concept scale * intention personal use	-.37	.40	1.90	-2.37*

* $p < .05$; ** $p < .01$; *** $p < .001$
multiple $R^2 = .623$; Adjusted $R^2 = .576$; $F(13,117) = 13.23$, $p < .001$
[a] Only significant interactions are shown, see Appendix 4 for all interactions

The interaction step of the analysis increased the total variance accounted for by 6% to a total of 68.4% with an adjusted r square of 0.598, $F(25,117) = 7.95$, $p < .001$, R2 change = .060; F change (12, 92) = 1.46, non-significant. The interaction of human concept and the grouping variable was significant, β (117) = -.37, p = .02. The interaction was decomposed to test the statistical significance of the simple slopes for each group separately (Aiken & West, 1991). The relation between human concept and decisional conflict in the NPU group showed a significant positive relation, β (117) = .42, p = .01 showing that a strong human concept was related to higher decisional conflict. In the PU the reverse picture was shown where the relation between human concept and decisional conflict was negative but non-significant, β (117) = -.15, p = .10 showing that a relatively strong human concept was unrelated to decisional conflict (see Figure 4.2).[3]

[3] The interaction of human concept and the grouping variable remained significant when all non-significant variables were excluded from the analysis, β (136) = -.11, p = .043.

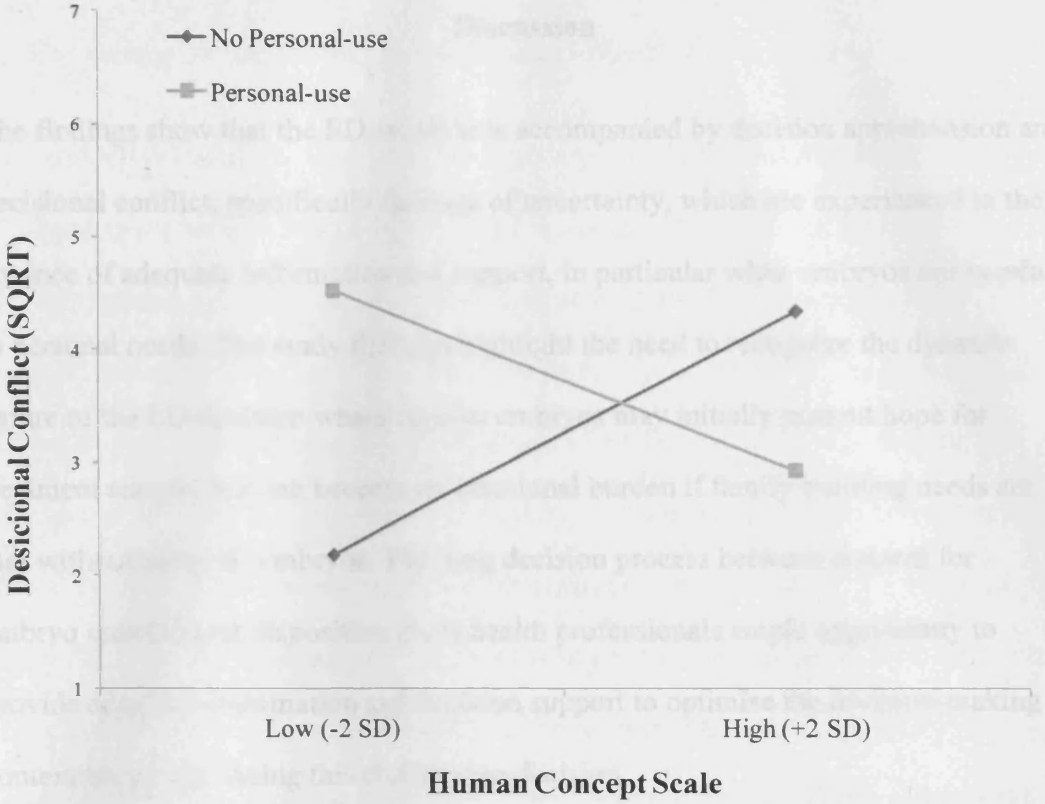

Figure 4.2: Decisional conflict in group PU versus NPU as a function of human conceptualisation.

Discussion

The findings show that the ED decision is accompanied by decision apprehension and decisional conflict, specifically feelings of uncertainty, which are experienced in the absence of adequate information and support, in particular when embryos are *surplus* to personal needs. The study findings highlight the need to recognize the dynamic nature of the ED decision where *surplus* embryos may initially present hope for treatment success but can become an emotional burden if family building needs are met without using all embryos. The long decision process between consent for embryo creation and disposition gives health professionals ample opportunity to provide adequate information and decision support to optimise the decision-making context for people facing this challenging decision.

The decision context differed for NPU and PU women. First, women who had no intention to use their cryopreserved embryos for further pregnancy attempts (NPU group) had a different treatment experience and family context than those who still intended to use their embryos for their own treatment (PU group). Because women in the NPU group had been more successful with fresh embryos they were in the paradoxical position of having achieved their desired family size but having more cryopreserved embryos left over than women in the PU group who were still trying to conceive. These opposite treatment outcomes create a very different ED context even though the decision (to use or dispose the embryos) is the same for both. These outcome results also indicate that those patients predicted to have the best response to treatment (younger age, normal body mass index, healthy life style, etc.) are more likely to end up in the position of having embryos they will not need. Efforts to minimise the chance of *surplus* embryos, for example via mild stimulation protocols

(Nygren, 2007) would therefore not only help ease the physical burden of treatment but also reduce the likelihood of being in this difficult position.

Second the NPU and PU women differed because the ED decision seemed more challenging for women who did not intend to use their embryos for personal use. The NPU group showed more decisional conflict, more decision uncertainty, more decision apprehension, and anxiety than group PU. In fact, most of the women in the NPU group exceeded the threshold indicative of decision delay on the uncertainty subscale of the DCS. Additionally, the anxiety of women in group NPU had increased after they filled in the questionnaire, whereas the opposite was true for women in group PU who had lower anxiety scores post questionnaire. These findings are consistent with previous work where the ED decision has been described as emotionally challenging (Fuscaldo et al., 2007; Nachtigall et al., 2009), but extend this body of work by demonstrating that this is particularly so for those who will not use embryos for themselves. This is an important finding because the differentiation between intention for personal use or not has been disregarded in past studies (Lyerly, et al., 2010; Newton, et al., 2007; Provoost, et al., 2009b; Zweifel, Christianson, Jaeger, Olive, & Lindheim, 2007).

In light of this it is imperative for ED researchers to recognise that not all *extra* embryos are *surplus* in the same way and how they are *surplus* makes a difference to the decision context women will face.

There was clear evidence of the dynamic nature of the ED decision, and this was demonstrated in two ways. First, the decision about what to do with embryos seems to be made more than once. The majority of women in both groups indicated the time of consent as first decision point but women in group NPU also indicated the end of

treatment as a decision point. As IVF clinics require a disposition decision before treatment is initiated, later decision-points would seem to reflect times when people revisited the decision of what to do with their embryos as they reached those stages. This finding is in line with previous work where disposition intentions at the time of consent had changed by the time patients had finished treatment (Hounshell & Chetkowski, 1996; Klock et al., 2001; Saunders et al., 1995). Thus, the time of consent may be important for introducing the disposition options but because treatment experiences (e.g., live birth from transfer) can influence the decision, ongoing communication between patient and clinic is required.

Second, the nature of associations between embryo conceptualisation and decisional conflict also points to the dynamic nature of the disposition decision. In prior work difficulty associated with the disposition decision had been linked to how couples viewed their embryos with couples who thought of them as human having more difficulty making a choice (McMahon et al., 2000; Nachtigall et al., 2005). The current findings draw a more differentiated picture in that the relationship between human concept and decisional conflict depended on whether embryos were intended for personal use or not. As shown in Figure 4.2, page 106 women in group NPU showed more decisional conflict when beliefs reflected a strong human concept whereas the reverse trend was displayed in group PU, with more decisional conflict associated with a weak human concept. There may be several explanations for these associations, including the extensive body of work on consequences of inconsistency between attitude and behaviour by Festinger (1957), showing that people are motivated to reduce dissonance resulting from attitude-behaviour inconsistency by changing attitude, belief or behaviour in order to restore consistency. When treatment is ceased and women do not need their cryopreserved embryos for their own family

building anymore, the only behavioural option to finalise this chapter in their lives is relinquishing the embryos (e.g., disposal or donation). If women conceptualise their embryos as strongly human disposing them (thawing, research) may conflict with beliefs on how humans ought to be treated and this may lead to cognitive dissonance and hence decisional conflict. In contrast, if women intend to relinquish their embryos whilst conceptualising them as non-human, their attitude-behaviour would be more consistent. Indeed, previous work has shown that solving the ED decision is contingent on the challenging task of re-conceptualising the embryos as something other than human (Nachtigall et al., 2009).

The opposite pattern applies to women who intend to use their embryos because if women view their embryos as non-human using them for further treatment to achieve a pregnancy would be inconsistent with their attitude and should cause conflict. This is further supported by studies showing that patients who refused to cryopreserve their embryos showed unusually high anxiety levels regarding the viability of cryopreserved embryos and any children developing from them (Laurelle & Englert, 1995). In the present, study prior treatment success with cryopreserved embryos was linked to decisional conflict (independent of group) and this too may be indicative of the changing nature of beliefs about the embryo, because this association represents the unique impact of having experienced concretely what cryopreserved embryos can potentially become (i.e., a baby) on conflict. Although causality cannot be inferred here because a cross-sectional design was employed, it could be speculated that needing the embryos makes people invest in them the potential to be human, whereas needing to discard or dispose of embryos makes people dissociate this potential for the purpose of dissonance reduction.

The results of the current study extend prior findings in that the nature of the link between difficulty associated with the disposition decision and couples' conceptualisation of their embryos is dependent on intention for personal use or not, whereas prior research has recruited participants based on the time since embryos were cryopreserved without further differentiation (McMahon et al., 2000; Nachtigall et al., 2005).

The dynamic nature of the ED decision has been described previously where it was proposed that couples go through four distinct ED stages, that is, couples are initially reassured by having spare cryopreserved embryos (Nachtigall et al., 2005; Skoog Svanberg, Boivin, Hjelmstedt et al., 2001) that is followed by avoidance, confrontation, and resolution of the decision (Nachtigall et al., 2005). The current study draws a somewhat different picture in that the initial emotional phase women go through is less clear-cut with women in group PU displaying a somewhat ambivalent decision profile with few negative feelings (i.e., less anxiety, apprehension, decisional conflict, uncertainty than women in group NPU), but 25% of PU women already experienced decisional conflict, were undecided about their intended disposition choice (30%) and 20% did not intend to use *surplus* embryos even though they had no children. The psychological profile of women in group NPU is in accord with decision avoidance in that they experienced more decision apprehensions and uncertainty (above the threshold of decision delay), while thinking about their embryos less frequently and preferring to keep them cryopreserved thereby not selecting any of the alternative options (70% chose to continue storage) even though women have no intention for further treatment. Thus, their profile is congruent with the theoretical definition of decision avoidance where negative emotions and selection

difficulty lead to omission, deferral or keeping the status quo and thereby avoiding the decision (Anderson, 2003).

Together these findings emphasize one of the biggest conundrums in IVF, which is why people keep embryos in storage that they never intend to use for themselves. The results of the present study partly elucidate why this phenomena may occur but more research will be needed to fully explain this complex decisional process.

Analysis of variables related to the clinic context provided some indication of factors that could be modified to improve the decision context for women. Women in both study groups were moderately satisfied with the quality of information and support they received, but the majority was interested in more information on procedures involved in ART, on potential consequences and likelihood of the disposition options (i.e., what is the likelihood that donation will result in a baby), and other people's experience with the decision. Women were open about how they received this information (discussion with their doctor, support group, website). Both groups were offered the same disposition options with about 15% of women stating they had not been offered any disposition option, which would clearly undermine the ED process. It may be that provision of clear information on the available disposition options needs to be made more concretely. Finally, only 50% of women in both groups received clinic letters, mainly once a year. More research needs to be done on whether that frequency is sufficient, but if clinics are concerned about patients not returning for unused cryopreserved embryos, as suggested elsewhere (Brzyski, 1998; Newton, Fisher et al., 2007), then perhaps more effort should be invested in sustaining good communication by providing embryo relevant information to all patients more frequently.

There were several methodological weaknesses in the current study. First, the sample composition consisted of women from different countries. This is particularly important for the ED decision as the legislative or regulatory context may vary between countries. Some countries like the United States do not have a statutory storage limit, whereas in others it varies between five (e.g., Canada; Government of Canada, 2004) and 10 years (e.g., parts of Australia; The Infertility Treatment Act 1995, 1997). Moreover, the number and characteristics of disposition options offered can vary even within countries especially when clinics do not have donor or research programmes in place. For these reasons, it can be assumed that the decision context genuinely varied between participants. However, country representation was similar in the PU and NPU group such that differences between these groups would not be accounted for by country differences. Further, it can be argued that the disposition decision process has a universal nature centred on the emotional response to and experience with treatment, independent of the option set or statutory storage limit.

Second, the majority of women in the study were highly educated (70% at university level) which calls into question the representativeness of the sample. However, similar education levels have been found in previous studies on infertility using internet samples (e.g., 75%, Bunting & Boivin, 2007) as well as clinic samples (e.g., 52%, Hammarberg & Tinney, 2006; 79%, Lyerly et al., 2010; 79%, Nachtigall, Dougall, Lee, Harrington, & Becker, 2010). Thus, it seems that although the participants in the current study are not representative of the general population, they are representative of the infertile population that takes part in research.

Third, women in this study were recruited among those using the internet which did not allow for formal verification of their status as a genuine ART patient. However,

the consistency of responses within groups and the fact that their answers were coherent with what was expected based on the empirical literature suggested that they had undergone ART treatment. Third, the study sample was mainly North-American, female, white and highly educated and therefore does not necessarily generalise to men's views and other populations. Men's views, on the other hand, are not represented because only ten men participated that were too few to be analysed separately. Together these biases mean that to fully explain this complex decisional process more efforts need to be invested in diversifying the sample.

Finally, due to the small sample size the study had low power to detect small or moderate effects that could be meaningful (Cohen, 1992). Additionally, high number of comparisons in the multiple regression increased the chance for alpha inflation and a Type I error , that is, it was more likely to detect an effect that was due to chance. In order to reduce chance of alpha inflation multivariate analysis of variance were used where variables formed a coherent grouping. Further, the results show consistently that women in group NPU have a different psychological profile than women in group PU and are widely consistent with the empirical literature. The cross-sectional design of the study does not allow inferring causality and therefore all conclusions were discussed as associations.

Despite these weaknesses, corroboration between the current results and those of others lend confidence to the validity of findings reported. Internal and external validity was shown as women in group NPU had on average two children that has been reported elsewhere to be the number of children couples generally aim for (Berrington, 2004). Achieving the desired family size would also be consistent with women in group NPU having no intention for further treatment and showing low

discrepancy between the number of children they wish for and the number they have. Further, the majority in group NPU were keeping their embryos in storage that was consistent with group means above the threshold of decision delay on the decisional conflict scale.

In summary, cryopreserved embryos can become an emotional burden when treatment is ceased before embryos are all used. It is a decision embedded in a potentially dynamic decision context where disposition intentions and views of the embryos at the time of consent may change as a result of treatment experiences. Attention to the specific emotional and decisional needs of ART patients according to their specific decision context would be vital in order to reduce decisional conflict, decision apprehensions and uncertainty and thereby facilitate decision-making. Information and support provision that is optional to patients and accessible throughout the embryo storage phase as well as efforts to update patients' disposition wishes as they go through the treatment process needs to be implemented in order to be in line with the dynamic nature of the decision process.

Part II: Embryo Representations and Embryo Disposition Decision Factors (Qualitative Analysis)

Introduction

The ED decision has been shown to be a complex and difficult decision (Nachtigall et al., 2005; Skoog Svanberg, Boivin, & Bergh, 2001; Söderström-Anttila et al., 2001) that has been linked to how couples perceive their embryos, for example, as human beings with moral status (Provoost et al., 2009), as a symbol of the couples' infertility and/ or the struggle they went through (Nachtigall et al., 2005), and as cells with potential for future medical purposes (Lyerly et al., 2006).

Another important factor that has been linked to decision-making is the emotional reaction of the decision maker, in particular, negative reactions have been reported to make decision-making more difficult (O'Connor, 1995), interfere with the person's ability to think clearly when making the decision (Fitten & Waite, 1990; Scott, 1983), and are the antecedents of decision avoidance (Anderson, 2003). The possibility of cryopreserving embryos has been shown to increase couples' optimism at the beginning of treatment (Skoog Svanberg, Boivin, Hjelmstedt et al., 2001), whereas negative emotions such as tearfulness (McMahon et al., 2000; Provoost et al., 2009), sadness (McMahon et al., 2000), and uneasiness (Kufner et al., 2009) have been associated with the decision-making phase at the end of treatment and thereafter. One women (aged 37) said:

> *"When I was going through [IVF] I didn't even think of them as embryos...whereas now [after birth] the realization of oh my gosh what a beautiful human being can be created; it*

changes your emotions just a little bit . . . maybe they are less cut and dried." (Lyerly et al., 2006, p. 1627).

These findings suggest that different stages of treatment may be associated with diverse emotional reactions but it is yet unclear how couples react emotionally to their stored embryos specifically and in what way their emotions play a role when contemplating ED options. Similarly, although there is some evidence regarding the factors that are associated with choosing specific disposition options, little is known about factors that facilitate decision-making and those that keep couples from making a decision.

The aim of the qualitative part of the study was to explore the way women perceive and emotionally react to their embryos (mental representations) as well as to identify factors that either facilitate ED decision-making or hinder choosing between disposition options. The use of the internet has been argued to be particular useful for this research aim because the anonymity of the internet provides an environment that is distant enough for people to describe experiences about sensitive issues that may be too embarrassing in a one-on-one interaction (Mann & Stewart, 2001) and safe enough to reveal true thoughts and feelings (Morton Robinson, 2001). In the EDS, open-ended questions were positioned within the online survey as the first question of each section, that is, before closed-ended questions were presented addressing similar aspects. In addition questions were worded in order to capture women's views and feelings without influencing them. Using this approach, it was hoped to achieve a richer account than by using qualitative methods alone in an attempt to better understand the ED decision context.

The open-ended questions allowed exploration of how women referred to these aspects in their own words. This approach provides textual data that, unlike other qualitative data, have been recorded without the intervention of a researcher (e.g., as through interviews, observations; Silverman, 2006). Thus, the researcher influence on the data collection goes as far as phrasing the research question. In contrast, during an interview the researcher has an active role of asking the research questions, probing some of the participant's answers in more depth and ending the interview when data collection seems to be sufficient. By using this approach, the researcher has more influence on the amount and type of interview questions asked (that can vary greatly between participants) and therefore the length of the interview. These potential effects would influence participants to a lesser degree during open-ended online questions. However, qualitative online research eliminates the opportunity for probing and/ or elaborating on poorly understood questions. Other forms of textual data such as newspaper or magazine articles, books, internet blogs or forums are considered naturally occurring textual data because they are not produced for research purposes to begin with. Lately, this type of textual data has been given more attention and the internet in particular has been discovered as a rich source of such naturally occurring text (Silverman, 2006). Textual data, in general, have the advantage to be readily available for further analysis without the need for time consuming and often costly transcriptions that have been shown to be prone to omission of entire paragraphs or scenes because they seemed irrelevant at the time of transcribing (Mann & Stewart, 2001). However, the downside of open-ended online questions is that participants might be unskilled in expressing their thoughts and feelings by means of typing. Therefore, this qualitative data collection method might only be used by a self-selected group of patients including those who are more experienced in expressing

themselves in writing. Nevertheless, it can be assumed that participants who fill in an online survey must be somewhat computer literate, and those using online forums seem to make great use of this medium to express their thoughts and feelings (e.g., see www.infertilitynetworkuk.com, www.askbaby.com). Overall, online open-ended research methods provide access to a wide range of potential participants, but are limited in that researchers' understanding is constrained by the extent to which people can articulate their thoughts and feelings without further probing.

The current textual data were analysed using content analysis based on grounded theory (Silverman, 2006). Grounded theory is an inductive methodology that is based on the generation of meaningful constructs and their relatedness (theory) through data, rather than through prior hypotheses (Henwood & Pidgeon, 1992; Silverman, 2006). Content analysis is a way of quantifying qualitative information. It involves establishing categories and then counting the number of instances those categories occur in a particular item of text (Silverman, 2006) in order to evaluate them using conventional reliability and validity criteria (Henwood & Pidgeon, 1992). This type of analysis is particularly appropriate for unidimensional data such as text stemming from open-ended questions where the focus lies on investigating the content of text. In contrast, multidimensional data such as dialogue would profit more from an analysis method that does not only focus on what has been said, but also on the interactive dynamics and non-verbal communication, for example, discourse analysis.

Content analysis based on grounded theory includes extraction of meaningful quotations from the textual data in order to subsequently engage in the creative process of linking quotations to form overarching categories at higher levels of abstraction (Henwood & Pidgeon, 1992). The key orienting approach underlying

grounded theory is the method of constant comparative analysis where quotations that have already been linked to a given category are repetitively compared to to-be categorised quotations regarding their similarities and differences (category belongingness) and checking the textual data for alternatives and counterexamples to ensure the full diversity and complexity of the data (Henwood & Pidgeon, 1992). Based on this method existing categories are restructured, re-labelled or new categories are created until coherence within categories is achieved and theoretical saturation has taken place, that is no new examples of variation exist (Henwood & Pidgeon, 1992; Silverman, 2006).

Method

Participants and recruitment

All women participating in the online survey (see Chapter 4, Part I for details of the final sample) replied to the open-ended survey questions and thereby provided textual data. Response rates differed between research questions with 97% (n = 154) providing answers to question 1 on embryo perceptions & meaning, 81% (n = 129) answered question 2 on affect towards embryos, 87% (n = 139) answered question 3 on reasons for disposition preference, 50% (n = 79) answered question 4 on decision facilitators, and 45% (n = 71) answered question 5 on decision hindrance.

Materials

Embryo Disposition Survey

The qualitative part of the EDS comprised five questions in three sections: 1) Embryo conceptualisation: 2) ED preference, and 3) Factors associated with ED decision-making. No set character limit was in place for the open-ended questions.

Embryo representations

The two questions in this section concerned women's perception and the meaning of their cryopreserved embryos ("H*ow do you think about your embryos and what do they mean to you?")* as well as women's emotional reaction towards their embryos ("H*ow does thinking about them make you feel?").*

ED preferences

In this section women's preferred disposition option and their justification for their choice were recorded ("W*hich disposition option looks best to you and why is this currently the best option for you?*").

Factors associated with the ED decision-making

Women were asked about their reason for not responding to clinic letters (if applicable) ("W*hy do you not respond to clinic letters?*"), reasons that kept them from making a disposition decision ("A*re there any reasons that keep you from making the decision?*"), as well as important factors for making the decision ("W*hat factors are important to you when making a decision about your embryos?*")

Procedure

Open-ended text boxes were positioned at the beginning of each section of the EDS in order to capture participants' opinion before they were potentially influenced by the closed-ended questions that followed. Women could type their answer by clicking into the open-ended textbox. The back and forward button of the internet browser enabled women to move between pages in case they wanted to revise their answers at a later stage. Textual data where electronically exported from Survey tracker into Excel and subsequently uploaded into Atlas.ti (Muhr, 2004) in order to analyse the data through several layers of emerging concepts. No data reduction or editing took place.

Analysis

Preliminary data screening produced one research question (response to clinic letters) that was excluded from the analysis due to too few responses (<10%).

As shown in Figure 4.3, data analysis was organised into four sequential steps each at a higher level at abstraction: The first analysis step involved extracting meaningful units of text (*quotations*) for further analysis. That is, long and complex sentences were broken down into shorter thematic units or segments (Webber, 1990). In the subsequent steps, three investigators (the author of the thesis and two students in the same research laboratory) who were blind to which group participants were in, independently engaged in the creative process of linking quotations that thematically belonged together to form *categories* at higher levels of abstraction (Henwood & Pidgeon, 1992).

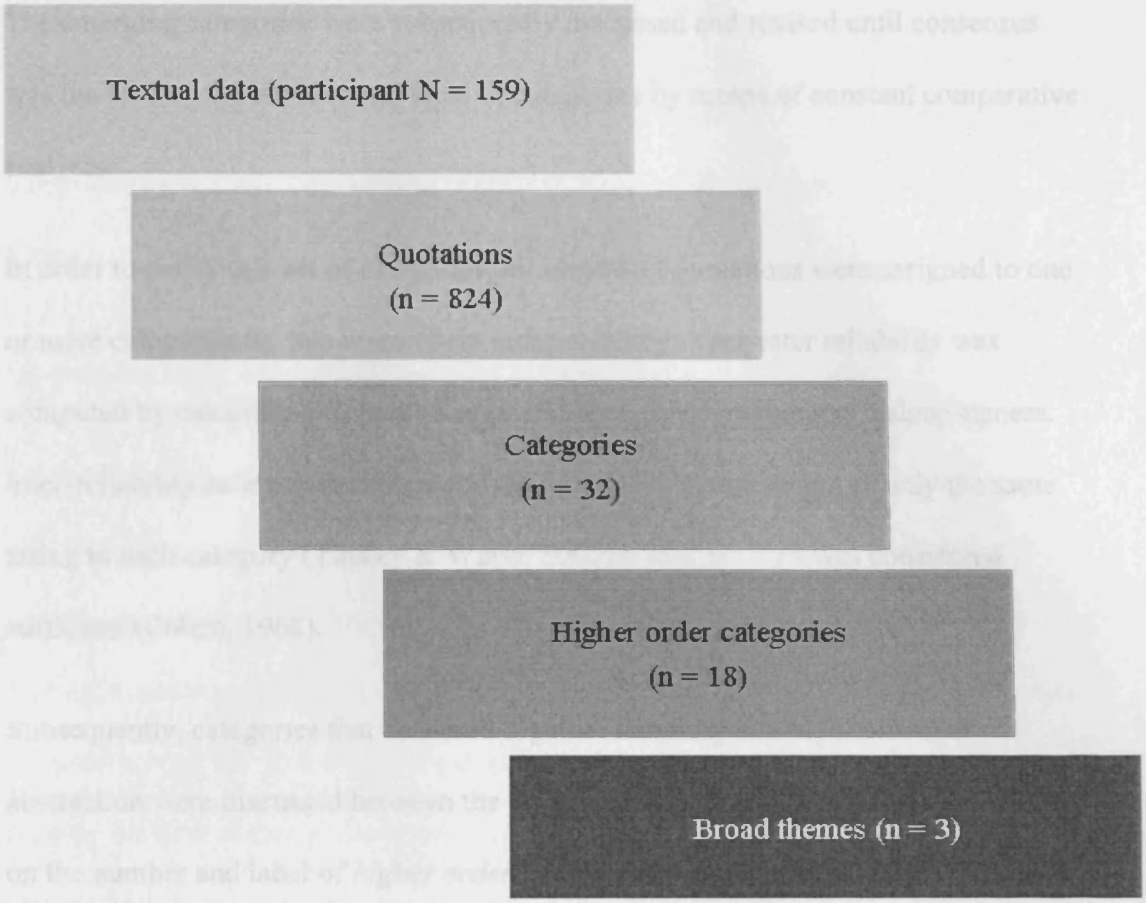

Figure 4.3: Four sequential steps of content data analysis. Numbers in parenthesis showing number of quotations, categories, higher order categories and broad themes emerging from the data.

The emerging categories were subsequently discussed and revised until consensus was reached on the number and label of categories by means of constant comparative analysis.

In order to verify this set of categories, all identified quotations were assigned to one or more categories by two researchers independently. Inter-rater reliability was computed by calculating Cohen's Kappa (K) for quotation-category belongingness. Inter-reliability refers to the extent to which different raters assign exactly the same rating to each category (Tinsley & Weiss, 2000) where $K > .70$ was considered sufficient (Cohen, 1968).

Subsequently, categories that clustered together naturally at a higher level of abstraction were discussed between the three researchers until consensus was reached on the number and label of *higher order categories* (step three) and finally *broad themes* (step four).

Notations

For illustration purposes quotations are presented using the following notation system:

i) [...] omission within the textual data. Some part of the quotation is not presented because it is irrelevant for the argument.

ii) (text) addition to the textual data. Where quotations were not grammatical additional text was added for ease of reading and comprehensibility

Each quotation is followed by the age and country of residence of the respondent in parentheses according to the list of country codes by the International Organisation of Standardisation (ISO; International Organization for Standardization, 2010). Where age or country of residence were not stated, n.s. is used.

Results

Results are presented according to their underlying analysis hierarchy with quotations being presented first, followed by categories, higher order categories and broad themes.

Quotations and categories

The textual data comprised a total of 824 quotations. As shown in Table 4.10, question one on women's perception and meaning of their embryos (Perception & Meaning) had the most quotations (n = 314, 38.1%) followed by question two on women's emotional reaction towards embryos (Embryo Affect; n = 170, 20.6%). Less quotations were found for question three on women's intended disposition choice and reasons for their choice (Disposition Intention; n = 135, 16.4%), question four on important factors for making the embryos disposition decision (Decision Facilitators; n = 129, 15.7%), and question five on reasons that kept from making the disposition decision (Decision Barriers; n = 76, 9.2%).

As shown in Table 4.10, there were 32 categories that emerged from the data. Although the identified categories are conceptually distinct, there is overlap between them in regards to their underlying quotations where some quotations fit more than one category. For example, the following statement applied to the *medical concept* category and *security* category: "We originally considered the frozen ones our possible stem cell source for our two sons if they ever needed that type of medical help" (30, CA).

Table 4.10

Number of quotations by category and research question (n = 805)

Category	Question*					Total
	Meaning & Perception (n = 312)	Embryo Affect (n = 144)	Disposition Intention (n = 135)	Decision facilitators (n = 129)	Decision barriers (n = 76)	
Life/ Human concept	83		1	4	8	96
Intend further transfer	1		79	10	4	94
Optimism	17	28	1			46
Potential or future children	48			1		49
Uncertain if more children	6	7	11	12	8	44
Negative emotions towards embryos		33		1		34
Attachment/ bond	23	5		1	3	32
Responsibility towards embryos	22	4		4	1	31
Security	5	16	3	5	2	31
Part of current family	29			1		30
Circumstances			2	19	7	28
Undecided which option	1	9	14		4	28
Health/ medical issues			1	17	7	25
Value/ importance of embryos	21		1	1		23
Conflicted/ ambiguous emotions	3	19				22
Potential of embryos	18			1		19
Issues with donation to couple			3	7	9	19
Difficulty/ distress about decision	15	1	1		1	18
Opinion of significant others				10	6	16
Positive emotion towards embryos		15				15
Financial issues	1		3	5	5	14
Help others/ science			7	7		14
Pessimism	3	5		1	2	11
Decision delay			8		1	9
Current/ future treatment outcome				9		9
Negative emotional state	3			2	2	7
Genetic link	5				2	7
Family size				6		6
Medical concept	6					6
Finality of decision				1	4	5
Religion				4		4
Neutral feelings	2	2				4

Note. Multiple responses possible. Shaded areas represent less than 10% of participants.
* See text for specific wording

Reliability analysis for belongingness of quotation to category showed good reliability for all research questions (Perception & Meaning: K = .81; Embryo Affect: K = .80; Disposition Intention: K = .82; Decision Facilitators: K = .86, Decision Barriers: K = .82).

Table 4.10 also shows that some of the identified categories occurred in response to more than one of the research questions. For example, two categories (*uncertain if more children* and *security*) applied to all research questions (5/5), whereas eight categories applied to four research questions (4/5), seven categories applied to three research questions (3/5), 10 categories applied to two research questions (2/5), and five categories applied to one of the research questions (1/5).

Figure 4.4a shows the frequency of each category per research question for group PU, and Figure 4.4b shows the frequency of each category per research question for group NPU. In both figures, for example, *life/ human concept* represents a third of all quotations underlying *Meaning and Perception.* In the *Embryo Affect* category, the most frequent emotion in group PU is positivity (including optimism and positive emotions, 38%), whereas group NPU reported negative emotions (58%) most frequently. Figures differ, for example, on *Disposition Intentions* where *intend further transfer* represents about 75% of all quotations in group PU, whereas *undecided which option* is quoted by the majority of women in group NPU.

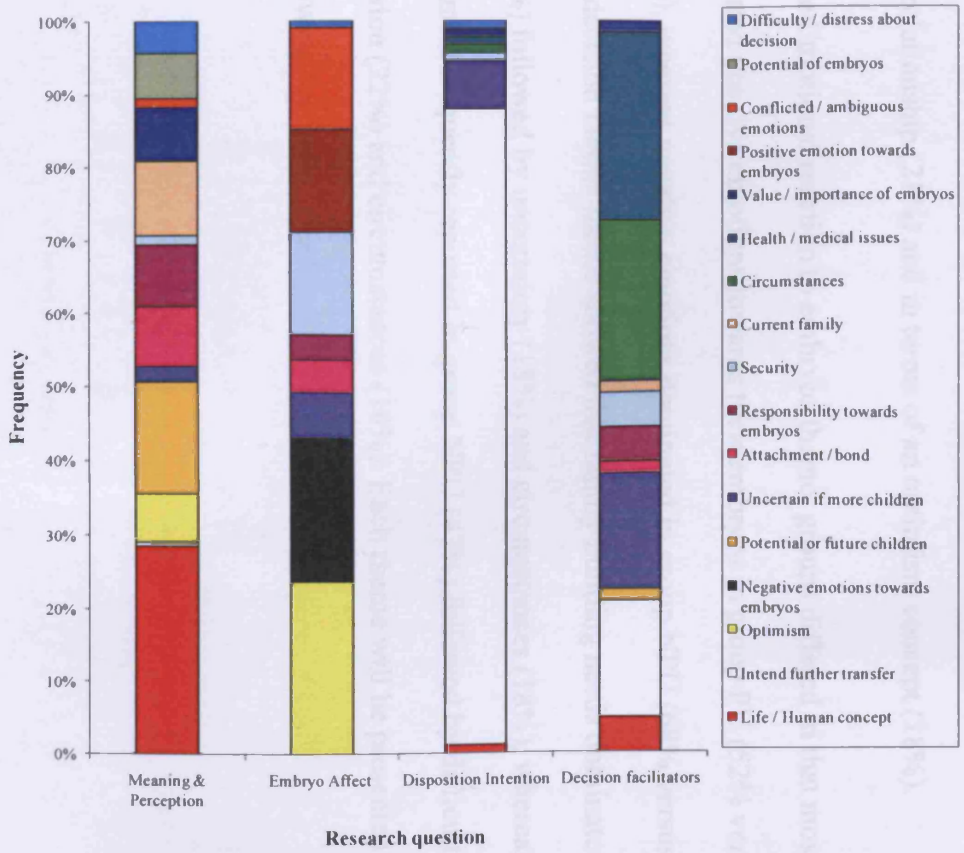

Figure 4.4a: Frequency of each category as a function of research question for group PU. Only categories that represent > 10% of participants are shown

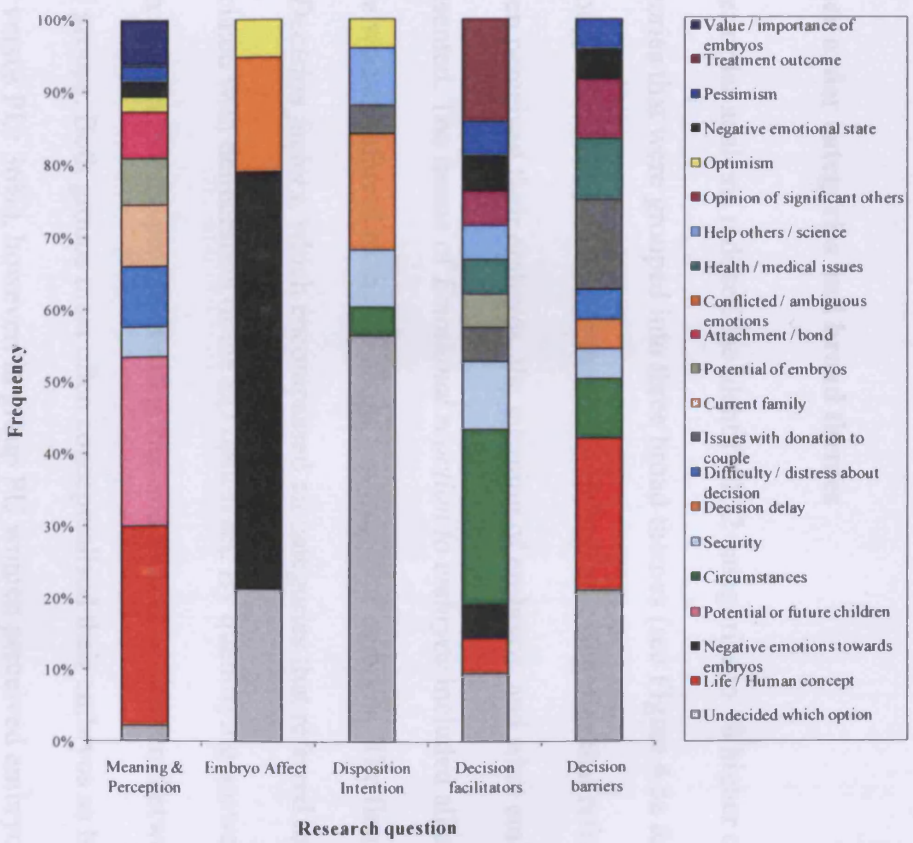

Figure 4.4b: Frequency of each category as a function of research question for group NPU. Only categories that represent > 10% of participants are shown

Higher order categories and broad themes

Higher order analysis reduced the identified 32 categories to 18 higher order categories that were grouped into three broad themes (see Figure 4.5a & b according to group). The *Embryo concept* theme comprised all categories that referred to how women perceived their embryos, the meaning of embryos, and what embryos represented. The theme of *Emotional reaction to embryos* included all categories where women referred to their feelings towards their embryos. The final broad theme was *Decision factors*, which encompassed all categories that referred to aspects associated with deliberation of the ED option set. By quantifying answers in this way it can be seen that the profile of categories and themes is different between PU and NPU groups. Both groups most often conceptualised their embryos as human (NPU: 59% versus PU: 36%), however, in group PU women perceived embryos also as part of a relationship (21%) and in terms of an optimism concept (18%).

In the Emotional reaction to embryos theme, groups differed in that most women reported positive emotions towards their embryos in group PU (52% versus NPU: 12%), whereas negative emotions dominated in group NPU (68% versus PU: 32%). The decision factors theme showed that family building needs dominated in group PU (48%) followed by uncertainty (18%) and circumstances (18%), whereas uncertainty was most frequently reported in group NPU (47%) followed by difficulty of the decision (22%) and circumstances (18%). Each theme will be presented in the following sections.

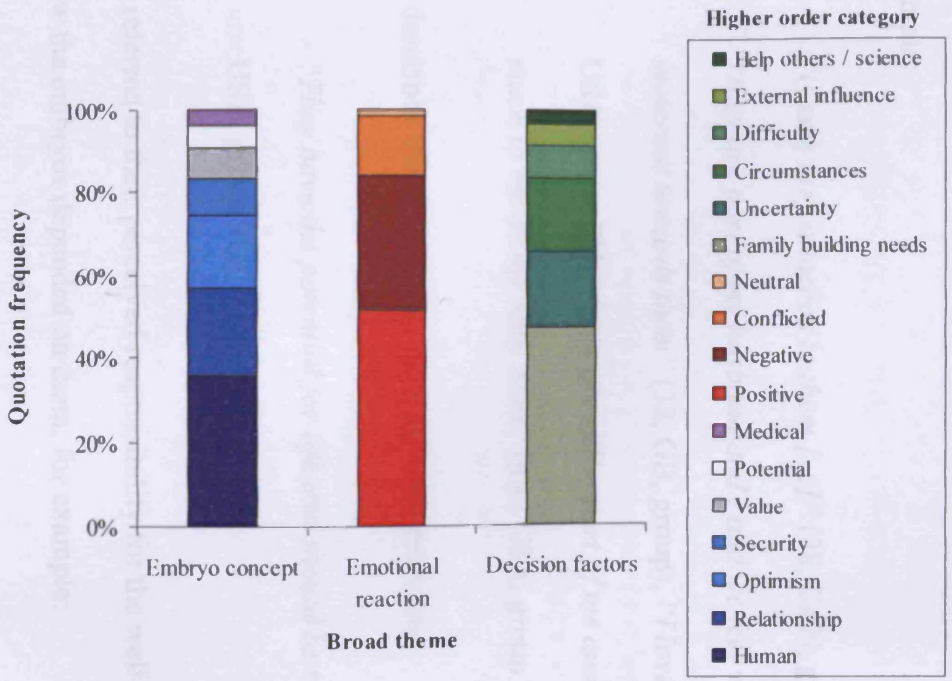

Figure 4.5a: Frequency of each category based on the number of its underlying quotations as a function of broad theme for group PU

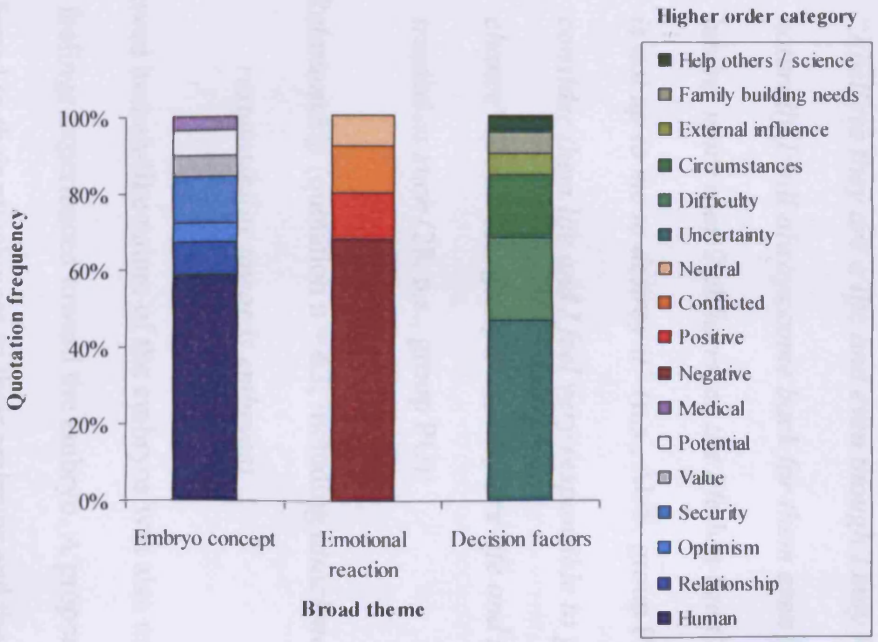

Figure 4.5b: Frequency of each category based on the number of its underlying quotations as a function of broad theme for group NPU

> *"I believe they are a life and even though I may fall pregnant naturally I will always come back for them even if it means having more than 2 children as the life has been started and it is not up to me to destroy it"* (n.s., AUS, group PU); *"I consider them life and I feel very responsible to give them a chance"* (34, USA, group PU); *they are life and should be treated as such* (28, n.s., group PU);

b. Relationship (quotation n = 63; including *attachment/ bond* and *responsibility towards embryos)*

The perceived human-like nature of the embryos was also manifested indirectly by the relational feelings experienced toward the embryo. A proportion of women (quotation n = 23) referred to their attachment to their embryos and the special bond they shared, for example:

> "(I am) *very attached to them [...]"* (38, CAN, group PU), *"they are part of my husband and I and we feel very strongly maternal towards them"* (33, GB, group), *"I love them"* (45, USA, group PU), *"they are still a part of me and they mean as much to me as my baby does"* (n.s., USA, group NPU).

Others described the respect they have for their embryos:

> *"They have the potential for life and should be respected"* (32, USA, group PU),

Others referred to their perceived responsibility for the well-being of their embryos and how the embryos depended on them, for example:

> *"I feel responsible to them in that they were intentionally created"* (42, USA, group PU); *"We won't make more embryos than we intend to give a chance at life"* (33, n.s., group PU)

The perceived humanness of the embryo and the responsibility associated with it meant for some women that having embryos became a burden, for example:

> "(I feel) *pressured to have another treatment cycle as I have an obligation to try and give this little person in waiting an opportunity at life"* (37, AUS, group PU).

c. ***Optimism*** (quotation n = 51)

Another frequent topic that women raised was that embryos represented optimism for further family building where for some women embryos were perceived to be their last hope for having their own biological children, for example:

> *"They are my ray of hope"* (46, USA, group PU), *"they mean everything - our only hope of having our own family, that I still have a chance"* (n.s., GB, group PU); *"I hope against reason that they will provide me with at least another child"* (37, USA, group PU)

Embryos were reassuring for those women who already had children in that having them meant women could have further treatment if they decided to have more children, for example:

"Knowing that they are there gives me hope for the future if I should decide to have another" (n.s., CAN, group NPU)

The decision to freeze embryos felt like the right thing to do for some women which they associated with a positive future, for example:

"I feel like something was telling me to freeze them for a reason so I feel optimistic about it" (n.s., USA, group PU)

d. Security (quotation n = 31)

Embryos represented a safety measure that was reassuring to women, for example:

"(I am) *relieved that we have those embryos frozen in the event the current cycle doesn't work"* (22, AUS, group PU); "(I am) *relieved that we have the chance for another child without needing to go through a whole cycle again"* (34, n.s., group PU).

Women also kept their embryos in place in case something happened to their existing children or in case fertility problems persisted in the future, for example:

"(They are) *security for children in the future* (and) *protection from further fertility loss from aging"* (37, AUS, group PU); "(I) *want to keep them for now as worried something may happen to one of my children [...]"*(n.s., GB, group NPU); "(I am) *making sure I have a backup in case I have a miscarriage, that if this cycle goes wrong, I have a `second` chance"* (42, GB); "*They are my insurance policy in case I run out of eggs for a fresh IVF" (34, GB, group PU)*

e. Value (quotation n = 23; including *value/ importance of embryos)*

A minority of women stressed the value of their embryos and the unique place their embryos had in their lives, for example:

> "(They) *are the most important thing to me in my life 10 plus"* (42, n.s.)

For some of these women the value of the embryo was associated with their human status, for example:

> *They are still a part of me, they mean as much to me as my baby does* (n.s., USA, group NPU)*; "they are the beginning of life and are precious to me"* (32, USA, group PU).

Whereas for others the value of the embryo was linked to how they were created and the genetic link to the couple, for example:

> *"they are precious as* (they) *are a part of me and my husband"* (n.s., GB, group PU), *"they mean hard work and lots of emotional investment"* (33, USA, group PU).

f. Potential (quotation n = 19; including *potential of embryos)*

Few women focussed on the potential of embryos in that if they were used they could become a child, for example:

> *"I view them as the potential to bless our family with future children"* (n.s., group PU); *"I am always wondering what they would turn out to be if they were born"* (34, USA, group NPU)*; "They have the incredible POTENTIAL to become our*

child(ren), but they are not `children` now" (38, CAN, group PU); *"At my age its the last chance I will have for a baby with my partner, and maybe wont get chance at all to be a mum"*(42, n.s., group PU)

Others also referred to their potential to contribute to science, for example:

"I respect their potential, whether that be future children or contributing to developing technology" (42, USA, group PU).

g. Medical (quotation n = 13; including *medical concept, genetic link)*

The least frequently mentioned concept was that of embryos as medical entities where women referred to their embryos as tissue that they specifically distinguished from (human) life, for example:

"I think of my frozen embryos as fertilized eggs, but also they are only cells at this point, not life" (40, USA, group NPU), and *"I see them as stored blood or any other kind of stored tissue"* (45, USA, group PU).

Embryos were also considered to be of medical use in the future, sometimes even for medical treatment that may not have been invented yet, for example:

"We originally considered the frozen ones our possible stem cell source for our two sons if they ever needed that type of medical help" (55, USA, group NPU); *"I see them as embryos and have learned to not see them as babies due to my miscarriages"* (33, CAN, group PU).

Another medical view of the embryo manifested in emphasising the genetic link between the couple and their embryos, for example:

> *"I feel strongly that they represent us genetically [...]"* (29, AUS, group PU); *"they are a part of myself and my husband. I feel sad at times that if I am successful in having 2 children, that the remainder of the embryos will not be used. As I feel strongly that they represent us genetically, I could not imagine donating them"* (29, AUS, group PU).

Emotional reaction to embryos

This broad theme covered 159 quotations within six categories that were underlying four distinct higher order categories:

h. Positive (quotation n = 73; including *optimism* and *positive emotion towards embryos)*

No women in group NPU expressed positive emotions towards their embryos in general. In group PU, however, expressions included:

> *"I have a very positive feeling about them"* (47, n.s., group PU) and "(I am) *happy that they are there [...]"* (n.s., GB, group PU) and "(I am) *very blessed and truly lucky"* (29, CAN, group PU).

Women in group PU felt also positive about their embryos because they gave them the opportunity to try for more children if they decided to do so in the future, which only applied to few women in group NPU (n = 2) who had not ruled out completely to have another child someday, for example:

> "(I am) *happy that I have them to use if I want to have another child"* (41, USA, group PU); "(I am) *excited and comforted that we might get to try to use them someday to expand our family" (33, USA, group PU); "(I am) happy that I still have a chance to have children"* (n.s., NL, group PU): *"Mostly I just think of them as future opportunities if we decide to have a larger family"* (n.s., CAN, group NPU).

Women in group PU expressed relief that having frozen embryos meant easing future treatment because they would not have to go through a full stimulation cycle to have another embryo transfer, for example:

> "(I am) *glad they are in storage and I get to do a frozen cycle and not a fresh one"* (33, USA, group PU).

In group PU, positive emotions towards the embryos were also manifested in an optimistic attitude towards the future in that having frozen embryos in storage may allow women to satisfy their family buildings needs at some point, for example:

> "(I am) *hopeful that we may be able to conceive again"* (n.s., USA, group PU); *"it makes me feel hopeful that someday they will be physically here with me"* (n.s., USA, group PU); *"I still don't have a child and they offer me hope for the future*" (45, USA, group PU).

i. ***Negative*** (quotation n = 60; including *negative emotions towards embryos* and *pessimism)*

The second most frequently expressed emotion towards embryos was negative where women in both groups experienced negative feelings in regards to their embryos because their circumstances prevented them from having another embryo transfer, for example:

> "(I feel) *sad and worried that we probably will never have the money to go through fertility treatment again and then I will not get to give them a chance to be born to us"* (48, USA, group PU); *"I worry about them as I feel too old to have another baby even though I would like a third [...]"* (46, GB, group PU); *"It is sad that I can't attempt to gestate all of them under the circumstances"* (n.s., group NPU).

In contrast women in group NPU experienced negative emotions in regards to their embryos' future and the disposition decision, for example:

> "(I am) *worried because my husband and I don't know what to do with 10 frozen embryos"* (48, USA, NPU); *"(I am) confused and sad"* (40, USA, group NPU); *"(I am) anxious and confused"* (34, USA, group NPU); *"(I am) sad that they are unlikely ever to be born"* (38, UK, group NPU); *"I am undecided as to their fate so it makes me feel a bit sad"* (n.s., USA, group NPU); *"I feel anxiety mostly, about what to do with them and what they mean to me"* (30, AUS, group NPU); *"(I) wish they weren't there* (33, USA, group NPU); *"Guilt over destroying potential life forms"* (35, USA, group NPU).

Women in group PU also worried about the outcome of a future embryo transfer anticipating it might not result in a pregnancy, for example

> *"It makes me feel helpless, because I know the embryos are part of me, but if they don't work it will be the beginning of the end for me, I prey they will work and feel depressed and tearful sometimes and just want them desperately to work"* (42, n.s., group PU); "(I feel) *nervous - I worry about feeling the same horrible thoughts that I felt after our 1st transfer with negative pregnancy results"* (n.s., group PU); "(I feel) *sad, as I don't know when I can use them or if they will implant when they are used*" (41, USA, group PU).

A woman in group PU also experienced guilt when thinking about not coming back for her embryos to attempt another transfer:

> *I feel feelings of guilt at time if we don't attempt to do a frozen cycle [...]"* (39, USA, PU),

j. Conflicted *(*quotation n = 22; including *conflicted/ ambiguous emotions)*

Some women were conflicted about their feelings towards their embryos where positive and negative emotions would either alternate or be experienced simultaneously. This emotional conflict manifested in differently between groups in that women in group PU would feel both reassured by having embryos and also guilty for possibly not using all of them, for example:

> *"Relieved that we have those embryos frozen in the event the current cycle doesn't work. Sad that it's come to this"* (22,

AUS, group PU); "(I am) *happy that we have the opportunity for a second child, sad because we will not be able to use all of them"* (29, USA, group PU), "(I feel) *hope and also frustration at not developing as they need to in order to become a child*" (33, USA, group PU), "(I feel) *loving and protective, unsure what to do with them if we decide not to have any more children. Confused*" (35,AUS, group PU), "(I feel) *worried but excited"* (31, USA, group PU), "*I feel hopeful because we plan to have another child but also I feel pressure because if we have twins this time then we need to decide what to do with the remaining embryos*" (38, n.s., group PU).

In group PU, emotional conflict was also expressed in women's hope but simultaneous fearful anticipation of the future and treatment outcomes, for example:

> *"I feel hopeful, because we plan to have another child (transfer date is in 10 days), but I also feel pressure, because if we have twins this time then we need to decide what to do with the remaining embryos"* (38, n.s., group PU); *"Sometimes I feel hopeful, other times I feel sad as I do not know if they are going to live"* (33, CAN, group PU); "(I feel) *hope and also frustration at not developing as they need to in order to become a child"* (33, USA, PU).

Some women in group PU also expressed conflict because they were uncertain as to whether they should aim for another embryo transfer or not, for example:

> "(I feel) *loving and protective, unsure what to do with them if I decide not to have any more children. Confused"* (35, AUS, group PU).

In contrast, women in group NPU expressed conflict about the existence and future of their embryos, for example:

> *"(I am) tentative – I wonder if we will ever need them for our two sons"* (55, USA, group NPU); *"(I am) sometimes content, sometimes worried"* (n.s., USA, group NPU); *"It feels strange that they exist and could produce a child"* (41, USA, NPU).

k. Neutral (quotation n = 4; including *neutral feelings)*

Very few women expressed neutral or no feelings towards their embryos, for example:

> *"I rarely think about the embryos- I* (am) *more concerned with questions like will I ever be able to conceive [...]"* (28, JO, group PU); *"(I have) no emotional ties to my embryos"* (40, USA, group NPU); *"At this stage I am fairly neutral"* (26, AUS, group PU).

Decision factors (quotation n = 385)

Decision factors covered 16 categories that were combined to form seven higher order categories:

I. ***Family building needs*** (quotation n = 153; including *intend further transfer, uncertain if more children, current/future treatment outcome, family size*)

The most frequent higher order category was concerned with women's family buildings needs where women either intended to use their embryos by having another embryo transfer, or they were undecided whether they wanted more children and whether they should have another transfer, for example:

> "(I) *don't think I want more children, but I'm not positive"* (40, USA, group NPU); "*I can not choose to destroy the embryos until I know for sure whether or not we will try a frozen transfer"* (31, CAN, group PU); *"I kept them frozen in case 5 or 6 years, I change my mind and want to have another child"* (30, USA); "*I am not sure I want to use them but I also know I will feel a sense of loss if/when we decide not to have additional children"* (36, USA, group PU).

It was also important to women to consider their current family size and the outcome of their ongoing or anticipated future treatment when making a decision about their embryos in that an only child was considered insufficient whereas a(n additional) birth may satisfy their family building needs, for example:

"(I am) *regretting having an only child"* (35, USA, group NPU). *The benefits of a sibling for our one child* (are important to me)*"* (41, AUS, group PU); "(Decision-making depends on) *if we would get pregnant with one or two babies if both embryos were transferred"* (39, USA); *"Whether my current pregnancy results in a live birth of twins"* (26, USA, group NPU).

m. Uncertainty (quotation n = 91; including *uncertain if more children, undecided which option, issues with donation couple)*

Women frequently expressed their indecisiveness either in regard to whether or not to try for more children (as mentioned above) or in choosing between the disposition options, for example:

"I cannot use them but cannot bring myself to give them away or discard them" (40, AUS, group NPU); *"(I) haven't decided between donation to another couple and trying to use them ourselves"* (34, USA)*; "I am not able to think of someone else raising my children whom I don't know"* (n.s., CAN, group NPU)*; "I would like to help out another couple. However, I worry it's like giving up a child for adoption"* (38, USA, group PU).

n. Circumstances (quotation n = 67; including *circumstances* and *financial issues, health/ medical issues)*

Women's circumstances also played an important role when making a decision about the embryos in that women had to deal with medical issues, separation, or financial issues that hindered their decision-making, for example:

> *(I am) divorced* (and my) *child has a genetic disability making adoption not an option" (42, USA, group PU); "My daughter has turners syndrome and (I) would hope that she could use them if we don't"(34, AUS); "(The) health (of) previous in vitro offspring"(26, n.s.); "Not being able to use the embryos due to doctor dying, temporarily living in another country etc" (41, USA, group PU); "My age and energy level to care for more children. (My) ability to get assistance in caring for children" (46, CAN, group PU); "Although I'm having issues disposing of them I'm not sure we can afford the treatment for a cycle and another child/children" (39, USA); "I am storing the babies, so I can prolong the need to make a decision to not use them for us, in the hopes that some miracle will happen and we will have the money to go through another cycle" (48, USA, group PU).*

o. ***Difficulty*** (quotation n = 40; including *difficulty /distress about decision, decision delay, finality of decision, negative emotional state)*

The difficulty of the decision about what to do with frozen embryos manifested in choosing between disposition options, for example:

> "(I am) *very distressed to think of disposing them, however unable to use them"* (40, AUS, group NPU)*; I struggle with*

the thought of 'actively' destroying the embryos and I can't fathom the thought of donating to another couple and having 'my child' out there, to whom I have no relationship" (35, AUS, group PU);

Other women were struggling with coming to terms with their treatment experience and their losses, for example:

"Only one was frozen and 10 did not divide properly, I felt like I had lost 10 babies" (33, CAN, group PU); *"I do not like dealing with this issue at all. I wish I never had to know what was done"* (38, USA, group NPU); *I get very emotional and cry when I don't get pregnant because I feel like I just killed my babies that I did something wrong to cause it [...]"* (45, USA, group PU);

Decision delay seemed to be a good way to avoid the prospect of contemplating the decision for some women, for example:

"We haven't decided what to do but continue to pay and renew the storage contract yearly until we are ready to make a decision" (37, AUS); *"I just don't want to make the decision, I keep putting it off"* (38, USA, group NPU); "(An important aspect is) *how I feel about the finality of the decision. That any decision is better than no decision, even if it isn't what I truly desire"* (42, USA, group PU).

Another factor that kept women from deciding was the finality of the decision in that once embryos were donated or disposed of the decision is irreversible, for example:

> "(A reason that kept me from making a decision was) *the finality of it all. I had to go through treatments for both children and I'm sure I will not get pregnant again without assistance. At my age these frozen embryos would most likely be my last opportunity to have more children"* (39, USA).

And finally, women's negative state of mind also made the decision more difficult, for example:

> "(I feel) *sad* (and) *frustrated with self for not being able to make a decision"* (n.s., CAN).

p. External influence (quotation n = 20; including *opinion of significant other* and, *religion)*

Another important factor for the decision-making process was the influence and opinion of women's social environment, for example:

> *"My husband is unsure if he wants more children considering we have 3 already"* (41, USA, group PU); *"My husband and I are currently separated"* (37, USA, group PU); *"(We experience) family pressure/ guilt over destroying potential life forms"* (35, USA, group NPU); *"(I am) bible trained conscience as to the value of life and when it starts"* (n.s., AUS, group PU).

q. Help others/ science (quotation n = 14; including *help others/ science)*

For a few women it was most important to be able to help advance science by donating their embryos, for example:

> *"(I) strongly believe in helping science to progress, that is how we have our miracles"* (46, USA, group PU); *"These doctors who perform miracles for me need to be trained. If embryos weren't donated, we couldn't train embryologists"* (29, CAN, group PU).

ED option specific factors

As shown in Table 4.11, most patients provided an answer to why they chose to keep their embryos frozen, where most patients did so for the purpose of further treatment. However, a substantial proportion also reported keeping their embryos frozen to delay the decision and because of difficulty making a decision (as noted previously).

For the remaining three disposition options (donation to other couple or research and disposal) too few patients responded (< 10%) in order to interpret the data meaningfully.

Table 4.11

Number of quotations by category for reasons for intended ED choice (Q3)

	Intended ED choice			
Category	Keeping stored (N = 103)	Donation to research (N = 12)	Donation to couple (N = 4)	Discard (N = 3)
Intend further transfer	79			
Decision delay	8			
Help others/ science		7		
Issues with donation couple		3		
Undecided which option	10	1	2	1
Circumstances		2		
Life/ Human concept	1			
Optimism	1			
Difficulty/ distress	1			
Value/ importance	1			
Financial issues		1		2
Health/ medical issues			1	
Security	2		1	

Note. Multiple responses possible.

Discussion

The findings depict a rich account of the diversity of women's cognitive and affective representations of their embryos that are dependent on the future intended use of the cryopreserved embryo(s). Cognitive and affective embryo representations are more differentiated when women intend to use their embryos for their own family building, but when no such intention exists the cognitive representations are more narrowly focussed on a human dimension and affective representations are more negative (uncertainty, sadness and anxiety). New perspectives on the embryo (attachment, security, conflicting emotions) were also identified that require attention in future research. Together the findings point to the need for validated embryo representation measures that could be used to systematically assess couples' representation of embryos throughout treatment and thereafter. Such research could help determine when embryo representations become negative and *surplus* embryos may become an emotional burden.

Embryo representations are complex

One aim of the current study was to better understand women's cognitive and affective representations of their embryos. Although, the findings are consistent with past work in showing that embryos were mainly perceived as human (regardless of intended use, e.g., Fuscaldo, 2005; Lyerly et al., 2006; McMahon et al., 2000; Melamed et al., 2009; Nachtigall et al., 2005; Provoost et al., 2009; Söderström-Anttila et al., 2001), the results also point to much more differentiated and complex embryo representations than previously reported. Additional embryo representations were found that have not received much attention in previous research. For example,

the *Relationship* concept concerned not only responsibility aspects as previously suggested (e.g., Lyerly et al., 2006), but also attachment and maternal bond towards embryos. In this broader view, embryos belonged to the women, were perceived to be a part of her, meant as much as her baby did, and were loved. This diversity may need to be taken into account when counselling people about their embryos and embryo dispositions. Whether and to what extent each cognitive representation (*Human, Relationship, Security* etc.) impacts on decision-making, as well as the way cognitive embryo representations are linked to disposition choices still needs to be investigated.

In past research, couples' main emotional reaction towards embryos centred on the opportunity that embryos provide for family building (e.g., increased optimism for a positive treatment outcome; Skoog Svanberg, Boivin, Hjelmstedt et al., 2001), whereas the present findings show a much more differentiated array of emotions including co-occurrence of conflicting emotions (e.g., happiness and sadness, hope and frustration). These ambivalent affective representations of embryos have received little attention in the literature to date. The few studies on ambivalence noted that it was associated with an inability to make the ED decision (Kufner et al., 2009) and linked to post-decisional conflict (McMahon et al., 2000).

The current findings also showed fundamental differences between groups on the origins of negative emotions. Quotations showed that negative affect towards embryos entailed feelings of helplessness and sadness among women in the PU group (who were uncertain whether the embryos would ever become children), whereas women in group NPU were sad about not being able to use them and anxious as well as confused about the ED decision. Although both groups may have experienced sadness, the nature of the sadness differed fundamentally.

Similarly, although conflict was present in both groups and manifested in the co-occurrence of positive and negative emotions towards embryos, the groups differed fundamentally as to the content of women's conflict. That is, conflict in group PU centred around feelings of reassurance and hope for more children but also guilt over storing them and fear of not being successful with treatment. In contrast, women in group NPU experienced conflict in regards to the future of their embryos and the available ED option set. Consequently, decision support needs to help couples clarify their affective embryo representations, in particular negative and conflicting emotions. The dynamic of the ED decision context needs to be acknowledged where negative and conflicting embryo representations can occur at various times depending on the context and underlying causes associated with these emotions.

The results in the current chapter also show that multiple cognitive (*Human, Relationship, Security*, etc.) and multiple affective (*Negative, Positive*, etc.) embryo representations are integrated. The role of cognition and emotion in the ED context has received little attention so far (e.g., Lyerly et al., 2006; Provoost et al., 2009), and it is not fully known what factors determine which cognitive or affective representations dominate. Previous work has shown that feeling emotionally attached to the embryos comes from seeing the embryos as human beings (Lyerly et al., 2006) or as hope for more children (Provoost et al., 2009). It has also been argued that couples try to avoid distress by refraining from getting too emotionally attached to their embryos, which is achieved by conceptualising them in medical terms (medical concept; Provoost et al., 2009). However, what is known is that adopting certain cognitive representations of embryos is linked to certain ED choices though findings are not always consistent. For example, seeing the embryos as unborn children was linked to donation to another couple (Elford et al., 2004), whereas seeing them as

(already existing) children (Lyerly et al., 2006) and emphasising the genetic link to the embryos (de Lacey, 2005) was linked to reluctance to donate to another couple. Future research should focus more on the integration of affective and cognitive embryo representations in the formation of attitudes towards the embryo and the ED decision.

Affective and cognitive representations in decision-making

A second aim of the current study was to investigate reasons that facilitate or hinder the decision process. The results showed that the decision context is linked to how affective and cognitive representations are integrated. When embryos were intended for personal use a predominantly human and positive embryo representation was adopted in the presence of little decision difficulty, uncertainty, and conflict. In contrast, when embryos were not intended for personal use, cognitive representation of the embryos was still mainly human but it was charged with negative emotions, uncertainty, and difficulty with little positive emotions and optimism (as shown in Figure 4.5a & b, page 130). This predominantly negative profile represents the antecedents of decision avoidance (Anderson, 2003) as outlined in chapter 4, part I.

From this cross-sectional research, it is impossible to say whether the difference between groups represents a shift in affective and cognitive embryo representations that all patients go through as they move from the initiation to the end of treatment, or whether group NPU started out with more negative feelings and therefore was more reluctant to use embryos (again). Future research should aim to trace the causal paths through longitudinal designs. Prospective studies to date have mainly concerned the shift in couples' disposition intentions from before initiating treatment to the end of treatment where it was found that up to 71% of couples change their disposition

preference (Klock et al., 2001). A change in preference has been linked to treatment experiences in particular the birth of a child and these, it has been argued, make couples less likely to donate their embryos to another couple (McMahon et al., 2003).

It can also be assumed that all people with embryos will need to achieve integration between cognitive and affective embryo representations and their intended disposition choice in order to make the ED decision. This interdependence of cognition and affect in ED decision-making is expected based on theoretical formulations. Katz and Stotland (1959) as well as Rosenberg and Hovland (1960) have argued that attitudes consist of three components: cognition, affect, and behaviour. The cognitive component includes beliefs that people have about the attitude object. The affective component consists of feelings or emotions that people have in relation to the attitude object, and the behavioural component encompasses people's actions with respect to the attitude object (Eagly & Chaiken, 1993). In the context of ED, the attitude object would be the embryo and/ or the ED option set, where cognitive and affective components correspond to the affective and cognitive embryo representations and the behavioural component would be represented by making a choice among ED options.

Achieving integration of all three components is particularly important for couples who have no intention for further treatment, where the primary goal is to prevent decision-avoidance and negative emotions post-decision (e.g., agony, regret, loss) as identified in previous work (McMahon et al., 2000; Skoog Svanberg, Boivin, Hjelmstedt et al., 2001). It is important for clinic staff to recognise that the integration process can sometimes be a struggle that is complicated by couples' future intended disposition choice. Patient support should help couples become aware of their

affective and cognitive representations of their embryos and any incongruence that may exist between their representations and their intended disposition choice.

Further investigation into the relationship between the three components needs to be carried out. However, such work is hampered by the lack of a standard way of measuring embryo representations. Past research has used various methods including interviews, focus groups and questionnaire assessment that resulted in some consistency between findings. However, the exact meaning underlying embryo representations such as "human concept" varied between studies in that some described it as life or living entities (e.g., Melamed et al., 2009; Nachtigall et al., 2005), as unborn or virtual children (e.g., de Lacey, 2005; Elford et al., 2004), as potential children (Söderström-Anttila et al., 2001), or as sibling to already existing children (Fuscaldo, 2005; Nachtigall et al., 2005). A standard approach to measure couple's affective and cognitive embryo representations would facilitate synthesis across studies that would help progress research on embryo disposition. Such a tool may also be useful in clinical support contexts and improve patient experience.

Consistency between qualitative and quantitative data

Findings from the quantitative section (part I) and qualitative section (part II) of this chapter have complemented one another in illustrating that the ED decision context differs according to women's family building intentions. Both methods showed that women have a predominantly human concept of their embryos independently of transfer intention that is dominated by decisional conflict and uncertainty (quantitative results) as well as negative emotions and uncertainty (qualitative results) in group NPU but not PU.

In addition to mirroring differences in the quantity of (decisional) conflict, uncertainty and decision apprehension (negativity) between the two methods, the qualitative methods also added in depth information to the findings. That is, the quantitative results did not reveal why women in group PU, who did not have to make a final ED decision, experienced conflict, uncertainty, and decision apprehension. The qualitative findings provided some answers in that conflict and uncertainty in group PU occurred because women felt both reassured and hopeful by their embryos but also fearful of not being successful with treatment. Similarly, negative affect in group PU meant that women felt helpless and sad about not knowing if the embryos would ever become children. In contrast, conflict and uncertainty in the NPU group centred around ending storage and the prospect of having to choose between ED options, and negativity included sadness and anxiety about the ED decision.

The quantitative results showed no difference between groups in regards to how strongly women conceptualised embryos as human, but revealed that the 3-way interaction of human concept x decisional conflict x group was significant. That is, women in the NPU group experienced more decisional conflict when they saw their embryos as human, whereas the opposite was true for the PU group. This finding was mirrored in the qualitative data in that both groups mainly had a human conceptualisation of their embryos, which was paired with negative emotions, uncertainty, and difficulty with little positive emotions and optimism in group NPU but not PU. Thus, both methods converged in finding that women in group NPU displayed the antecedents of decision avoidance (Anderson, 2003) as outlined in chapter 4, part I.

These findings show that quantitative and qualitative methods can complement one another in that a mixed-methods approach increases the validity, reliability, and - most importantly - the depth of findings. Using this methodology, the two parts of the current chapter advanced understanding of the ED decision context in highlighting the complexity of the decision and the need for systematic measures to assess embryo representations. In order to investigate the dynamic of the decision context further, longitudinal studies are required that allow inferences about change.

Chapter 5: Embryo Scale Evaluation

Introduction

Results from previous chapters and the empirical literature have shown that the embryo disposition decision is complex in that couples adopt affective and cognitive embryo representation that are associated with the decision. Although previous work on couples' attitudes towards disposition options has contributed greatly to the literature and the general understanding of the nature of the ED decision, there is no reliable measure of embryo representations, which makes it difficult to fully compare and integrate results across ED studies and hampers further research on the role of embryo representations in ED decision-making.

In previous work, the measure of embryo representations has been carried out in multiple ways. To date, various ways of measuring couples' mental representation of their embryos and attitudes towards the ED decision have been employed including semi-structured interviews (Melamed et al., 2009), in depth interviews (de Lacey, 2007; Lyerly et al., 2006; McMahon et al., 2000; Nachtigall et al., 2009; Provoost et al., 2010), and focus group discussions where couples were asked to reflect on the ED decision and/ or discuss their reasons for their disposition choice and their experiences with the decision-making process (Fuscaldo et al., 2007). A disposition ranking task has also been used to investigate couples' reasons for choosing between disposition options. This employs a think aloud protocol wherein couples verbalise their reasons for ranking the disposition options (Kufner et al., 2009). Quantitative studies have used Likert-type response scales asking couples, for example, to indicate the moral status of their embryos (ranging from no moral status to maximum moral status on a 7-point scale; Lyerly et al., 2010), whether they regarded their embryos as children (indicated on a 3-point scale including definitely not, definitely, or somewhere in the

middle; Zweifel et al., 2007), or choosing all applicable statements from a list of reasons for specific disposition options (e.g., "embryos are not fully human so discarding is not an issue of moral or religious concern"; Hammarberg & Tinney, 2006, p. 87). Some of the quantitative work based the exact wording of scale items on prior clinical experience (Zweifel et al., 2007), especially from counselling of infertile patients (Hammarberg & Tinney, 2006). These multiple methods have helped to achieve some generalisation of findings (e.g., a primarily human concept of embryos across studies).

Additionally, methodological weaknesses led to inconsistency in study findings. For example, in some studies, multiple statements were combined in single items making it impossible to interpret the data, for example, "embryos are not fully human so discarding is not an issue of moral or religious concern" (Hammarberg & Tinney, 2006, p. 87). Participants may have agreed to the first half of the statement (embryos are not fully human) but may have disagreed with the second half (discarding is not an issue of moral or religious concern), or they may have regarded it an issue of moral but not religious concern. Moreover, some findings, although related, consisted of a variation of the phenomena which complicated the interpretation. For example, one study reported that couples thought of their embryos as having legal or moral status but not as potential for life (Melamed et al., 2009), whereas another study reported that discarding unused embryos was considered the moral equivalent of abortion (Klock et al., 2001). Further, one report showed that embryos were considered life with the right to live (Lyerly et al., 2006), whereas in another report a women said "I don't know if life begins at conception, but it might, and [the decision] felt morally wrong based on our Christian beliefs" (Paul, Berger, Blyth, & Frith, 2010, p. 263). Thus, although these findings across studies are clearly related they are difficult to

combine because of the variation in couples perspectives which may be a result of the way couples were assessed (e.g., range of questions asked, answer format etc.).

Standardised measures for mental representations of embryos would allow understanding of how an individual's scores compare with group norms ("norm-referenced tests") and facilitate interpretation (Glinger & Morgan, 2009, p. 334). In the present study, quantitative and qualitative data from the EDS survey (Chapter 4) were used to generate an embryo representation scale and this scale was then evaluated in a new sample of people with cryopreserved embryos.

Theoretical considerations

The interdependence of cognition and affect in ED decision-making is expected because theoretically it is assumed that attitudes towards an attitude object (e.g., embryos and the ED decision) consist of three components, a cognitive response, an affective response, and a behavioural response as shown in Figure 5.1 (Eagly & Chaiken, 1994). All three components are seen as evaluative statements where thoughts can be conceptualised as beliefs that are commonly evaluated in positive versus negative terms, though it is also acknowledged that they can be non-evaluative (or involve very little evaluation) in that they express other aspects of meaning (Eagly & Chaiken, 1994). In the context of ED the attitude object (embryo and ED decision), can be evaluated by mentally representing the embryo in affective (e.g., positive affect) and cognitive terms (e.g., human concept) and ED behaviour (e.g., keeping embryos in cryo-storage).

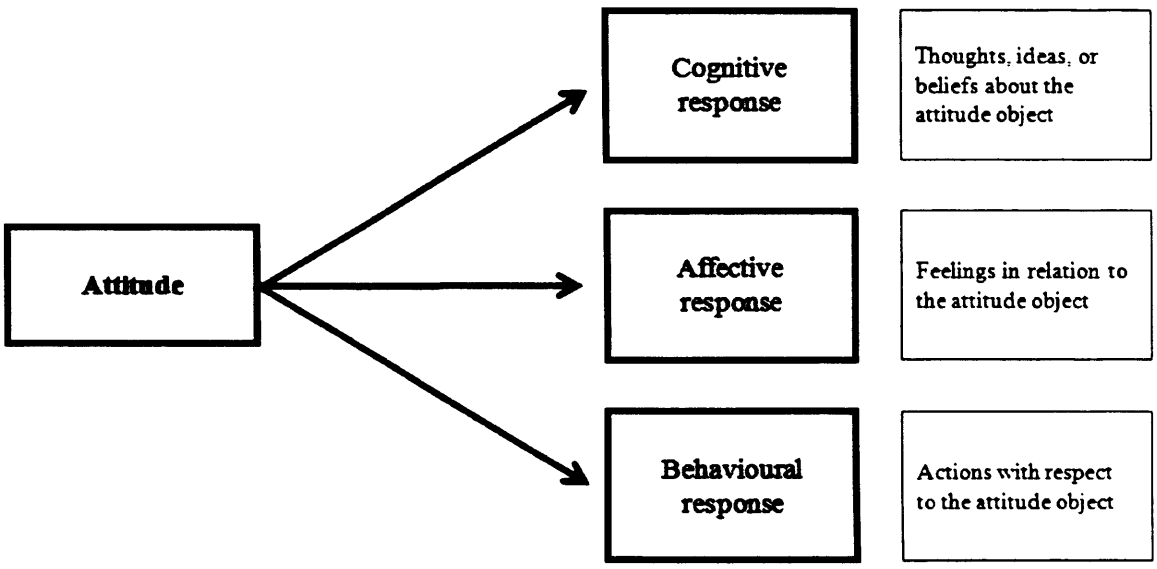

Figure 5.1: Attitude component model (reproduced with permission from Eagly & Chaiken, 1994)

Empirical evidence has shown that the relative weighing of the affective versus cognitive component is important in that an emphasis on the affective component can lead to the formation of a different attitude than a cognitive focus (van den Berg, Manstead, van der Pligt, & Wigboldus, 2006). In the context of organ donation, affective evaluations (but not cognitive and overall evaluations) predicted future donor-relevant decisions (van den Berg, Manstead, van der Pligt, & Wigboldus, 2005). This evidence shows that affective and cognitive evaluations were distinguishable and that the affective component uniquely predicted future decision-making, emphasising the importance of assessing both affective and cognitive components in measures of attitude.

The aim of the study presented in this chapter was to develop an embryo representation scale consisting of an affective and a cognitive component for men and women who undergo IVF or ICSI treatment resulting in *extra* embryos. A validated scale for measuring the behavioural component of ED already exists in form of the Choice Predisposition Scale (O'Connor, 1996). Therefore, behaviour was not included in the embryo representation scale. The secondary aim was to evaluate the preliminary psychometric properties of the new scales

Scale construction

The Cardiff Cognitive Embryo Representation (CCER) and Cardiff Affective Embryo Representation (CAER) scales were developed and evaluated based on the Hinkin (1995) approach that comprises three sequential steps: item generation, scale development, and scale evaluation (Hinkin, 1995). After a satisfactory set of items has been generated the psychometric properties, usually reliability and validity, are evaluated (American Psychological Association, 1985). Reliability refers to the extent

to which items proposed to measure the same general construct produce similar scores. Validity is differentiated into (1) content validity, the extent to which a measure represents all facets of a given construct, (2) criterion-related validity, assessing the relationship between the new measure and a criterion variable (or variables) representative of the construct, and (3) construct validity, assessing the extent to which the set of items measure the construct that they are theoretically purported to assess.

According to Clark and Watson (1995), item generation is achieved based on the systematic sampling of all content that is potentially relevant to the target construct. The generated item pool can include content that will not be retained, for example, because of poor frequency distributions or being too tangential to the underlying constructs. However, in developing scales "one always should err on the side of over-inclusiveness" (Clark & Watson, 1995, p. 6) to ensure sufficient items with excellent properties remain after psychometric evaluation to adequately assess the proposed constructs. This assumption is based on the premise that psychometric analyses can identify weak and unrelated items that can subsequently be excluded, but it cannot detect content that should have been included in advance (Clark & Watson, 1995). The resulting scale was assessed by means of exploratory factor analysis (EFA) which is commonly used when no prior hypothesis in regards to the underlying factor structure exists (Tabachnik & Fidell, 1997). EFA has been shown to be the most widely used analysis technique in a review on scale development and scale refinement (Hinkin, 1995). The final selection of items was based on the results of the EFA and the conceptual work presented in Chapter 4, Part II based on the notion that should not be derived post-hoc based only on the results of statistical analyses (Hinkin, 1995)

because items that load on the same component do not necessarily measure the same theoretical construct (Nunnally, 1978).

In the present study an embryo representation scale was developed consisting of an affective and a cognitive component for men and women who undergo IVF or ICSI treatment resulting in *extra* embryos. The representation scale was then evaluated in regards to its preliminary psychometric properties. The component structure of the resulting measure was expected to correspond to the embryo categories identified in Chapter 4, part II.

Method

Participants and recruitment

The final sample consisted of 420 participants (410 women, 8 men, 2 not specified). All participants had undergone an IVF/ICSI cycle that resulted in cryopreserved embryos. Participants were recruited online during a three-month period. The exclusion criteria were women and men who never had cryopreserved embryos (n=2).

Respondents were assigned to one of two groups according to their embryo status. The "Current Embryo Storage" group (n = 251, CES) comprised participants who currently had embryos in storage, and the "Past Embryo Storage" group (n = 171, PES) included participants who had embryos in the past but not anymore.

The demographic and infertility characteristics of the final sample are shown in Table 5.1. The majority were from North America. Women were in their mid thirties (range 21-53 years) and men were in their late thirties (range 32-53 years).

Table 5.1

Descriptive statistics for demographic variables and family history (N = 421)

Variables	Group CES (n = 248)	Group PES (n = 171)	t / χ^2
Demographics			
Age (M ± SD)	33.91 ± 5.06	36.02 ± 5.80	3.94***
Country of origin (% (n))			2.41
United States	40.7 (101)	45.8 (77)	
United Kingdom	11.3 (28)	11.9 (20)	
Australia	30.2 (75)	29.8 (50)	
Canada	16.9 (42)	11.9 (20)	
New Zealand	0.8 (2)	0.6 (1)	
Education (% (n))			10.67**
University	47.0 (116)	35.3 (60)	
Post-Secondary/College	36.8 (91)	42.4 (72)	
Secondary School	16.2 (40)	20.0 (34)	
Primary School		2.4 (4)	
Family history			
Marital status (% (n))			3.91
Living with partner/ married	96.0 (238)	94.7 (162)	
Separated/ divorced	1.6 (4)	4.1 (7)	
Single	2.0 (5)	0.6 (1)	
Widowed	0.4 (1)	0.6 (1)	
Participants who have children (% (n))	77.4 (192)	77.1 (131)	0.01
Number of children (only those who have children) (M ± SD)	1.65 ± 1.00	2.06 ± 1.16	3.36***
Discrepancy between number of children wished for and current number of children (M ± SD)	1.08 ± 0.78	0.60 ± 0.77	5.25***

Note. N varies between variables
*** $p < .001$

The majority were in a partnership, educated to college or university level and had, on average, one child (participants in group CES had 1.65 ± 1.0 (M ± SD) children, participants in group PES had 2.06 ± 1.16 children) including adopted and step-children.

Materials

The study materials included the Embryo Scale Evaluation Survey (ESES) that was designed specifically for this study to assess demographic and embryo history as well as to evaluate the CAER and CCER scales. Participants also completed the emotional reaction to IVF treatment subscale of the Daily Record Keeping (DRK) form to assess emotional reations at the beginning of survey completion, the Dissonance Thermometer to assess feelings of dissonance, and the Choice Predisposition Survey to assess intentions towards ED options (see Appendix 5 for these materials).

Socio-demographic factors

Socio-demographic factors included age, education, partnership status, and family composition (e.g. number of children (if any), intended family size).

Emotional reactions to treatment

Emotional reaction specific to IVF and ICSI treatment were measured using the emotion subscale of the Daily Record Keeping form (Boivin, 1997; Boivin & Takefman, 1995; Boivin & Takefman, 1996). The emotion-subscale of the DRK consists of 20 items asking patients to what extent they felt an emotion (e.g., confident, anxious, positive) in the last 24 hours on a 5-point scale comprising 0 = not at all, 1 = a little, 2 = a moderate amount, 3 = very much, 4 = an extreme amount. The

emotion subscale of the DRK was developed specifically for the emotional reactions to infertility treatment and is based on Folkman and Lazarus' Ways of Coping Questionnaire (1988). For the present study, two subscales (positive and negative) were computed by calculating an average for all positive and all negative items respectively. The emotion subscale of the DRK has shown good criterion-related validity and good convergent validity with other conceptually related scales, such as the Spielberger State Anxiety Inventory. The scale has shown good internal consistency: Cronbach coefficient alphas varied from 0.76 to 0.88 for the individual subscales (Boivin, 1997).

Dissonance

Dissonance was measured using the dissonance subscale of the dissonance thermometer (Devine, Tauer, Barron, Elliot, & Vance, 1999; Elliot & Devine, 1994) that measures the affective component of cognitive dissonance.

The affective component is the extent to which people experience incongruence measured via three items (uncomfortable, uneasy, bothered) using a 5-point Likert-type response scale comprising 0 = not at all, 1 = a little, 2 = a moderate amount, 3 = very much, 4 = an extreme amount. An overall score on the scale is computed by averaging the three items. In past research, the dissonance subscale of the DT has shown good reliability (coefficients > .77; McNally, Palfai, & Kahler, 2005).

Embryo history

Embryo history included prior history of having cryopreserved embryos (e.g. how many times were embryos frozen, number of frozen embryos, and outcome of embryo transfer(s)).

Choice and choice predisposition

The Choice Predisposition Scale (O'Connor, 1996) was adapted to the ED context and was used to assess to what extent patients lean towards choosing any of the three common disposition options (donation to research, donation to another couple, thawing and disposal) when they have decided they no longer need to store their embryos (see further details of this scale in Chapter 4 Part I, page 85).

Cognitive and affective embryo representations – prototype development

The CCER scale assesses on 40 items cognitive representations of embryos (e.g., like children, belong to me etc.) and the CAER scale assesses on 29 items affective embryo representations (e.g. content, worried, pleased etc.). Embryo representations are assessed on a 5-point Likert scale ranging from 0=strongly disagree to 4= strongly agree. This response format was chosen as it is commonly used in attitude research (Likert, 1932) where the five point range has been argued to be superior in terms of its psychometric properties to a smaller or wider range (Dawes, 2008; Lissitz & Green, 1975). For easier comprehensibility, scores for each subscale were averaged so that scores would range from 0-100 using the following formula:

$$((\bar{x} - 1) * 25)$$

where $\bar{x}$ = participant mean.

Generation of items

Item generation was based on the findings of the qualitative data presented in Chapter 4 Part II. Specifically, patient quotations were derived from the seven identified dimensions underlying cognitive embryo representation (e.g., human concept) and the four dimensions of affective embryo representations (e.g., positive).

Patient quotations presented in Chapter 4 Part II were modified to fit the structure of the scale. Systematic sampling was conducted to produce a comprehensive list of items by including the full diversity of patient quotations regarding affective and cognitive embryo representation where wording was kept as close to the original quotations as possible. Sampling for quotations regarding affective embryo representations focussed on the positive and negative domains as identified in Chapter 4, Part II. The conflicted emotion domain was not included because it was assumed that it would be accounted for by the combination of positive and negative emotions. Sampling for the quotations regarding cognitive embryo representations included all categories identified in Chapter 4, Part II. This process resulted in 40 items for CCER and 29 items for CAER that were randomly ordered within each scale except for items in the relationship category of the CCER scale which were placed at the end of the scale because of differences in phrasing of the items. Item wording was based on the method of DeCoster (2005) in that items were worded to avoid double-barrelled and vague items, ordered randomly, and written in simple English to allow participants to complete the scale with minimal instruction and to minimise misunderstanding.

A five point Likert scale ranging from strongly disagree to strongly agree was chosen to be the most appropriate assessment scale because internal consistency has been shown to increase in Likert-type scales up to the use of five points and level thereafter (Lissitz & Green, 1975).

Procedure

The study materials were transferred online using Survey Tracker® (Training Technologies, 2008), a software that allows the design of web-based questionnaires as well as the recording and storing of participant data.

A link to the survey was posted on the wall of eight patient advocacy groups on facebook regarding infertility (IVF.CA, IVF, Pregnant Through IVF, Infertility Support Group, Support Public Funding for IVF Treatment, Fertility Friends UK, Fertility Troubles, I want a BABY – Infertility) and via facebook pay-by-click advertisement from April 2010 through June 2010. The advertisement included an ED logo reading Embryo Decision-Making (see Appendix 6) and a short statement about the survey ("this is a 10 minute survey on what embryos mean (or meant) to you that will be used to improve patient support"). Clicking on the logo took participants to the Cardiff Fertility Studies homepage, where participants were given a description of the content and purpose of the questionnaire, explaining that the study was anonymous and that throughout the questionnaire participants had the option to click out and close the window with no data being submitted. At the end of the study outline page, participants were asked to confirm that they were 18 years or over and to consent to taking part in the study by ticking a box.

Questions were presented in five sections and took about 10 minutes to complete. At the end of the survey an item evaluation section asked participants to indicate (a) which items, if any, were unclear and why, (b) whether there were other important feelings and views regarding embryos that were not mentioned in the survey and (c) to provide any other additional comments on thoughts and feelings regarding the survey, questions that were difficult, and topics that were left out. Participants were

then given additional information regarding the aims of the study. The Ethics committee of the School of Psychology, Cardiff University, provided ethical review and approval for the study.

Data analysis

For the evaluation of each scale EFA using Principal Component Analysis (PCA) with varimax roation were computed. The Kaiser-Meyer-Olkin index of sampling adequacy indicating suitability of the correlation matrix for factor analysis was used where an index of .70 was considered middling, .80 was meritorious, and .90 was marvellous (as cited in Tabachnik & Fidell, 1997). Bartlett's test of sphericity was employed to test whether there was sufficient intercorrelation among where p-values of .001 were considered significant (Tabachnik & Fidell, 1997).

Two sets of analyses were computed. The first set was computed on the 29 candidate items of the CAER scale concerned with affective embryo representations and the second set was computed on the 40 candidate items of the CCER scale regarding cognitive embryo representations. Both sets of analyses included an initial PCA on data from the PES group (n = 171) that presented the basis for item selection for the final CAER and CCER scales. Items were selected according to the method of Dawis (1987) that suggests selecting those items that are most diverse in regards to their underlying construct and of highest component loadings. The PCA was then repeated on the responses to the selected items in a second, meaningfully different, population (CES group, n = 251) in order to explore whether the same scale structure emerged.

Loadings above .30 were considered significant as per Tabachnik & Fidell (1997). In order to achieve adequate statistical power, an item-to-respondent ratio of

approximately 1:10 was ensured (Hinkin, 1995). Power was also estimated to be sufficient based on the assumption that good power is provided by having five to ten participants per variable up to a total of 300, beyond which test parameters in EFA are considered stable (Field, 2009, p. 639; Kass & Tinsley, 1979; Tabachnik & Fidell, 1997, p. 640).

Preliminary data screening produced 11 participants who were excluded from the analysis due to duplicate responses (n = 9) or incomplete/ invalid data (> 50% of data missing, n = 2). Data were examined to determine suitability for univariate and multivariate analyses. Raw values are presented in tables, but for analytic purposes extreme skewness (≥ 2.58) was reduced by square root transformation instead of deleting items and losing diversity in concepts. Skewness was reduced in the following items of the CAER scale a) guilty, b) tense, c) frustrated, d) sad, e) upset, f) confused, g) helpless, h) undecided, i) pressured, j) conflicted, k) stuck. Skewness was improved in group CES to a) 5.96, b) 4.69, c) 5.9, d) 5.03, e) 7.81, f) 2.85, g) 7.94, h) 2.27, i) 6.47, j) 3.19, k) 6.69. In group PES, skewness was improved to a) 5.78, b) 1.65, c) 1.8, d) 2.55, e) 2.6, f) 2.6, g) 1.75, h) 3.88, i) 6.46, j) 3.05, k) 5.46. Extreme skewness was also present in the CER scale items, but could not be improved by transforming variables. Given the relatively large sample size, all variables were retained for the analyses according to the assumption that with large samples factor analysis is relatively insensitive to departures from normality (Gorsuch, 1974, p. 128).

Reliability analysis consisted of computing alpha coefficients for the items of the CCER and CAER scales where $\alpha > .70$ was deemed satisfactory (Field, 2009). Analyses were performed with the software Statistical Package for the Social Sciences (SPSS) 16.

Mean score were computed for the final version of the CCER and CAER scales by multiplying the sum of each participant by 25 / k, where k is the number of items. This produced a standardised score on a scale from zero to 100.

Results

The modifications of patient quotations for the creation of scale items are presented in Tables 5.2 and 5.3. The resulting scale items were used for EFA on the CEAR and CCER scales. The frequency distributions for the CAER and CCER subscales are described first followed by PCA on these scales. Summary statistics (e.g., reliability coefficient, mean, standard deviation) were computed and are presented for each scale and its subscales. Finally, group comparisons for the PES and CES groups are presented for each scale, emotional reactions to treatment, and dissonance.

Table 5.2

Original patient quotations and derived scale items for CAER scale

Patient quotation	Scale item
	My extra embryos make me
Positive	
(I am) happy that they are there	happy
(I am) hopeful that we may be able to conceive again	hopeful
(I am) glad they are in storage and I get to do a frozen cycle and not a fresh one	glad
I have a very positive feeling about them	positive
(I am) very blessed and truly lucky	lucky
Negative	
It is sad that I can't attempt to gestate all of them under the circumstances	sad
I also feel pressure, because if we have twins this time then we need to decide what to do with the remaining embryos	pressured
I worry about them as I feel too old to have another baby even though I would like a third	worried
I feel anxiety mostly, about what to do with them and what they mean to me	anxious
Guilt over destroying potential life forms	guilty

Table 5.3

Original patient quotations and derived scale items for CCER scale

Patient quotation	Scale item
	My extra embryos
Human concept	
I think of them as my children	are like children
Optimism	
I hope against reason that they will provide me with at least another child	are hope for having children in the future
Security	
(They are) protection from further fertility loss from aging	are protection if fertility problems persist in the future
(I) want to keep them for now as worried something may happen to one of my children	are a back-up if something happens to my/our children
Value	
(They) are the most important thing to me in my life 10 plus"	are important to me
They are the beginning of life and are precious to me	are precious
Potential	
I view them as the potential to bless our family with future children	are future opportunities for having a(nother) child
Medical	
We originally considered the frozen ones our possible stem cell source for our two sons if they ever needed that type of medical help	could be used for stem cell therapy in case of illness
Relationship	(Stand-alone statements)
I feel emotionally connected to them	I am emotionally attached to my extra embryos
I love them	I love my extra embryos

Cardiff Affective Embryo Representation (CAER) scale

Past Embryo Storage (PES) group

Intercorrelations conducted on the 29 items of the CAER scale showed a range from .004 to .82 (N = 146). One item (curious) showed low intercorrelations with all items (< .43) and was removed from further analyses.

PCA on the remaining 28 items (n = 148) showed a Kaiser-Meyer-Olkin index of common variance of .92 (Zwick & Velicer, 1986). Bartlett's test of sphericity χ^2 (325) = 3393, $p < .001$, indicated that correlations between items were sufficiently large for PCA. Three components had eigenvalues > 1 and in combination explained 66.3% of the variance. Inspection of the scree plot showed inflexions that confirmed a three-component solution fitted the data best (see Figure 5.2 in Appendix 7). Component loadings after rotation for the three components are shown in Table 5.4. The eleven items that loaded highly on component one (> .64) with cross loadings on component three (< .57) suggested that component one represents *Distress* (nervous, worried, anxious, tense, frustrated, uncertain, helpless, upset, concerned, sad, depressed). The *Distress* component had an eigenvalue of 11.12 and accounted for 39.7% of the variance.

The ten items that loaded highly on component two (> .66) suggested that it symbolises *Positivity* (happy, optimistic, pleased, glad, positive, comforted, relieved, hopeful, lucky, content). The *Positivity* component had an eigenvalue of 5.80 and accounted for 20.7% of the variance.

Table 5.4

Rotated component matrix for CAER items of the PES group (N = 148)

Items	Component		
	Distress	Positive	Conflict
Nervous	.860		
Worried	.821		
Anxious	.819		
Tense	.782		.
Frustrated	.737		.380
Uncertain	.735		
Helpless	.719		.421
Upset	.662		.491
Concerned	.650		.456
Sad	.646		.535
Depressed	.643		.566
Happy		.896	
Optimistic		.860	
Pleased		.855	
Glad		.843	
Positive		.812	
Comforted		.806	
Relieved		.777	
Hopeful		.773	
Lucky		.743	
Content		.660	
Conflicted			.828
Undecided			.778
Confused	.368		.707
Stuck	.444		.640
Pressured			.601
Guilty			.533
Tentative	.470		.525

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
Only component loadings >.30 are shown
Highlighted items were selected for the final CAER scale

The seven items that loaded highly on component three (> .54) with cross loadings on the *Distress* component (< .46) suggested that component three embodied *Conflict* (conflicted, undecided, confused, stuck, pressured, guilty, tentative). The *Conflict* component accounted for 5.9% of the variance with an eigenvalue of 1.65.

Creation of the CAER scale

Following the method of Dawis (1987), that suggests selecting those items that are most diverse in regards to their underlying construct and of highest component loadings, six items were selected for each component. For the *Distress* subscale *nervous, worried, anxious, tense, frustrated* and *uncertain* were selected. The selected items for the *Positivity* subscale were *happy, optimistic, pleased, glad, positive*, and *comforted,* and the selected items for the *Conflict* subscale were *conflicted, undecided, confused, stuck, pressured* and *guilty.*

Current Embryo Storage (CES) group

The analysis was repeated on the other group (CES, N = 232) and revealed a similar scale structure with mean loading differences of .066 between the groups. The selected 18 items were subsequently subjected to a PCA. The Kaiser-Meyer-Olkin index was .91. Bartlett's test of sphericity χ^2 (153) = 2783.84, p < .001, indicated that correlations between items were sufficiently large for PCA. Three components had eigenvalues > 1 and in combination explained 68.7 % of the variance. Inspection of the scree plot showed inflexions that confirmed a three-component solution fitted the data best (see Figure 5.3 in Appendix 8). The first component explaining item variance was the *Distress* subscale, which explained 41% of the variability with an eigenvalue of 7.37. The second component, the *Positivity* subscale, explained 18.9%

of the variance with an eigenvalue of 3.4, and the third component, the *Conflict* subscale, explained 8.9% of the variance with an eigenvalue of 1.6. Loadings after rotation for the three retained components are shown in Table 5.5. The PCA results for group CES showed similar item loadings and scale structure as in group PES where all six items loaded highly on their respective components, and only weak to moderate cross-loadings (< .52) occurred between component *Distress* and component *Conflict*.

Psychometric properties of the scale

Frequency distributions, mean values, range and skewness were computed for the CAER subscales according to group (CES versus PES) showing some deviation from normality (skewness sores ranged between 1.24 – 5.38) as presented in Figures 5.4 and Table 5.6. Internal reliability coefficient for the subscales of the CAER was computed on the overall sample (N = 391) with Chronbach's alpha ranging from .86 - .92 (see Table 5.6).

A Multivariate Analysis of Variance (MANOVA) was computed to examine differences between subscales according to group (PES versus CES). For affective embryo representations the MANOVA showed a significant multivariate group effect ($F(3, 410) = 15.36$, $p < .001$; Wilks $\lambda = .90$) that was due to a significant difference between groups on the *Distress* subscale where distress was significantly higher in group PES than CES ($F(1, 412) = 17.79$, $p < .001$). There was no significant difference between groups on *Positivity* ($F(1, 412) = .005$, $p = .944$) and *Conflict* ($F(1, 412) = 2.19$, $p = .140$).

Table 5.5

Rotated component matrix for CAER items of the CES group (N = 232)

Items	Component		
	Distress	Positivity	Conflict
Nervous	.878		
Anxious	.845		
Worried	.788		
Tense	.737		.401
Frustrated	.717		
Uncertain	.649		.323
Happy		.907	
Glad		.842	
Positive		.814	
Optimistic		.797	
Pleased		.781	
Comforted		.770	
Conflicted			.825
Pressured			.808
Undecided			.803
Guilty	.390		.688
Confused	.520		.651
Stuck	.469		.582

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
Only component loadings >.30 are shown

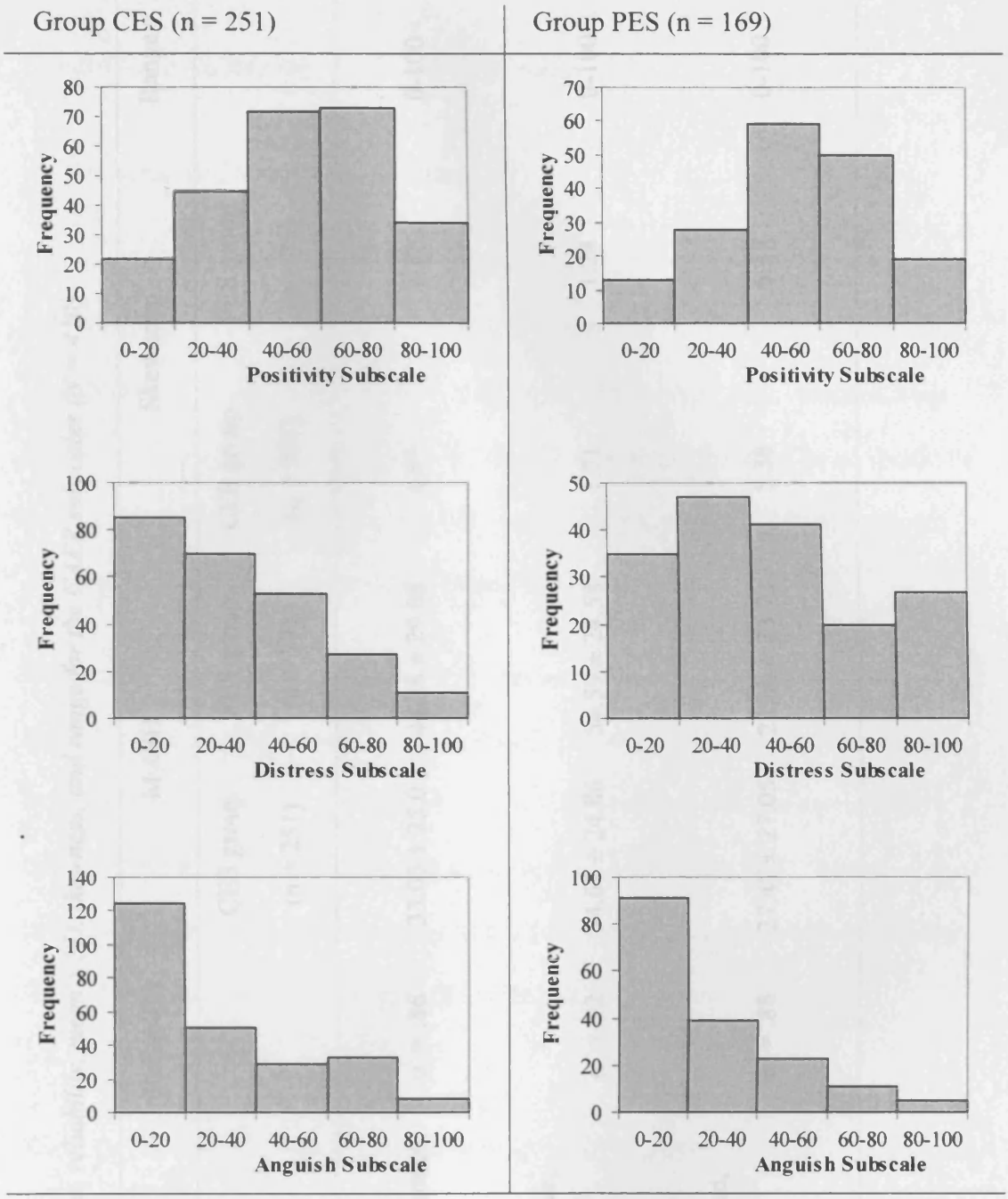

Figure 5.4: Frequency distributions of the CAER subscale. The left hand panel shows group CES, right hand panel shows group PES.

Table 5.6

Embryo affective representation items, reliability, mean ± SD, skewness, and range for the CAER subscales (N = 410)

	Items	Reliability	M ±SD		Skewness		Range
Subscale			CES group (n = 251)	PES group (n = 171)	CES group (n = 251)	PES group (n = 71)	
Distress	Nervous, anxious, worried, tense, frustrated, uncertain	α = .86	33.03 ± 25.0	44.38 ± 29.08	4.57	2.13	0-100
Positivity	Happy, glad, positive, optimistic, pleased, comforted	α = .92	54.61 ± 24.86	54.59 ± 24.58	1.71	1.24	0-100
Conflict	Conflicted, pressured, undecided, guilty, confused, stuck	α = .88	27.47 ± 27.05	23.66 ± 23.73	5.38	5.37	0-100

Cardiff Embryo Representation (CCER) scale

Past Embryo Storage (PES) group

Intercorrelations conducted on the 40 items of the CCER scale showed a range from .004 to .82 (N = 146). Four items (my/ our children, like children, family, a form of life) showed high correlations (0.81 – 0.87) with all items and were removed from further analyses. Low intercorrelations (< 0.33) were found for three items (could be used for stem cell therapy, are a back-up if something happens to my children, are stem cell sources) and were removed from further analyses.

PCA on the remaining 33 items (n = 142) showed a Kaiser-Meyer-Olkin index of .86. Bartlett's test of sphericity χ^2 (528) = 3642.03, $p < .001$, indicated that correlations between items were sufficiently large for PCA. Six components had eigenvalues > 1. However, inspection of the scree plot (see Figure 5.5 in Appendix 9) showed inflexions that suggested a three-component solution fitted the data best accounting for 69.6% of the variance. Component loadings after rotation for the three components are shown in Table 5.7.

The eighteen of the 33 items that loaded moderately to highly on the first component (>.56) with cross loadings on the second and third component (< .50) suggested that component one represents *Attachment & Human Concept*. The *Attachment & Human Concept* component had an eigenvalue of 13.6 and accounted for 41.1% of the variance.

Table 5.7

Rotated component matrix for CCER items of the PES group (N = 143)

Items	Component		
	Attachment & Human Concept	Hope	Genetic Relation & Ownership
I love my embryos	.792		
My embryos are human life	.783		
I am emotionally attached to my embryos	.778		
My embryos are already babies	.773		
My embryos are like family members	.763		
My embryos are like unborn children	.747		
My embryos are miniature versions of our children	.727		
My embryos should be given a chance at life	.705		
My embryos mean the world to me	.689		.326
I am protective towards my embryos	.678		
My embryos are living organisms	.673		
The life of my embryos depends on me	.666		
My embryos are our children in the future	.642	.504	
My embryos are clusters of cells	-.610		
I would never abandon my embryos	.599		
My embryos are precious	.578	.343	.429
My embryos are special to me	.578	.338	.462
My embryos should be respected	.555		

Table 5.7 continued

Items	Component		
	Attachment & Human Concept	Hope	Genetic Relation & Ownership
My embryos are a possibility of having a(nother) child		.798	
My embryos are hope for (more) children		.796	
My embryos are a chance to have a baby		.785	
My embryos are options for having children in the future		.774	
My embryos are future opportunities for a(nother) child		.709	
My embryos are hopefully become my children someday		.691	
My embryos are hope for having our own (biological) children		.653	.423
My embryos are protection if fertility problems persist in the future		.559	
My embryos are my/ our genetic make-up			.758
My embryos are genetically related to me (and my partner)			.705
My embryos are important to me	.318	.440	.582
My embryos belong to me	.379		.565
My embryos are my responsibility	.488		.538
I own my embryos	.317		.534
My embryos are valuable to me	.353	.357	.418

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
Only component loadings >.30 are shown
Highlighted items were selected for the final CCER scale

The nine items that loaded strongly on the second component (>.56) with cross loadings on the third component (< .42) suggested that component two symbolises *Hope*. The *Hope* component had an eigenvalue of 3.5 and accounted for 10.7% of the variance.

The seven items that loaded moderately to highly on the third component (> .42) with cross loadings on the first and second component (< .48) suggested that component three embodied *Genetic Relation & Ownership.* The *Genetic Relation & Ownership* component had an eigenvalue of 1.9 and accounted for 5.8% of the variance.

Creation of the CCER scale

According to the method of Dawis (1987) eight items were selected for the *Attachment & Human Concept* component, four items were selected for the *Hope* component and four items for the *Genetic Relation & Ownership* component.

As highlighted in Table 5.7, the following items were selected for the *Attachment & Human Concept* subscale: *I love my embryos, my embryos are human life, I am emotionally attached to my embryos, my embryos are already babies, my embryos should be given a chance at life, I would never abandon my embryos, my embryos are living organisms, my embryos are clusters of cells.* The selected items for the *Hope* subscale were *my embryos are a possibility of having a(nother) child, my embryos are hope for (more) children, my embryos are a chance to have a baby, my embryos are options for having children in the future.* The selected items for the *Genetic relation & Ownership* subscale were m*y embryos are my/ our genetic make-up, my embryos are genetically related to me (and my partner), I own my embryos,* and *my embryos belong to me.*

Current Embryo Storage (CES) group

The analysis was repeated on the other group (CES, N = 229) and revealed a similar scale structure with mean loading differences of .072 between the groups. The selected 16 items were subsequently subjected to an EFA. The Kaiser-Meyer-Olkin index was .88. Bartlett's test of sphericity χ^2 (120) = 2168.30, $p < .001$, indicated that correlations between items were sufficiently large for PCA. Four components had eigenvalues > 1, however, inspection of the scree plot showed inflexions that suggested a three component solution fits the data best explaining 64.3% of the variance (see Figure 5.6 in Appendix 10). The first component explaining item variance was the *Attachment & Human Concept* subscale, which explained 42.1% of the variability with an eigenvalue of 6.7. The second component, the *Hope* subscale, explained 13.1% of the variance with an eigenvalue of 2.1, and the third component, the *Genetic Relation & Ownership* subscale, explained 9.2% of the variance with an eigenvalue of 1.5. Loadings after rotation for the three retained components are shown in Table 5.8.

The PCA results for group CES showed similar item loadings and scale structure as in group PES where all items loaded highly on their respective components, and only weak to moderate cross-loadings (< .45) occurred between the scales.

Table 5.8

Rotated component matrix for CCER items of the CES group (N = 229)

Items	Component		
	Attachment & Human Concept	Hope	Genetic Relation & Ownership
My embryos are already babies	.824		
My embryos are human life	.806		
My embryos should be given a chance at life	.785		
I love my embryos	.772		
I am emotionally attached to my embryos	.739		
I would never abandon my frozen embryos	.608		
My embryos are living organisms	.587		.406
My embryos are clusters of cells	-.434		
My embryos are a possibility of having a(nother) child		.900	
My embryos are hope for (more) children		.868	
My embryos are options for having children in the future		.846	
My embryos are a chance to have a baby		.818	
My embryos are genetically related to me (and my partner)			.852
My embryos are my/ our genetic make-up			.824
My embryos belong to me		.450	.602
I own my embryos		.320	.463

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

Only component loadings >.30 are shown

Psychometric properties

Frequency distributions, range and skewness were computed for the CCER subscales according to group (CES versus PES) showing some deviation from normality (skewness sores ranged between 1.9 – 14.93) as presented in Figures 5.7 and Table 5.9. Internal reliability coefficient for the subscales of the CECR was computed on the overall sample (N = 408) with Chronbach's alpha ranging from .88 - .89 (see Table 5.10).

A Multivariate Analysis of Variance (MANOVA) was conducted in order to examine group differences on cognitive embryo representation and showed a marginally significant group effect ($F(3, 412) = 2.06$, $p = .104$; Wilks $\lambda = .99$) that was due to a significant difference between groups on the *Attachment & Human Concept* subscale where *Attachment & Human Concept* was significantly higher in group PES than CES ($F(1, 414) = 3.96$, $p = .047$). There was no significant difference between groups on *Hope* ($F(1, 414) = .09$, $p = .761$) and *Genetic Relation & Ownership* ($F(1, 414) = .001$, $p = .976$).

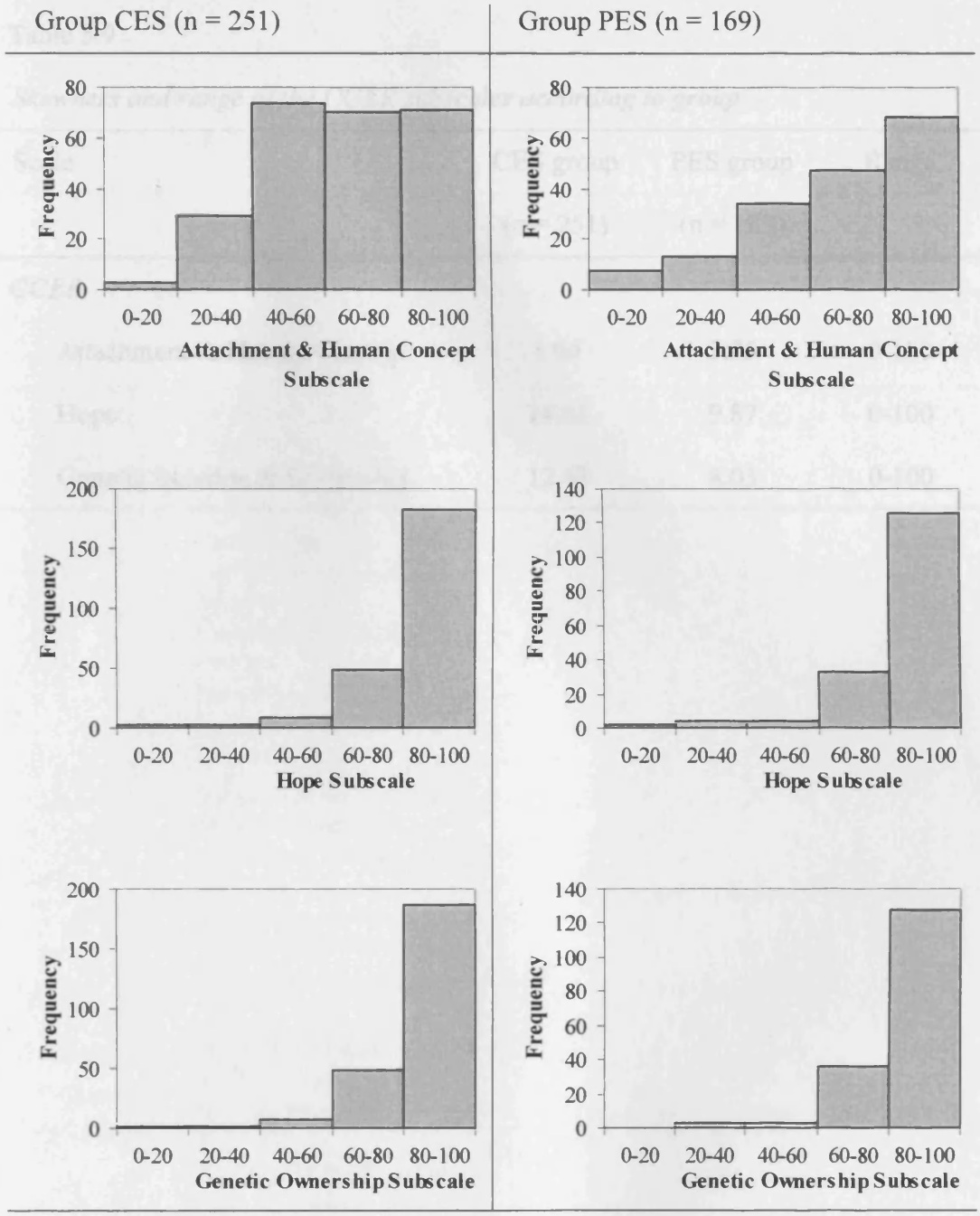

Figure 5.7: Frequency distributions of the CCER subscale. The left hand panel shows group CES, right hand panel shows group PES.

Table 5.9

Skewness and range of the CCER subscales according to group

Scale	CES group (n = 251)	PES group (n = 169)	Range
CCER			
Attachment & Human Concept	1.90	3.75	0-100
Hope	14.93	9.87	0-100
Genetic Relation & Ownership	12.47	8.03	0-100

Table 5.10

Embryo conceptualisation items, reliability and mean for the CCER scale and its subscales (N = 408)

	Items	Reliability	M ±SD	
Subscale			CES group (n = 251)	PES group (n = 171)
Attachment & Human Concept	I love my embryos My embryos are already babies My embryos are human life My embryos should be given a chance at life I am emotionally attached to my embryos I would never abandon my frozen embryos My embryos are living organisms My embryos are clusters of cells (reversed)	α = .88	65.11 ± 21.48	69.73 ± 23.56
Hope	My embryos are a possibility of having a(nother) child My embryos are hope for (more) children My embryos are options for having children in the future My embryos are a chance to have a baby	α = .89	88.68 ± 17.98	88.15 ± 17.21
Genetic Relation & Ownership	My embryos are genetically related to me (and my partner) My embryos are my/ our genetic make-up My embryos belong to me I own my embryos	α = .74	87.78 ± 15.20	87.81 ± 14.54

Correlations among CAER and CCER subscales

The *Positivity* subscale correlated negatively with both the *Distress* and *Conflict* subscales, and the *Distress* and *Conflict* subscales correlated negatively, as shown in Table 5.11. Table 5.11 also shows correlations of the three subscales with emotional reactions to treatment and dissonance where *Distress* and *Conflict* correlated negatively with positive treatment reactions and positively with negative treatment reactions as well as with dissonance. *Positivity* correlated positively with positive treatment reactions. No significant correlation was found between *Positivity* and negative treatment reactions or dissonance.

Attachment & Human Concept correlated positively with negative treatment reactions and correlated negatively with positive treatment reactions. No significant correlations were found between the *Hope* or *Genetic Relation & Ownership* subscales and the DRK subscales.

Associations between the affective (CAER) subscales and the cognitive (CCER) subscales revealed a positive association between *Attachment & Human Concept* and all three affective subscales. Positive correlations were also found between *Hope* and the two affective subscales *Positivity* and *Distress*, as well as between *Genetic Relation & Ownership* and the two affective subscales *Distress* and *Conflict* (as shown in Table 5.11).

Table 5.11

Intercorrelations of the CAER and CCER subscales, emotional treatment reactions, and dissonance for the overall sample (N = 417)

		Group	1	2	3	4	5	6	7	8	9	Mean ± SD
1	Attachment & Human Concept		-									66.99 ± 22.44
2	Hope	CES	.455***	-								88.47 ± 17.65
		PES	.399***									
3	Genetic Relation & Ownership	CES	.490***	.480***	-							87.79 ± 14.92
		PES	.466***	.360***								
4	Positivity	CES	.149*	.273***	.048	-						54.61 ± 24.72
		PES	.060	.259***	.085							
5	Distress	CES	.248***	.173**	.206***	-.233***	-					37.67 ± 27.27
		PES	.352***	.209**	.106	-.190*						
6	Conflict	CES	.163**	.005	.142	-.306***	.650***	-				25.92 ± 25.79
		PES	.245***	-.010	.114	-.250***	.619***					
7	Positive treatment reaction	CES	-.067	.099	-.019	.451***	-.358***	-.235***	-			3.14 ± .75
		PES	-.171*	-.056	-.045	.207**	-.126[t]	-.029				
8	Negative treatment reaction	CES	.068	.078	.003	-.110	.493***	.259***	-.478***			2.28 ± .93
		PES	.177*	.112	.038	-.039	.354***	.325***	-.467***			
9	Dissonance	CES	.035	.062	-.039	-.071	.445***	.242***	-.336***	.845***	-	2.08 ± .91
		PES	.076	.015	-.029	-.012	.265***	.322***	-.286***	.860***		

[t] p < .10; *p < .05; ** p < .01; *** p < .001

Discussion

The CAER and CCER scales offer reliable and sensitive measurement tools for couples' affective and cognitive representations of their embryos. The two scales were generated from a comprehensive literature review, consultations of four international experts, and importantly, a mixed-methods survey comprising 157 women in diverse embryo disposition contexts. The scales were submitted to an empirical acceptability and psychometric evaluation survey comprising 421 individuals in five countries. These evaluations showed high coherence and reliability among subscale items and concurrent validity. This work addressed an important gap in ED research and clinical practice and it is hoped the new scales will help integrate research, improve patient experience and inform patient support.

The CAER and CCER scales consist of three subscales each. The CAER subscales address affective representations of embryos, that is, the way people feel about their embryos. It consists of three components *Positivity*, *Distress* and *Conflict* that are generally in line with findings from the qualitative results in Chapter 4 Part II. Specifically, the *Positivity* and *Distress* components resemble the *Positive* and *Negative* higher order categories. The *Conflict* component can also be found in previous research where the ED decision has been described as being accompanied by anguish and agony (de Lacey, 2005) as well as anxiety and sorrow (McMahon et al., 2000; Skoog Svanberg, Boivin, & Bergh, 2001).

The CCER subscales comprise cognitive representations of embryos, that is, the way people think about their embryos and their beliefs about them consisting of *Attachment & Human Concept*, *Hope*, and *Genetic Relation & Ownership*. These

three components are generally in line with findings from the qualitative results in Chapter 4, Part II in that the *Attachment & Human Concept* component resembles the *Human* and *Relationship* higher order categories, whereas the *Hope* components is similar to the *Optimism* and *Potential* higher order categories. The *Genetic Relation & Ownership* component appears to be related to the *Medical* higher order category but seems to fit to a lesser degree than the other components in that the *Medical* higher order category also refers to perceptions of the embryos as stem cell sources. The structure of the CCER scale is further supported by the empirical literature in that embryos are frequently conceptualised as humans (e.g., de Lacey, 2005; Hammarberg & Tinney, 2006; McMahon et al., 2000; Nachtigall et al., 2005). Hope for (more) children (Karpel et al., 2007; Parry, 2006) and an increase in optimism (Skoog Svanberg, Boivin, Hjelmstedt et al., 2001) have also been documented in previous research and therefore support current findings. Similarly, the importance of the genetic relation between the couple and their embryos for ED decision-making has been reported on many occasions (Fuscaldo, 2005; McMahon & Saunders, 2009; Nachtigall et al., 2005; Provoost et al., 2009). However, an ownership representation has received comparably little attention to date (Paul et al., 2010), where support for this components stems mostly from ethical (Pennings, 2000) and legal considerations (Waldman, 2003). As the items for the CAER and CCER scales were derived from patient quotations and extant research, the consistency between the EFA and psychometric analyses indicated that the scales adequately replicate what has been considered to be important affective and cognitive aspects of embryo representations.

The integration of cognition and emotions has not received much attention in previous research. However, the few available studies show that those couples who see their embryos as human (e.g., as children or potential children) also have a stronger

emotional attachment to their embryos (de Lacey, 2005). A strong emotional attachment to the embryos has been linked to negative emotions, in particular when embryos are perceived as children (Fuscaldo, 2005). Accordingly, it has been argued that couples' view of embryos as non-human is a way to protect themselves from getting too emotionally attached to the embryo (Provoost et al., 2009). The results from the current study may support these findings. Strong correlations were found between the *Distress* and *Conflict* subscales of the CAER scale and the *Attachment & Human Concept* as well as *Genetic Relation & Ownership* subscales of the CCER scale. However, causality cannot be inferred from the cross-sectional design of the current study and more prospective research is required to examine these relationships.

Previous research has shown that couples' positivity increases when they are able to cryopreserve embryos in that it makes them more optimistic (Skoog Svanberg, Boivin, Hjelmstedt et al., 2001), which has been linked to couples' hope for (more) children (Karpel et al., 2007; Parry, 2006). Similar associations were found in the current study in that *Attachment & Human Concept* correlated positively with *Hope,* and *Hope* correlated positively with *Positivity* providing further support for the validity of the scale structure. Significant correlations were also found between *Hope, Genetic Relation & Ownership* and *Distress*, whereby associations with between *Distress* and *Genetic Relation & Ownership* were only significant in group CES. Couples' hope for a positive treatment outcome and their beliefs regarding the genetic relation to their embryos has received comparatively little attention in research. Some studies have shown, however, that couples' genetic relation to their embryos complicated the disposition decision (de Lacey, 2005) and thinking about the genetic relation to their embryos made couples fearful of potential consequences when

choosing certain disposition options (e.g., donation to another couple; McMahon et al., 2000). It seems plausible that couples' genetic relation to their embryos is more distressing when embryos are still in storage which was reflected by significant associations in group CES only.

The sensitivity of the scales was demonstrated by mean differences between groups on *Distress* and *Attachment & Human Concept*. Given that patients who currently have cryopreserved embryos need to make a disposition decision in the future, *Distress* was expected to be higher in the CES group than the PES. However, the opposite pattern emerged in the data (significantly higher distress scores in group PES). Previous work investigating couples' feelings after disposing of embryos has shown that many couples agonised about their choice (McMahon et al., 2000), regretted their decision (de Lacey, 2005; McMahon et al., 2000), grieved their loss (Skoog Svanberg, Boivin, & Bergh, 2001) and experienced ongoing anxiety (Hammarberg & Tinney, 2006) years after making the decision. In the current study, phrasing of the items differed between groups in that participants in the PES group were asked to indicate how they felt and thought of their embryos when they were still in storage. That is, the PES group provided retrospective accounts that have been extensively shown to be less accurate than assessments that take place at the time of experiencing the phenomena under investigation (Bernard, Killworth, Kronenfeld, & Sailer, 1984). However, it is also important to note, that since participants in group PES are at a post-decisional stage they have the additional experience of making a final decision about their embryos in contrast to participants in group CES who are at a pre-decisional stage. Thus, in line with much of the empirical literature that suggests the ED decision is difficult it is plausible that group PES scored higher on the Distress subscale because they had a difficult time making the decision. Similarly, the lack of

difference between groups on the *Conflict* subscale might be partly due to elevated post-decisional conflict in group PES.

Participants in group CES would have been expected to score higher on *Hope* which was not found in the current study. This apparent inconsistency may have emerged because in the current study people in group CES were not differentiated according to whether they intended to have another embryo transfer or not. Almost 80% of participants in group CES already had children (M = 1.65, SD = 1.0). Thus, it may be that a good proportion of participants in group CES did not intend to use their embryos for their own family building which would explain the lack of hope in this group. Future research is needed to confirm these speculations in particular by investigating more differentiated groups.

The concurrent validity of the scale was demonstrated by correlations between the CAER subscales, CCER subscales and the DRK emotion subscales. As expected, the *Positivity* subscale correlated negatively with the *Distress* and *Conflict* subscales, the Distress and Conflict subscales correlated positively. Additionally, the *Positivity* subscale correlated positively with positive treatment reactions, whereas the *Distress* and *Conflict* subscales correlated positively with negative treatment reactions, and negatively with positive treatment reactions (CES group only). Correlations between participants' treatment reactions and other variables generally differed between groups. This apparent inconsistency may be explained by the characteristics of the DRK scale, which was designed specifically for people in infertility treatment (groups CES) but not for people who had infertility treatment in the past (group PES).

The results of the preliminary scale evaluations are promising for using the two scales in future research investigating the difficulty of the decision and improving patient

experience. The CAER and CCER scales meet standard requirements for scales to be used in heterogenous populations. The scales consist of 18 (CAER) and 16 (CCER) items which is considered to be a reasonable scale length to minimise response bias (Schriesheim & Hinkin, 1990), short enough to prevent respondents from fatigue in filling out the scale and comprehensive enough to provide content and construct validity, internal consistency, and test-retest reliability (Nunnally, 1978).

However, further scale evaluation is needed to address the limitations of the current methodology (the sample was mostly female, from North America, highly educated, and recruited online using a cross-sectional design). Internet populations in particular have been shown to be more highly educated than clinical samples despite the wide use and availability of the internet worldwide (Bunting & Boivin, 2007). Accordingly, the CAER and CCER scales need to be evaluated on non-American clinical samples preferably by employing a longitudinal design were special efforts should be invested in the recruitment of men. Evaluation of the scales in longitudinal cross-cultural studies will allow further assessment of the sensitivity of the scales, that is, to what extent the scales are sensitive to different stages of the decision process and different patient populations.

The CAER and CCER scales are hoped to be useful for clinicians and researchers. In clinical context the scales can be used by clinicians to identify affective and cognitive representation profiles that are empirically linked to a more difficult decision process and theoretically linked to decision avoidance (for theoretical considerations see Anderson, 2003; for the role of representations see e.g., McMahon et al., 2000; for the role of emotions see e.g., Nachtigall et al., 2005). If people at risk of decision avoidance can be identified early, then psychosocial resources can be delivered to

those who need it most. Support could be provided by decision deliberation exercises that are commonly embedded in so called decision support tools (DST). In general, these tools consist of three components: information component, deliberation component and an outcome measure (Elwyn, Stiel, Durand, & Boivin, in press). Decision deliberation including value or preference clarification has been argued to be beneficial to the quality of decisions (Elwyn et al., in press). Assessments of couples' embryo representations by use of the CAER and CCER scales could be conducted before and after information provision and decision deliberation in order to examine the impact of these interventions on embryo representations.

In research contexts the scales could be used to assess couples' embryo representations at different treatment stages (e.g, before initiating treatment, at the beginning of treatment, after a life birth, at the end of treatment). Research presented thus far suggests that embryo representation and ED preferences change over time (e.g., Ferling et al., 2004; Hounshell & Chetkowski, 1996; Klock et al., 2001; Lornage et al., 1995; Newton, Fisher et al., 2007). In particular changes in disposition preference occurred when couples were counselled in regards to their thoughts and feelings about disposition options (Saunders et al., 1995). It has been argued that ED options chosen at the initiation of treatment are somewhat abstract (Cooper, 1995), with couples following an ideal plan rather than a purposeful decision (de Lacey, 2005). Using the CAER and CCER scales to assess couples' representations of embryos could help them clarify their disposition preferences. Little is known about the way that affective and cognitive embryo representations impact on ED decision-making. Therefore, future research should employ longitudinal designs to investigate the causality between affective and cognitive embryo representations and their effects on ED decision-making.

Chapter 6: Affective and Cognitive Embryo Representations and their Change as a Function of Treatment Experience

Introduction

In the previous chapters the ED decision was shown to be a difficult decision that may be embedded in a dynamic decision context with ED preferences potentially changing over time. Additional, evidence for this proposition was provided by the empirical literature showing that patients' initial disposition choice at the time of consent had changed by the time they were finished with treatment (e.g., Newton, Fisher et al., 2007). A change in disposition preference has been associated with couples' treatment experiences in particular the experienced of a live birth from an embryo (McMahon et al., 2003). Despite these associations, it is still unclear what other factors play a role in changing couples' disposition preferences. However, research provided thus far suggests that cognitive and affective representations of the embryo may be critical in attitude formation towards the embryo and potentially the disposition decision (see original and adapted version of the attitude component model in Figure 5.1, page 162 and Figure 6.1, respectively). However, the stability of cognition and emotion in the ED context across different treatment stages is not known due to a lack of prospective research in general and throughout the treatment cycle specifically. To address this gap in knowledge, in the present study affective and cognitive representations were assessed from oocyte collection (time 1, T1) to embryo transfer (time 2, T2) to examine how important treatment events during this period impact on embryo representations and to examine how earlier affective representations impact on later cognitive representations (and vice versa).

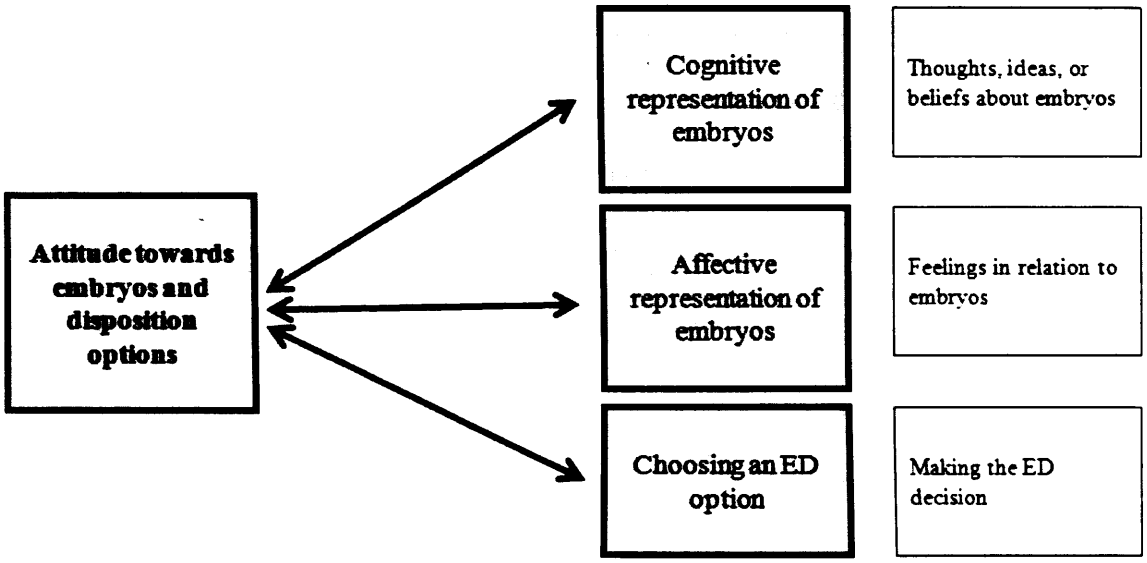

Figure 6.1: The attitude component model by Eagly & Chaiken (1994) adapted to the ED decision context

During the period between oocyte retrieval and embryo transfer, several events take place that may impact on cognitive and affective representations of embryos. At the collaborating ART clinic, these involved the retrieval of oocytes (after a 9-12 day period of ovarian stimulation) and fertilisation of the oocytes by means of IVF or ICSI. About 36 hours after fertilisation couples receive a call from the embryologist to inform them whether fertilisation has taken place, and if yes, the number of embryos that were created. Couples are then scheduled for their embryo transfer (1-3 days later) when they will first be allowed to view the projected microscopic image of their embryos on a large screen. Showing embryos on a screen or as a picture just before the embryo transfer has become standard practice in many ART clinics (e.g., Nachtigall et al., 2010).

It has been reported that couples were amazed by the sight of their embryos (Givens & Conaghan, 2005), which led to an increase in attachment to the embryo (Nachtigall et al., 2010). In related areas, seeing a foetus on an ultrasound scan has shown to increase maternal attachment and health behaviour in pregnancy (Sedgmen, McMahon, Cairns, Benzie, & Woodfield, 2006). Thus, seeing the embryos under the microscope is assumed to be a meaningful event that may make embryos more concrete to couples. After seeing the embryo, the women will be positioned for the embryo transfer in a quiet room with subdued lightning. The partner is present for the transfer. The embryo is loaded to a catheter and a maximum of two embryos are transferred to the women's uterus. The couple is then moved to another room where the woman is asked to lie for a further 20 minutes before the couple can leave the clinic. This is an intimate and important period in the treatment cycle because the transfer of viable embryos is perceived by couples as the beginning of a pregnancy with women reporting to "feel pregnant" after their embryo transfer (Seibel & Levin,

1987). While oocyte retrieval can be accompanied by an increase in stress due to uncertainty about fertilisation, once transfer has taken place emotional reactions are markedly optimistic (Boivin & Takefman, 1996) lasting for at least three or four days (Boivin & Lancastle, 2010). These events (visualising embryos, embryo transfer) are clearly significant to couples and may have an impact on couples' representation of embryos.

To this author's knowledge, studies to date have not examined the change in cognitive (e.g., human concept, genetic relatedness) and affective (e.g., positivity, distress) embryo representations during these important periods of treatment. Therefore, it is unclear whether these change over time, what relationship exists between the representations, and whether these aspects differ between men and women. Studies on gender differences have suggested that, although women experience more distress, spouses are generally similar in their emotional reaction to treatment during this treatment phase. In particular, they showed a similar profile for intimacy and optimism that were highest during oocyte retrieval and embryo transfer (Boivin et al., 1998).

The thrust of research has suggested a variety of links between cognitive and affective embryos representations, for example feeling emotionally attached to the embryos has been linked to seeing the embryos as human beings (Lyerly et al., 2006) or as hope for more children (Provoost et al., 2009). It has also been argued that couples try to avoid distress by refraining from getting too emotionally attached to their embryos by conceptualising them in medical rather than human terms (Provoost et al., 2009). However, the lack of research on bi-directional links makes it difficult to make

conclusive statements about the causal relation between affective and cognitive components of embryo representations.

Theoretical and empirical work on the relationship between cognition and affect in other domains began some 30 years ago and is still intensely debated today (Forgas, 2008). Research efforts have concerned exploring the cognitive antecedents of affect, that is, the thoughts, beliefs and appraisals preceding emotional responses (e.g., Smith & Kirby, 2000). The significant effect of cognitions on emotions is a well established finding that represents the core of cognitive therapy: pathological emotional responses (e.g., high levels of anxiety) are altered by modifying the way people think about the stressor (i.e., people's cognitions such as thoughts, beliefs, appraisals; Beck, 1995). In a study on pregnant women who had to choose a mode of delivery for their child it was shown that women who were taught a more constructive way of thinking about childbirth by means of cognitive therapy had reduced anxiety levels and were more likely to choose a vaginal birth instead of caesarean section (Saisto, Salmela-Aro, Nurmi, Könönen, & Halmesmäki, 2001).

Parallel associations, that is, the effect of affect on cognition has also received significant attention. One line of research has been concerned with the *feelings-as-information theory* that proposes that people attend to their emotions as a source of information, with different emotions providing different types of information (Schwarz, 2010). In regards to the ED context, this theoretical assumption would mean that couples' emotions (e.g., distress) towards embryos determine couples' cognitive representations (e.g., human being).

There have been various approaches to studying the relationship between cognition and affect including experimental cross-sectional designs, longitudinal studies, and

retrospective accounts to name a few. In the current study, a longitudinal methodology was chosen because it allows investigation of how embryo representations are linked and develop over time and treatment experiences. In particular, using multi-level regression allows investigation of the directionality of the causal relationship by reversing the time-lagged predictor and outcome variables (Duckworth, Tsukayama, & May). The longitudinal design was used to investigate the stability and direction of effect of patients' affective and cognitive embryo representations from before oocyte collection (T1) to after having experienced an embryo transfer (T2). Specifically, the effect of the three affective embryo representation subscales on each of the three cognitive embryo representation subscales and vice versa was examined. Gender differences for each of the subscales and across time were also examined. Between T1 and T2 couples would have experienced oocyte retrieval, fertilisation of the oocytes, seeing the embryos on screen and having an embryo transfer. It is hypothesised that treatment experiences between T1 and T2 will impact on embryo representations which may manifest differently in men and women. According to evidence from previous research (e.g., Boivin et al., 1998) it is hypothesised that couples will be predominantly optimistic during this treatment phase.

Method

Participants and recruitment

The final sample consisted of 29 couples that provided survey responses at both assessment times. The inclusion criteria were couples who had no previous experience with embryos, who had *extra* embryos at T2, and English language skills sufficient to fill in the study materials.

In total 87 couples were initially contacted when they attended the clinic at T1 but analysis was computed on 29 couples because n = 8 had previous embryos, n = 28 did not want to take part in the study, 10 couples filled in the T1 survey at oocyte retrieval but did not have *extra* embryos, n = 4 couples were not given the survey at T2, n = 6 couples did not provide T2 survey responses for unknown reasons, and n = 2 couples returned incomplete datasets. There were no differences on any of the study variables between the 29 couples included in the study and the 6 couples who dropped out and did not provide T2 responses.

The demographic and infertility characteristics of the final sample are shown in Table 6.1. Women were in their early thirties (range 26-41) and men in their mid thirties (range 26-48). All couples were married and most women and men were educated to college or university level. A minority already had children from the present or a past relationship (13% of women, 11% of men). On average people had two children including adopted and step-children. Couples had on average 3 *extra* embryos at T2.

Materials

Table 6.2 and Figure 6.2 present an overview of the study design and study materials. The study materials included questions about demographic background, number of embryos at T2, the CAER subscales and the CCER subscales. Participants also completed the emotional reactions to treatment subscale of the Daily Record Keeping form and the Choice Predisposition Survey to assess intentions towards ED options (see Appendix 11 part I and II, and Appendix 12 for the materials).

Table 6.1

Descriptive statistics for demographic variables and family history (N = 29)

Variables	Women	Men
Demographics		
Age (M ± SD)	33.24 ± 3.74	35.63 ± 5.56
Education (% (n))		
University	62.1 (18)	59.3 (16)
Post-Secondary/College	27.6 (8)	22.2 (6)
Secondary School	10.3 (3)	18.5 (5)
Primary School	-	
Family and fertility history		
Participants who have children (% (n))	13.8 (4)	11.1 (3)
Number of children (only those who have children) (M ± SD)	2.0 ± 0.82	2.33 ± 0.58
Discrepancy between number of children wished for and current number of children (M ± SD)	2.25 ± 1.07	2.19 ± 0.98
Number of embryos at T2	3.21 ± 1.72	

Note. N varies between variables

Table 6.2

Materials completed by patients at each assessment

Number of items	Variable	Measure and author	Assessment schedule	
			Oocyte retrieval (time 1)	Embryo transfer (time 2)
6	Socio-demographic factors (e.g., age, education)	Socio-demographic factors	x	
20	Emotional reaction to IVF/ ICSI	Emotion subscale of Daily Record Keeping form (Boivin, 1997; Boivin and Takefman, 1995, 1996)	x	x
5	Embryo history (e.g., total number of frozen embryos)	Embryo history	x	x
9	Intention for embryo transfer and ED options	Choice Predisposition Decision Scale (O'Connor, 1996)	x	x
18	Affective embryo representation	CAER	x	x
16	Cognitive embryo representation	CCER	x	x

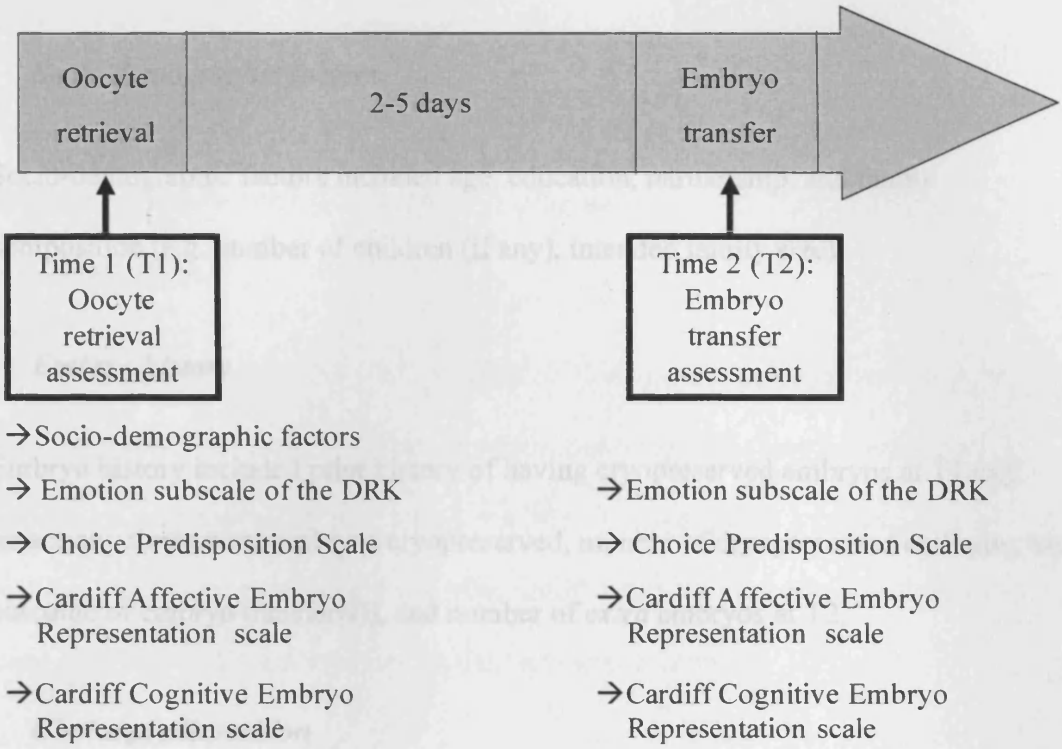

Figure 6.2: IVF/ICSI treatment schedule (shaded areas) and study assessment schedule (bold areas).

Socio-demographic factors

Socio-demographic factors included age, education, partnership, and family composition (e.g. number of children (if any), intended family size).

Embryo history

Embryo history included prior history of having cryopreserved embryos at T1 (e.g. how many times were embryos cryopreserved, number of cryopreserved embryos, and outcome of embryo transfer(s)), and number of *extra* embryos at T2.

Choice predisposition

The Choice Predisposition Scale (O'Connor, 1996) was adapted to the ED context and was used to assess to what extent patients *lean towards* using their embryos for further treatment at the time of their participation. Additionally, the CPS was used to assess to what extent patients lean towards choosing any of the three disposition options (donation to research, donation to another couple, thawing and disposal) when they have decided they no longer intend to use their embryos for themselves.

The response scale for the CPS is a 15-point Likert-type scale ranging from 1 = e.g., no, I don't want to use my frozen embryos for further treatment to 15 = e.g., yes, I want to use my frozen embryos for further treatment where the exact wording of each end of the scale depends on the option set. For further information on the scale see Chapter 4, page 85.

Emotional reactions to treatment

Emotional reaction specific to IVF and ICSI treatment were measured using the emotion subscale of the Daily Record Keeping form (Boivin, 1997; Boivin & Takefman, 1996).

The emotion-subscale of the DRK consists of 20 items asking patients to what extent they felt an emotion (e.g., confident, anxious, positive) in the last 24 hours on a 5-point scale comprising 0 = not at all, 1 = a little, 2 = a moderate amount, 3 = very much, 4 = an extreme amount. For further information on the scale see Chapter 5, page 167. Reliability information for the subscales is shown in Table 6.3.

Affective embryo representation

The Cardiff Affective Embryo Representation (CAER) scale was developed based on a literature review and empirical study as described in Chapter 5. The CAER scale assesses on a 5-point Likert scale ranging from 1=strongly disagree to 5= strongly agree affective embryo representations on 16 items that are grouped into three subscales: *Positivity* (e.g., *my extra embryos make me* happy, glad, etc.), *Distress* (e.g., nervous, anxious, etc.), and *Conflict* (e.g., conflicted, pressured, etc.). Scores for each subscale were averaged so that scores would range from 0-100 using the following formula:

$$((\bar{x} - 1) * 25)$$

where $\bar{x}$ = participant mean. Reliability information for the subscales is shown in Table 6.3.

Table 6.3

Reliability for DRK subscales, CEAR and CCER subscales (N = 29)

Variables	Time 1		Time 2	
	Women	Men	Women	Men
DRK subscales				
Positive	.88	.86	.89	.90
Negative	.77	.91	.82	.72
CAER subscales				
Positivity	.92	.95	.93	.93
Distress	.76	.71	.86	.74
Conflict	.57	.67	.84	.60
CCER subscales				
Attachment & Human Concept	.79	.75	.79	.83
Hope	.91	.85	.87	.95
Genetic Relation & Ownership	.79	.77	.76	.82

Cognitive embryo representation

The Cardiff Cognitive Embryo Representation (CCER) scale was developed based on a literature review and empirical study as described in Chapter 5. The CCER assesses on a 5-point Likert scale ranging from 1=strongly disagree to 5= strongly agree cognitive embryo representations on 16 items that are grouped into three sub-scales: *Attachment & Human Concept* (e.g., *my frozen embryos* are human beings), 2) *Hope* (e.g., are options for having children in the future), 3) *Genetic Relation & Ownership* (e.g., are my/ our genetic make-up).

One item (clusters of cells) on the *Attachment & Human Concept* subscale was reversed so that higher scores indicated stronger *Attachment & Human Concept*.

Scores for each subscale were averaged so that scores would range from 0-100 using the following formula:

$$((\bar{x} - 1) * 25)$$

where $\bar{x}$ = participant mean. Reliability information for the subscales is shown in Table 6.3.

Procedure

A member of the embryology team approached couples that attended the clinic for oocyte collection and sperm sampling (T1) and introduced the study. The embryologist explained the objectives of the study and provided interested patients with a research pack containing the patient information form, a consent form, all study materials and a freepost return envelope. Patients were asked to read the information in the research pack and ask any questions.

At T2, patients who attended the clinic for an embryo transfer were shown their embryos on a screen that is connected to a camera in the microscope used to prepare embryos for transfer. Embryo viewing is standard practice at IVFWales and takes place immediately before the embryo transfer. A member of the embryology team gave participants the T2 research pack when women were resting for 20 minutes after embryo transfer. Whether or not couples chose to participate, they returned questionnaires and consent forms either in a marked collection box at the clinic, or if they wanted to take the materials home, sent back the forms to the research team in the freepost return envelope. A member of the embryology team assigned each research pack a participant code unique to the couple that was noted on a master list linking patients' names with their research code. Patients were advised to not put their names anywhere on the materials returned to the research team. This way, patient names remained anonymous to the research team.

The South East Wales Research Committee Panel B of the National Health Service (NHS) as well as the Research & Development department of the Cardiff and Vale University Health Board provided ethical review and approval for the study (see Appendices 13 and 14).

Data analysis

A multivariate within-subject analysis of variance (MANOVA) was conducted using the Statistical Package for the Social Sciences (SPSS) 16.0 in order to determine differences in affective and cognitive representation of embryos according to gender and across time. Significant interactions were followed up with paired t-tests.

In order to explore the direction of the causal effect between affective and cognitive embryo representations a cross-lagged design was used. In a full cross-lagged design the effect of the predictor variable(s) at T1 on the outcome variable at T2 is tested while controlling for the predictor variables at T2 and the outcome variables at T1. Due to a small sample size (N = 29 couples) and its associated lowered power, computing a full cross-lagged was not advisory (Cranford, 2004). In such situations, a partial cross-lagged design is advocated (Pelz & Andrews, 1964). This design solely controls for outcome variables at T1. The appropriateness of this design notwithstanding, caution needs to be taken in regards to the causality of the observed effect because predictor variables at T2 are not controlled.

A multi-level regression approach was used to conduct the partial cross-lagged analyses using Hierarchical Linear Model software (HLM 6.06; Raudenbush, Bryk, & Congdon, 2004). In general, multi-level regression is used when data are nested. In the current study it allowed treating all participants (men and women) as the unit of analyses without violating the assumption of independence by controlling for the dependence of the data due to participants being members of a couple (Snijders & Bosker, 1999).

A total of six multi-level regression analyses were conducted. First, a set of three multi-level regression analyses was conducted, each with the three CAER subscales (*Positivity, Distress, Conflict*) at T1 as the simultaneous predictor variables, and one of the three CCER subscales at T2 as the outcome variable, while controlling for the respective outcome variable (CCER subscale) at T1. Figure 6.3 illustrates this multi-level partial cross-lagged analysis with the CCER *Hope* subscale as the outcome variable.

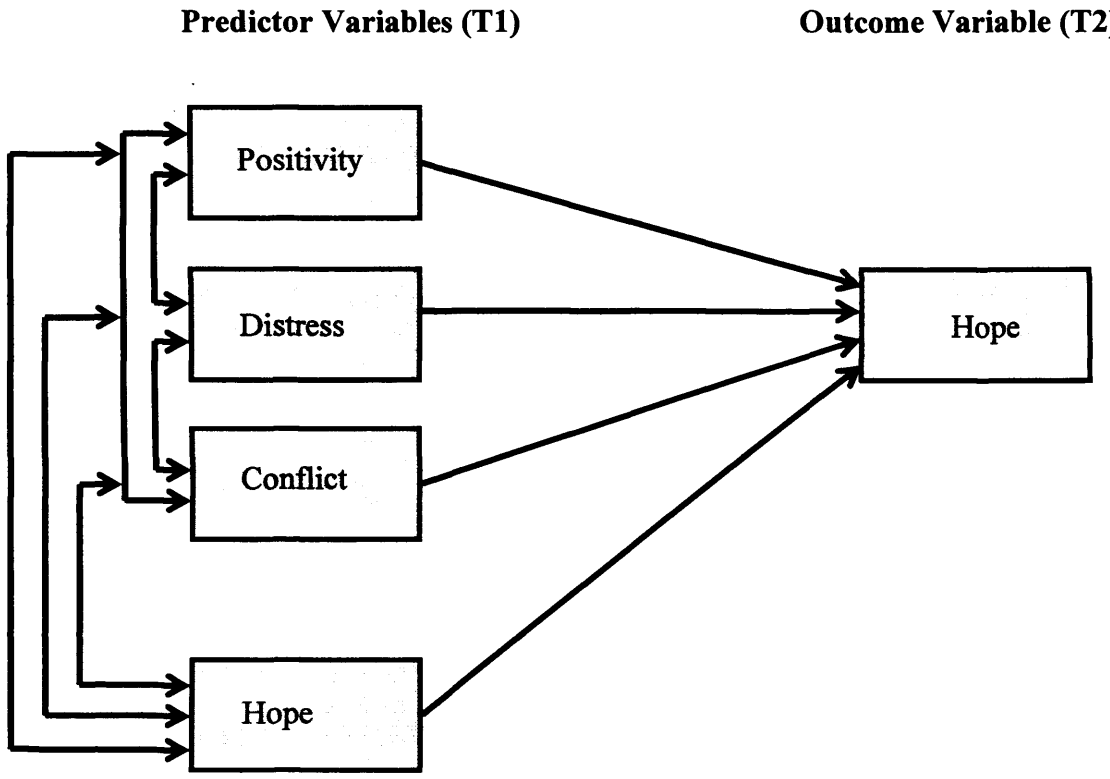

Figure 6.3: Multi-level partial cross-lagged analysis with the CCER Hope subscale as the outcome variable

Second, another set of three multi-level regression analyses was conducted to test the competing reversal direction of effect. Analogous to the first set, the three CCER subscales (*Attachment & Human Concept, Hope, Genetic Relation & Ownership*) at T1 served as the simultaneous predictor variables, and one of the three CAER subscales at T2 served as the outcome variables while controlling for the respective outcome variable (CAER subscale) at T1.

Following the recommendations by Cohen, Cohen, and West (2003) and Luke (2004), scores of all predictor variables were grand-mean-centred.

Together, HLM estimated equations of the following form:

Level 1 model: $Y_{T2} = л0 + л1(X1_{T1}) + л2(X2_{T1}) + л2(X3_{T1}) + л3(Y_{T1})\ e$

Level 2 model: $л0 = \beta00 + r0$

In these models, Y_{T2} = CCER subscale (e.g., *Attachment & Human Concept*) at T2 is predicted by $X1_{T1}$ = *Positivity* at T1, $X2_{T1}$ = *Distress* at T1, $X3_{T1}$ = *Conflict* at T1 and $X4_{T1}$ = CCER subscale (e.g., *Attachment & Human Concept*) at T1. The equation also includes e = error term of Level 1 model, and r0 – r3 = error terms of the respective Level 2 equations (which are used to identify the parameters of the Level 1 model). Power calculations were conducted using G*Power (Faul, Erdfelder, Buchner, & Lang, 2009). For the within-subjects MANOVAs based on N = 29, 2 x 2 repeated measures design, medium effect size (f= .15), and alpha = .05 criteria power was estimated to be .76. For the multi-level regression criteria power was estimated to be .70 based on N = 29, a medium effect size for regression (f= .15), and alpha = .05. Both power estimations were within an acceptable range for psychological studies (Rossi, 1990).

Data were examined to determine suitability for univariate and multivariate analyses. Raw values are presented in tables and frequency distributions for the CAER and CCER subscales according to men and women across are presented in Figures 6.4 – 6.9 (see Appendix 16). Skewness (≥ 2.58) was present in the negative emotional reaction subscale of the DRK for men at T1 (3.91), and in the *Conflict* subscale for women at T1 (3.86) and T2 (5.06), and for men at T2 (6.22). Items were retained without transformation because of the relatively mild skewness.

Results

The results will be presented in three sections. Section I shows the summary statistics for the DRK emotion subscale, ED intentions, and the CAER and CCER subscales. In section II Multivariate Analyses of Variance (MANOVAs) were computed on the CAER and CCER subscales according to time and gender. Finally, section III will show associations between subscales of the CAER and CCER scales that were computed by means of a hierarchical linear model (HLM).

I. Summary statistics on study variables

Summary statistics for the DRK emotion subscale, ED intentions, and the CAER and CCER subscales were computed and are shown in Table 6.4. The CAER and CCER subscales varied in range from 0-100 (*Positivity*), 0-50 (*Distress*), 0-50 (*Conflict*), 3.1-81.2 (*Attachment & Human Concept*), 50-100 (*Hope*), 37.5-100 (*Genetic Relation & Ownership*).

Table 6.4

Mean and confidence intervals 95% (M (CI lower/ upper bound)) for emotional treatment reactions, ED intention, CAER and CCER subscales (N = 29)

Variables	Time 1		Time 2	
	Women	Men	Women	Men
DRK subscales				
Positive	2.69 (2.42/2.94)[a]	3.12 (2.88/3.36)[a]	2.70 (2.41/2.99)[a]	3.05 (2.75/3.35)[a]
Negative	2.16 (1.99/2.34)[b]	1.68 (1.47/1.89)[b]	1.90 (1.70/2.09)[b]	1.76 (1.63/1.90)[b]
ED Intentions				
Future embryo transfer (if pregnant)	12.79 (11.67/13.92)[a]	13.11 (12.22/14.00)[a]	12.25 (11.08/13.42)[a]	12.22 (10.85/13.59)[a]
Future embryo transfer (if not pregnant)	14.31 (13.71/14.91)[b]	13.29 (11.84/14.73)[b]	13.46 (12.17/14.76)[b]	14.11 (13.13/15.08)[b]
Donation to another couple	5.18 (3.46/6.89)[b]	6.68 (4.68/8.68)[b]	4.89 (3.24/6.54)[b]	6.52 4.83/8.21)[b]
Donation to research	8.29 (6.13/10.44)[b]	9.5 (7.58/11.42)[b]	8.75 (6.58/10.92)[b]	9.63 (7.49/11.77)[b]
Discard	6.38 (4.95/7.81)[b]	6.46 (4.77/8.15)[b]	6.79 (5.13/8.44)[b]	7.56 (5.92/9.20)[b]
CAER subscales				
Positivity	55.10 (46.38/65.81)[a]	58.40 (48.19/68.60)[a]	50.99 (42.35/61.04)[a]	55.40 45.91/64.89)[a]
Distress	13.98 (9.86/18.89)[b]	8.64 (4.96/12.33)[b]	15.00 (9.69/19.83)[b]	9.41 (5.91/12.91)[b]
Conflict	6.48 (3.21/9.28)[c]	5.59 (2.53/8.64)[c]	8.64 (3.43/13.83)[c]	3.70 (1.19/6.22)[c]
CCER subscales				
Attachment & Human Concept	46.88 (40.94/52.14)[c]	44.10 (37.07/48.86)[c]	46.36 (40.71/52.02)[c]	42.59 (35.99/49.20)[c]
Hope	82.64 (78.55/87.97)[c]	82.64 (78.73/87.78)[c]	86.27 (81.37/91.16)[c]	82.87 (76.95/88.79)[c]
Genetic Relation & Ownership	75.69 (70.59/80.75)[b]	74.07 (68.61/80.49)[b]	75.77 (70.44/81.10)[b]	75.23 (68.22/82.24)[b]

Note. N varies between variables

[a] is significantly greater than [b] and [c], and [b] is significantly greater than [c].

II. Emotional reactions and disposition intentions during oocyte collection and embryo transfer

A 2 (gender) x 2 (time) MANOVA was conducted in order to examine differences between men and women across time on positive and negative treatment reactions. The MANOVA showed a significant multivariate main effect of type of emotional reaction to treatment ($F(1, 27) = 52.69$, $p < .001$; $\lambda = .34$) with positive reactions being significantly higher than negative reactions ($t(28) = 2.84$, $p < .01$). There was no significant main effect for Time ($F(1, 27) = 1.30$, $p = .265$; $\lambda = .95$) or Gender ($F(1, 27) = .37$, $p = .548$; $\lambda = .99$), and no significant interaction effect.
A 2 (gender) x 2 (time) MANOVA was employed to examine differences between men and women across time on disposition intentions.

The MANOVA showed a significant multivariate main effect of disposition option ($F(3, 24) = 34.67$, $p < .001$; Wilks $\lambda = .19$) in that couples were significantly more likely to use their embryos for further treatment (if pregnant) than choosing any of the relinquishing disposition options (donation to research [$t(27) = 3.56$, $p = .001$], donation to another couple [$t(27) = 8.29$, $p < .001$], disposal [$t(28) = 7.56$, $p < .001$]).

There was also a significant multivariate main effect of gender ($F(1, 26) = 5.02$, $p = .034$; Wilks $\lambda = .84$). Follow-up tests showed that men's disposition intentions were marginally stronger than women's ($t(26) = 1.93$, $p = .065$) (see Table 6.4).

Affective embryo representations during oocyte collection and embryo transfer

A 2 (gender) x 2 (time) MANOVA was employed to examine differences between men and women across time on affective embryo representations. A significant multivariate main effect of type of affective subscale ($F(2, 25) = 68.90$, $p < .001$,

Wilks $\lambda = .15$) was obtained. Table 6.4, page 223 shows means and standard deviations for *Positivity*, *Distress* and *Conflict*. Follow-up tests showed that couples had higher scores on the *Positivity* than the *Distress* subscale ($t(27) = 8.54$, $p < .001$) and *Conflict* subscale ($t(27) = 10.05$, $p < .001$). Further, scores on the *Distress* subscale were higher than on the *Conflict* subscale ($t(27) = 4.19$, $p < .001$). There was no significant main effect of Time ($F(1, 26) = .23$, $p = .634$, Wilks $\lambda = .99$), and no significant main effect of Gender ($F(1, 26) = .55$, $p = .464$, Wilks $\lambda = .98$) (see Table 6.4, page 223). There were also no significant multivariate interaction effects (see Appendix 17).

Cognitive embryo representations during oocyte collection and embryo transfer

A 2 (gender) x 2 (time) MANOVA was employed to examine differences between men and women across time on cognitive embryo representations. A significant multivariate main effect of type of cognitive subscale ($F(2, 25) = 1.28$, $p < .001$, Wilks $\lambda = .09$) was revealed. Table 6.4 (page 223) shows means and standard deviations for Hope, *Genetic Relation & Ownership* and *Attachment & Human Status*.

Follow-up tests showed that couples had higher scores on the *Hope* than the *Genetic Relation & Ownership* subscale ($t(27) = 3.55$, $p < .001$) and the *Hope* than the *Attachment & Human Status* subscale ($t(27) = 12.41$, $p < .001$). Further, scores on the *Genetic Relation & Ownership* subscale were higher than the *Attachment & Human Status* subscale ($t(27) = 12.48$, $p < .001$) (see Table 6.4, page 223). There was no significant main effect of Time ($F(1, 26) = .21$, $p = .653$, Wilks $\lambda = .99$), and no significant main effect of Gender ($F(1, 26) = .73$, $p = .401$, Wilks $\lambda = .97$) There were also no significant interaction effects (see Appendix 17).

III. Relationship between affective and cognitive embryo representations

Using multi-level regression analyses the simultaneous longitudinal effect of the three CAER subscales (*Positivity, Distress, Conflict*) at T1 on each of the CCER subscales at T2 was examined, while controlling for the respective CCER subscale at T1. Thus, six multi level regressions were conducted. Figures 6.10 - 6.12 present these analyses graphically.

The unstandardised beta coefficients shown in path arrows are those obtained from the simultaneous model after controlling for the scores on the target T1 outcome variable.

Cognitive outcome variables

Attachment & Human Concept

As shown in Figure 6.10, there was a longitudinal negative effect of *Distress* at T1 on *Attachment & Human Concept* at T2 (B = -.18, t (49) = -2.1, p = .032). That is, a stronger *Distress* representation of embryos at T1 was associated with a weaker *Attachment & Human Concept* at T2. There was also a marginally significant effect of *Positivity* at T1 on *Attachment & Human Concept* at T2 (B = -.20, t (49) = -1.95, p = .056) showing that a stronger *Positivity* representation of embryos at T1 was associated with a weaker *Attachment & Human Concept* at T2. At the same time, there was no effect of *Conflict* at T1 on *Attachment & Human Concept* at T2 (B = -.02, t (49) = -.33, p = .740).

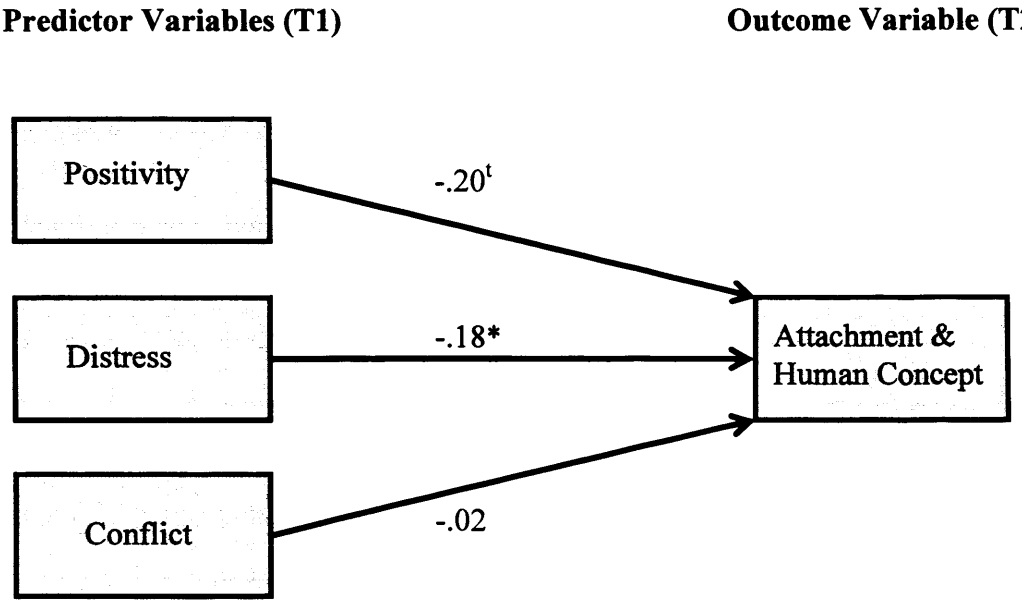

Figure 6.10: The simultaneous effect of the three affective embryo representation subscales at T1 on *Attachment & Human Concept* at T2 while controlling for *Attachment & Human Concept* at T1. Values show unstandardised beta weights, * $p < .05$, ^{t} $p < .10$.

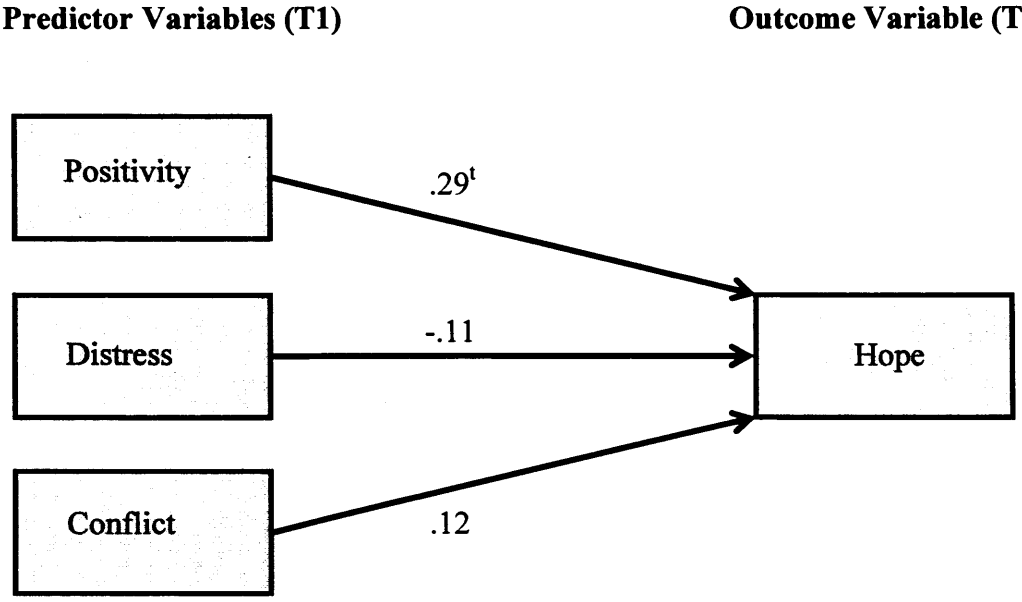

Figure 6.11: The simultaneous effect of the three affective embryo representation subscales at T1 on *Hope* at T2 while controlling for *Hope* at T1. Values show unstandardised beta weights, * $p < .05$, ^{t} $p < .10$.

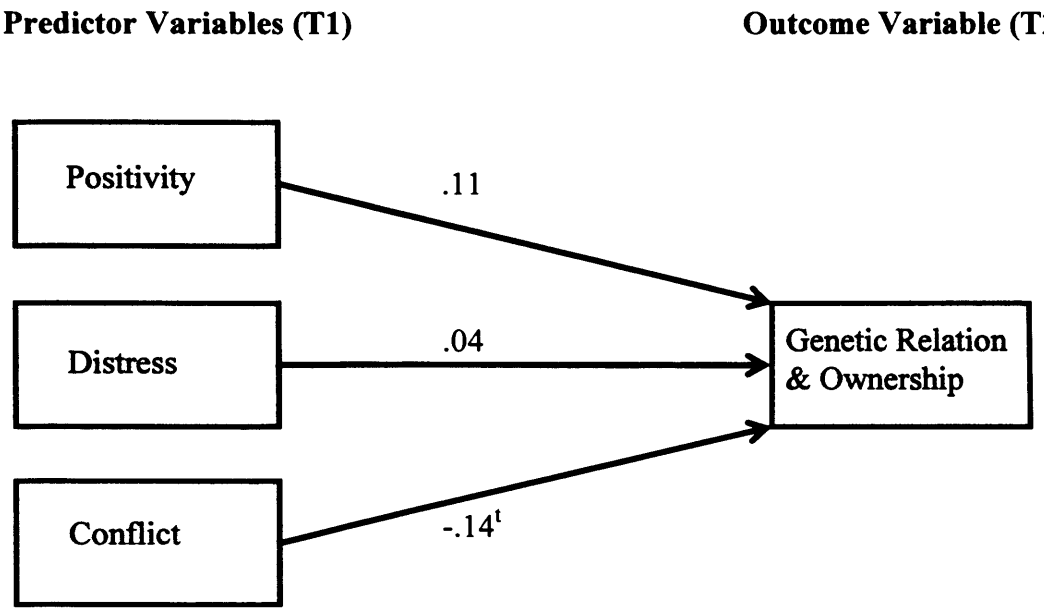

Figure 6.12: The simultaneous effect of the three affective embryo representation subscales at T1 on *Genetic Relation & Ownership* at T2 while controlling for *Genetic Relation & Ownership* at T1. Values show unstandardised beta weights, * $p < .05$, ^{t} $p < .10$.

Hope

As shown in Figure 6.11, page 228, there was a longitudinal positive effect of *Positivity* at T1 on *Hope* at T2 (B = .29, t (49) = 1.76, p = .084), which reached marginal significance. That is, patients who had a stronger *Positivity* representation of their embryos at T1 developed stronger Hope representation at T2. At the same time, there was no effect of *Distress* and *Conflict* at T1 on *Hope* at T2 (*Distress*: B = -.11, t (49) = -1.11, p = .275; *Conflict*: B = .12, t (49) = .94, p = .354).

Genetic Relation & Ownership

As shown in Figure 6.12, there was a marginally significant longitudinal effect of *Conflict* at T1 on *Genetic Relation & Ownership* at T2 (B = -.14, t (49) = -1.94, p = .058). That is, patient who had a stronger *Conflict* representation of their embryos at T1 developed a weaker *Genetic Relation & Ownership* presentation at T2. There was no significant effect of *Positivity* at T1 on *Genetic Relation & Ownership* at T2 (B = .11, t (49) = 0.92, p = .364), and no significant effect of *Distress* at T1 on *Genetic Relation & Ownership* at T2 (B = .04, t (49) = 0.37, p = .712).

Affective outcome variables

The causal association between T1 cognitive representations on T2 affective representations was also examined. To this end three multi-level regression analyses were conducted.

The three CCER subscales (*Attachment & Human Concept, Hope, Genetic Relation & Ownership*) at T1 were entered into the model as simultaneous predictors of each of the CAER subscales (*Positivity, Distress, Conflict*) at T2 as the dependent variable.

Additionally, the respective criterion (CAER) subscale at T1 was entered into the model. This revealed non-significant associations for all analyses (see Table 6.5).

Gender

The moderating effect of gender on the longitudinal associations was examined. Interactions were computed for each of the CAER subscales at T1 (centred) and gender (dummy coded, 0 1) as well as for each of the CCER subscales at T1 (centred) and gender (dummy coded, 0 1) according to the method of West, Aiken, and Krull (1996). All interaction analyses showed non-significant results (see Table 6.6 in Appendix 18).

Table 6.5

The causal association between T1 cognitive representations on T2 affective representations (N = 29)

Variables	*Positivity* T2	*Distress* T2	*Conflict* T2
Attachment & Human Concept T1	B = - 0.11, t (49) = - 0.92, p = 0.419	B = 0.04, t (49) = 0.34, p = 0.731	B = 0.06, t (49) = 0.46, p = 0.644
Hope T1	B = - 0.10, t (49) = - 0.68, p = 0.502	B = - 0.08, t (49) = - 0.62, p = 0.536	B = 0.01, t (49) = 0.07, p = 0.942
Genetic Relation & Ownership T1	B = 0.19, t (49) = 1.48, p = 0.146	B = - 0.03, t (49) = - 0.18, p = 0.856	B = - 0.25, t (49) = - 1.31, p = 0.197

Discussion

The findings showed that the treatment phase between oocyte collection and embryo transfer manifested in general positivity and stable cognitive and affective embryo representations. Further, spouses presented a unified profile; they held similar embryo representations, were in agreement on their preferences for further family building and ED intentions and had similar emotional reactions to treatment. Affective and cognitive embryo representations integrate in the way that emotions towards embryos determine thinking about the embryos to some degree but not vice versa. These findings highlight the need to recognize that initial emotional reactions towards embryos may have a lasting effect on how embryos are later conceptualised. The waiting period before initiating treatment gives health professionals ample opportunity to help couples clarify and if necessary adjust their emotional reaction to any future embryos and help them preserve their positive state of mind for the remaining cycle.

The dominating mental representations of embryos, positivity and hope, were found to be stable across oocyte retrieval and embryo transfer. This finding generally supported previous work where it was reported that having cryopreserved embryos increased couples' optimism and decreased their pessimism (Skoog Svanberg, Boivin, Hjelmstedt et al., 2001). Additionally, studies focussing specifically on the treatment phase of oocyte retrieval and embryo transfer showed that optimism was particularly high and stress levels remained relatively low during this time (Boivin & Takefman, 1996; Seibel & Levin, 1987). Further, the current results showed that *Positivity* towards embryos at the beginning of the treatment phase was associated to some degree with *Hope* at the end of it. These findings suggested that positive emotions

could have been carried over in that *Positivity* early on may determine concepts of *Hope* later in the treatment process. More research is needed to broaden these findings to additional treatment stages (e.g., before consent, after pregnancy test) and to investigate how general stress levels relate to embryo representations. Nevertheless, the current findings show that although treatment may be stressful (as suggested elsewhere) couples are particularly hopeful and positive during this specific treatment phase which is consistent with the fact that couples have passed important milestones in treatment (creation and transfer of embryos).

Affective embryo representations such as *Distress* and *Conflict* as well as the cognitive representation of *Attachment & Human Concept* have emerged as principal conceptualisations in previous work but were secondary in the current study. Previous work suggested that a human concept dominates couples views (e.g., Lyerly et al., 2006) and that contemplating the disposition decision can cause intense distress and anguish (e.g., Fuscaldo, 2005; Hammarberg & Tinney, 2006; McMahon et al., 2000). The present findings showed that at this phase of treatment (retrieval and transfer) embryos were primarily conceptualised for their potential (help to achieve parenthood) rather than as entities per se. This appreciation may emerge at a later treatment stage. Indeed, the accounts of embryos as human beings stem mainly from patients who have already achieved a live birth (e.g., Fuscaldo, 2005; Lyerly et al., 2006; McMahon et al., 2000; McMahon et al., 2003; Nachtigall et al., 2005). Thus, it may be that embryos are conceptualised positively in terms of hope for more children when couples have not had a live birth yet and are still aiming for further treatment, whereas a strong human concept may only be adopted when couples have experienced a live birth. The following quotations emphasise these point:

> *"When I was going through [IVF] I didn't even think of them as embryos...whereas now [after birth] the realization of oh my gosh what a beautiful human being can be created; it changes your emotions just a little bit . . . maybe they are less cut and dried."* (Lyerly et al., 2006, p. 1627).

and

> "*After having a daughter who was a frozen embryo it has made it more difficult to think of embryos as some scientific thing when we look at her and remember what she looked like at three cells. All of our embryos are now humanised for us. Before she was born we were much more detached.*" (McMahon et al., 2003, p. 875).

In the few studies that examined couples' cognitive embryo representations before or during treatment, it was argued that couples who undergo treatment refrain from referring to their embryos as human beings in an attempt to protect themselves from getting too emotionally attached (Provoost et al., 2009). This claim is partly in line with the current findings in that *Distress* at the beginning of the treatment phase may determine a weaker human concept of the embryos, and less emotional attachment at the end of the treatment phase. From these findings it cannot be inferred whether couples actively avoided a human concept during this particular treatment phase. Other explanations could also account for why distressing embryo representations could be linked to a weaker human concept. People might be distressed at the beginning of treatment because they fear that cryopreservation will result in increased malformations in the foetus as suggested elsewhere (e.g., Provoost et al., 2010; Skoog

Svanberg, Boivin, & Bergh, 2001), which may also cause them to have a low human concept. Another plausible explanation is that couples were told the embryos were of bad quality (distressing) and that caused low human conceptualisation. For patient support it is important to acknowledge that although couples have mainly positive representations of their embryos, some also represent their embryos negatively and may be in need for emotional support. However, further research is needed to investigate why some couples feel distressed, have low attachment and a low human concept of their embryos during this specific treatment phase.

Gender and partner effects

Couples showed a united profile in regards to their emotional reactions to treatment, their embryo representations and intended family building. Similarity between spouses in emotional reactions to treatment has been reported previously (Boivin et al., 1998) and shows that the creation and transfer of embryos is as stressful and as hope eliciting for men and women alike. This body of work was extended by showing that spouses also have similar embryo representations during this treatment phase. Couples' agreement on further family building irrespective of whether the current treatment is successful or not was to be expected given that few couples already had children and couples have been shown to generally aim for two children (Berrington, 2004). This disposition intention may also be driven by a lack of belief that treatment will actually be successful and result in a child (Lyerly et al., 2006; Seibel & Levin, 1987).

Scale evaluation

Data for the CAER and CCER subscales were demonstrated to be normally distributed, highly reliable and showed construct validity in that couples' affective and cognitive embryo representations were in line with what was expected for this treatment phase (i.e., general positivity). These findings suggest that the newly developed measures can be used with clinical populations, which offers the opportunity to use the scales in future research and clinical work. Further scale evaluation is needed to investigate the sensitivity of the new measures across a wider range of treatment phases (e.g., before initiating treatment, after the pregnancy result).

It is important to note that results from the current study are based on a small sample size that resulted in moderate statistical power. Given the observed trends that did not reach significance it may be that small effects were not detected. Additionally, multiple comparisons were conducted that may have increased the chance of alpha inflation and Type I error, that is the increased likelihood of detecting an effect that was due to chance. In order to reduce chance of alpha inflation, multivariate analyses of variance were used where variables formed a coherent grouping and follow-up tests were only conducted when there was a significant effect at the multivariate level. Support for the validity of the findings stems from the fact that the current results are largely consistent with previous findings for this specific treatment phase. That is, emotional reactions to treatment as well as embryo representations were similar to what has been suggested previously, and disposition intentions were in line with what would be expected at this stage of treatment.

The strengths of the current study consist of its longitudinal design and recruitment from an ART clinic. The longitudinal nature of the study allowed causal inferences

about the relation between affective and cognitive embryo representations. Recruitment of a clinical sample allowed for formal verification of participants' status as genuine ART patients, allowed recruitment of a homogeneous group of people and provided control over extraneous variables. In fact, inclusion criteria resulted in a highly homogenous group of patients (first time IVF/ ICSI treatment, successful fertilisation, extra embryos, few had previous children, all married) that made findings more likely to be attributed to study factors than external variables. And finally, this is one of the few studies recruiting men and women into research where commonly very little is known about men's views on embryos. Together the strengths and limitations suggest that the design of the current study provided valuable insights into embryo representations during treatment. Although findings were intriguing and increased understanding of the ED context it was noted that additional assessment points during treatment (e.g., before initiating treatment, after the result of the pregnancy test) would strengthen the findings.

In summary, when going through oocyte collection and embryo transfer couples are in agreement about further family building while in a mainly positive and hopeful state of mind. Attention to the specific emotional needs of couples during this treatment phase would be vital to reduce negative emotions even further and importantly preserve couples' positive state of mind for the remaining treatment cycle.

Chapter 7: General Discussion

The aim of the studies presented in this thesis was to better understand the embryo disposition decision context, establish factors associated with the decision (facilitators and impediments), and identify targets for decision support to improve patient experiences. The current chapter will present an overview and integration of the main findings, discuss the clinical implications of these findings, and identify areas for future research.

Complexity of the Embryo Decision Context

The present research comes at a time when embryo accumulation is recognised as a problem for ART clinics worldwide. Conservative estimates suggest that over 180,000 embryos are currently in storage in the United Kingdom (Chapter 2). This high number may seem surprising given that significant physical, financial, and emotional effort is invested in the creation of embryos to fulfil parenthood goals. However, accumulation exists because many couples keep their embryos in storage despite having satisfied their family building needs.

Evidence in this thesis has demonstrated that embryos remain in storage because the ED decision is embedded in a complex and distressing decision context that makes it difficult for couples to dispose of their embryos. The complexity of the decision context emerges from couples' affective and cognitive representation of embryos, their treatment experience, reproductive life stage and personality characteristics. In order to make a disposition decision couples need to achieve integration of their embryo representations with their disposition intentions – a process that is most likely influenced by people's personality type as well as reproductive life stage. These

findings were supported by two theoretical models. The theory of planned behaviour (Ajzen, 1985) states that any intended behaviour (e.g., intended disposition choice) and actual behaviour (e.g., choosing an ED option) are contingent on the person perceiving behavioural control over the decision. In Chapter 3 it was shown that women who keep their embryos in long-time storage may lack perceived behavioural because they have an external locus of control and a dependent personality.

Additionally, evidence from Chapter 4 supported dissonance theory and the rational emotional model of decision-avoidance. Dissonance theory (Festinger, 1957) suggests that dissonance arises when attitude (e.g. embryo representations) and behaviour (e.g. disposition intentions/ choice) are incongruent and the rational emotional model of decision-avoidance (Anderson, 2003) states that people avoid making decisions in order to control negative pre- and post decisional emotions. In Chapter 4 it was shown that women who saw their embryos as human and who had to choose among the three embryo relinquishing disposition options experienced decisional conflict, distress and general negativity. The reverse was also shown; women who did not view embryos as human and who intended to use the embryos also experienced decisional conflict.

The process of cognitive and affective integration is further complicated by the dynamic nature of the decision context. *Extra* embryos that give couples hope for a pregnancy can eventually become *surplus* to couples' family building needs and a burden. Embryo representations as well as ED disposition preferences may change as a function of treatment experience, especially treatment success. Given the dynamic nature of the decision context, couples may need to accomplish integration of their embryo representations and disposition intentions repeatedly, with potentially a different decisional outcome emerging at each reiteration.

Findings in this thesis highlighted the importance of emotions in the ED context in that positive affect prevailed as long as embryos were still needed for further family building but when embryos became *surplus* negative emotions dominated and embryos became a burden. Further, emotional reactions to embryos at the initiation of treatment seemed particularly important in that they were shown to remain stable at subsequent treatment phases and to determine the way couples' cognitive embryo representations manifested at later treatment stages.

The research in this thesis addressed the lack of a suitable embryo representation measure. The Cardiff Affective Embryo Representation (CAER) and Cardiff Cognitive Embryo Representation (CCER) scales were shown to be sensitive, reliable and valid measures of how people view their embryos and feel towards them. These measures are the first to allow a multifaceted assessment of embryo representations. It is hoped that these measures will be used in research, help integrate findings from cross-cultural settings, and support patients during treatment.

From this research it becomes apparent that some couples with cryopreserved embryos will be in need of decision support regarding disposition options. This may be achieved by the use of decision support technologies (DST) that provide guidance about how to determine the most superior disposition option. That is, DSTs aid decision-making by providing detailed information on the option set and by structuring people's deliberation. DSTs have been developed and extensively used in a variety of health conditions and treatments that involve complex decision making (e.g., deciding whether or not to take an amniocentesis test; Durand, Stiel, Boivin, & Elwyn, 2009). In recent years, much attention has been given to aiding people in deliberating their decisions because it was argued that the deliberation of the option

set determines the quality of the decision (Elwyn & Miron-Shatz, 2010). According to this line of research the deliberation process can be aided by helping people to process their emotional reactions to the option set at the time of treatment (anticipatory emotions) and guide them in affective forecasting of their post-decisional emotions (anticipated emotions) (Elwyn & Miron-Shatz, 2010). To this end, the embryo representation scales developed as part of this thesis could be used to aid couples in clarifying how they feel about and view their embryos at the time of decision-making but also to guide them in anticipating how any of the ED options may make them feel after the decision has been made.

The current findings also suggest that the timing of providing decision support may be crucial given the dynamic nature of the decision. Generally, decision support should be available when it is needed the most. In the case of embryo disposition, this is likely to be after embryos became *surplus* because at that point one of the embryo relinquishing disposition options (e.g., donation to research, donation to another couple or disposal) needs to be chosen, and it is these options which have been shown to generate negative emotions and decisional conflict. Once embryos become *surplus* couples are usually not in treatment anymore and are therefore absent from the clinic, where support could more easily be organised and provided. Hence, other distribution platforms would need to be developed and evaluated. For example, online DSTs have been shown to be feasible and acceptable and to result in an increase in knowledge about the option set and in a reduction of decisional conflict (Evans et al., 2010). In the current thesis the majority of women have expressed need for information on disposition procedures, their potential outcomes, the likelihood of these outcomes (e.g., likelihood of a live birth from a donor embryo), and other people's experience with the decision. Options set information including probabilities and footage of other

people's experience have already been implemented into online DSTs in other health contexts (Evans et al., 2010) and therefore, it seems plausible to develop such a tool for the ED context.

Future Research

Several issues arising from the present studies warrant further investigation. Almost all of the findings in this thesis pointed towards the need for more longitudinal research. In particular, studies are needed that assess the full range of treatment phases, ideally spanning from before couples consent to cryopreservation of any potential future embryos till after couples have made a final decision about their embryos. By using such a design some of the cross-sectional proposition in this thesis, particularly the dynamic nature of the decision, could be more comprehensively addressed. A longer period of observation would make it possible to pinpoint when embryo are most likely to become a burden, and to investigate more conclusively the causal mechanisms that underlie the decisional trajectories observed in embryo disposition. Further, the predictive power of the embryo representation scales on disposition choice could be estimated. Knowing when and under what circumstances embryos become a burden would facilitate targeting those embryo presentations early on that are empirically and theoretically linked to decision avoidance, and such knowledge could be embedded in decision support technologies (e.g., *Attachment & Human Concept*).

Further validation of the CAER and CCER scales is needed. In particular the applicability and usability of the scales in clinical work and patient support needs to be investigated. The structure of the scale requires further validation in a wider range of patient populations including cross-cultural samples and samples at different stages

of the treatment process. The goal of this line of research would be to define the acceptability range of the scales and adapt the scales for other disposition decision contexts.

More research is needed to inform the design of an embryo DST, in particular, what type of information on the ED option set couples need and how best to present the information. In particular, women's expressed need for information on other people's experience needs to be further investigated in order to determine how best to present the information (e.g., short leaflet, video or audio footage, etc.).

Further, the integration of the affective and cognitive embryo representation scales into the deliberation component requires investigation. Importantly, it needs to be investigated how personalised feedback from these measures could be used to deliberate the set of embryo disposition options. This line of research could be informed by the experiences from clinicians who use the scales in patient consultation.

All efforts have been focussed on facilitating decision-making assuming that making any decision is better than making no decision. This assumption neglects the possibility that couples' refusal to choose a disposition option is a decision itself and one that might be a functional coping mechanism. For some couples, keeping the embryos in storage may in fact be the *best* decision for them. In difficult decision contexts, it is acknowledged that people cannot achieve psychological closure post-decision if they regret the outcome of their decision (Beike, Markman, & Karadogan, 2009). As was demonstrated elsewhere, not all couples who make an ED decision achieve closure in that some have been shown to agonise and regret their choice (McMahon et al., 2000) and grieve their loss (Skoog Svanberg, Boivin, & Bergh,

2001) years after making the decision. It is therefore not only important to support couples in achieving *good* decisions but also to investigate whether some couples may be better off if they never have to make a final decision about their embryos. This raises the question as to whether requesting pre-treatment ED decisions at the time of consent should be limited to a dedicated period, for example, one year. In fact, it has been argued that pre-treatment consent should be limited to the rare occasion of one or both spouses becoming mentally incompetent to execute an update directive (Pennings, 2002). The notion, that some couples may be better off when they never have to make a final ED decision also calls statutory storage limits into question. As has been pointed out, storage limits vary across countries and it has been argued that they are chosen arbitrarily (Brinsden et al., 1995; Van Voorhis et al., 1999). In many countries storage limits are unrelated to reproductive age or how long embryos can remain in storage without damage.

A final consideration of the present research is the lack of male and cross-cultural data. Internet research has repeatedly demonstrated that recruitment of men into research is particularly challenging (e.g., Bunting & Boivin, 2007) which was mirrored in Chapters 4 and 5 despite efforts to target gender neutral websites (e.g., infertility network UK, facebook). As shown in this thesis recruitment of men was also difficult in clinic samples despite the fact that both partners were present when studies were initiated. Previous literature does suggest that it is the female partner who takes the prominent role in decision making regarding reproductive impairment (Greil et al., 1988), however, the ED decision requires both partners to agree on their disposition choice. Therefore, exploring factors associated with ED decision making from a male perspective warrants future examination. More research on cross-cultural samples would also help extend the current findings. As shown in Chapter 2, the

embryo disposition context varies widely between countries because of a diversity of statutory storage lengths and available disposition option sets, yet few studies carry out international comparisons. In countries with a short storage period (5-year storage limit in many European countries), couples may be pressed for time and the ED decision may become an issue earlier in treatment than in countries where no storage limit exists such as Sweden.

Key Methodological Issues

Sampling issues

The major methodological weaknesses of the research presented in this thesis were sampling issues. Recruiting men and women with cryopreserved embryos was incredibly difficult. In comparison to other online surveys on reproductive issues conducted in the same research laboratory, the embryo surveys in the present thesis achieved less than half of the sample sizes of other studies (e.g., (Bunting & Boivin, 2007, 2010), and the clinical samples were particularly small. Small sample sizes have low power to detect small or moderate effects that could be meaningful (Cohen, 1992). In some of the presented studies, it would have been beneficial to further split samples into more coherent groups, in particular in Chapter 3 splitting of the Cohort Control group into those who never had stored embryos versus those who had stored embryos but had used them would have been beneficial. Thus future research would benefit from investing more efforts into identifying why research on embryo disposition may attract few participants.

Sampling was also restricted by recruitment sources (the internet, specific ART clinics) which resulted in specific biases namely, bias due to internet access, active

use of English infertility advocacy and fertility websites, early treatment phase, primiparous and married. A main aim in conducting research is having a sample that is representative of the population under study (Heiman, 1999). This aim is pursued in order to reduce potential biases that may impact on any assumptions or conclusion drawn (e.g., education, socio-economic status, age) and to make findings applicable to the wider population. Online and clinic recruitment also had advantages in that the internet offered the opportunity to recruit women at all stages of having cryopreserved embryos and from diverse cultural backgrounds, whereas clinical recruitment offered access to patients at an early stage of conceptualising embryos. Indeed in all studies participants were from at least four countries, at a variety of different treatment stages (before and after their first treatment cycle, after finishing treatment). However, ART treatment also encompasses additional treatment phases, and given the language restriction of the author, the sampled countries were all English-speaking (including the United Kingdom, Australia, Canada, New Zealand, and the United States) which may limit the applicability of the findings.

A final sampling issue was the emphasis on female views on the ED decision because few men signed up to the research. The ED decision has been shown to cause much dispute between couples with prominent cases reaching out to the British High Court, Court of Appeal, and the European Court of Human Rights in Strasbourg. Therefore, men share equal responsibility for the ED decision and knowing more about the factors that makes the decision challenging for men in particular would advance understanding of this complex decision context.

Clinical Implications

In the UK alone, 16,000 embryos exceed couples' family building needs annually. This high number could be reduced with mild stimulation protocols, but these will take time to be fully implemented in fertility clinics. In the meantime, couples are likely to continue to face the embryo disposition dilemma. Research from this thesis raises several issues that could be considered in the ED decision context.

The time of consent is commonly considered to be couples' first ED decision point in that they are asked to indicate what disposition option they want clinic staff to carry out in case of mental incapacity or death (see HFEA consent form, Appendix 1). This decision point has been challenged by health professionals and ethicists (e.g., Pennings, 2002) for two reasons. Firstly, it has been argued that pre-treatment consent should not be considered valid as long as couples can still make a(n informed) decision about their embryos (Pennings, 2002). Secondly, a pre-treatment decision is likely to require couples to fully appreciate and understand what it is like to have cryopreserved embryos. As has been demonstrated by models of affective forecasting (Wilson & Gilbert, 2005) and considerations on the hot-cold empathy gap (Loewenstein, 2005), it is highly unlikely that couples will accurately anticipate how they will feel about their cryopreserved embryos in the future. It is therefore, questionable whether pre-treatment consent should be considered valid as long as couples are still capable of choosing an option. As with all of medical consent the core principal of it is to have evidence of the exact terms of the medical agreement in order to protect the patient from medical misconduct and the clinic from legal claims (Paterick, Carson, Allen, & Paterick, 2008). However, in the context of embryo disposition pre-treatment consent has also the purpose of allowing the clinic to dispose of embryos in case couples fail to return for their embryos or couples become

incapable of providing consent for any other reason. Although pre-treatment consent does solve this issue it is arguable whether this is the best way to do so. The results of the thesis suggest that regular contact needs to be maintained between clinic and patients, as is already done in many clinics to ensure couples' disposition preferences are updated. In clinician-patient consultations, the scales can be used to identify affective and cognitive embryo representation profiles that are empirically linked to a more difficult decision process and theoretically linked to decision avoidance (for theoretical considerations see Anderson, 2003; for the role of representations see e.g., McMahon et al., 2000; for the role of emotions see e.g., Nachtigall et al., 2005). It is acknowledged that some couples may prefer the clinic to make the disposition decision for them and that decision-avoidance may be a reflection of this strategy. In supporting couples' ED decision-making it is imperative for clinicians to recognise that not all *extra* embryos are *surplus* in the same way and how they are *surplus* makes a difference to the decision context couples will face. In particular couples with *surplus* embryos may struggle to integrate their embryo representations and disposition intentions. Hence, patient support needs to help couples clarify their embryo representations and aid them in detecting any incongruence with their preferred disposition option.

Conclusions

The present research comes at time when the embryo disposition dilemma is affecting an ever-increasing population as the number of people requiring ART treatment rises. The research presented in this thesis proposes that the ED decision is influenced by many factors and decisional closure can only be achieved when couples experience congruence between their embryo representations and their preferred disposition

choice. Although congruence may not always be possible, couples can and should be helped to reach a decision that ensures their long-term well-being with regard to the embryo disposition decision. It is hoped the present research provides the foundational groundwork for the development of an embryo decision support technology to aid couples in making this complex and at times distressing decision.

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Appendices

Appendix 1: HFEA Consent Form for the Use and Storage of Embryos

Your consent to the use of your eggs and embryos for your treatment and the storage of your embryos HFEA WT form

About this form

Who should fill in this form?

Fill in this form if you are a woman, and you are receiving treatment using embryos created in vitro with your eggs.

Why do I have to fill in this form?

Under the Human Fertilisation and Embryology Act 1990 (as amended), you need to give your consent in writing if you want your eggs, or embryos created in vitro with your eggs, to be used or stored. You will also need to decide what will happen if you die or lose the ability to decide for yourself (become mentally incapacitated).

You can make changes to, or withdraw your consent at any point until the time of embryo transfer or use of eggs or embryos in research or training. If you would like to change or withdraw your consent, you should ask your clinic for new forms.

Before filling in this form

Before you fill in this form, your clinic should make sure that you receive all the relevant information you need about your treatment. You should also have been offered counselling about the implications of having treatment.

Why is there a declaration on every page of this form?

There is a declaration on every page where you sign to confirm that you have completed the section or page and fully agree with the consent and information given.

After filling in this form

After you have filled in this form, make sure that you have a photocopy of it.

1 About you

1.1 Your first name(s) *Place clinic sticker here*

1.2 Your surname

1.3 Your date of birth D D M M Y Y

1.4 Your NHS/CHI/passport number *(please circle)*

2 About your partner

2.1 Your partner's first name(s) *Place clinic sticker here*

2.2 Your partner's surname

2.3 Your partner's date of birth D D M M Y Y

2.4 Your partner's NHS/CHI/passport number *(please circle)*

For clinic use only

HFEA centre reference

Patient number *Assigned by clinic*

Other relevant forms

HUMAN FERTILISATION & EMBRYOLOGY AUTHORITY

Version 3 (12/05/10)

3 Your treatment

3.1 **Do you consent to your eggs being used to create embryos in vitro for your treatment?**

Please note that the sperm provider also has to give his consent for embryos to be created.

☐ No ☐ Yes

4 Storing embryos

4.1 **Do you consent to the embryos (created in vitro with your eggs) being stored?**

Please note that embryos can only be stored if the sperm provider has also given his consent.

☐ No ▸▸ *Go straight to section 5*

☐ Yes ▸ *Continue below*

For how long do you consent to your embryos being stored?

You can consent to the storage of your embryos for up to 55 years. Your embryos may only be stored for more than 10 years if you or someone to whom your embryos have been allocated to (including your partner) is prematurely infertile or is likely to become prematurely infertile. A medical practitioner must certify in writing that the medical criteria have been met.

Where the criteria have been met the storage period will be extended by ten years from the date the criteria are met. The storage period can then be extended by further 10 year periods if it is shown at any time within each extended storage period that the criteria continue to be met. There is a maximum storage period of 55 years. The medical practitioner's statement(s) should be attached to this form.

☐ For 10 years

☐ For 55 years

☐ For a specific period (up to a maximum of 55 years) ▸ *Specify the number of years*

☐ years

5 Using eggs and embryos for research and training

5.1 **Are you willing to be approached about your eggs being used in research projects?**

☐ No

☐ Yes *(You will be asked to give specific consent for each research project that the eggs are used in)*

5.2 **Are you willing to be approached about your embryos (already created in vitro with your eggs) being used in research projects?**

Please note that embryos can only be used if the sperm provider has also given his consent.

☐ No

☐ Yes *(You will be asked to give specific consent for each research project that the embryos are used in)*

Continues on next page

Page declaration

Your signature ✗ **Date** D D M M Y Y

For clinic use only Patient number

5 Using eggs and embryos for research and training *continued*

5.3 Do you consent to your eggs being used for training purposes?

☐ No
☐ Yes

5.4 Do you consent to embryos (already created in vitro with your eggs) being used for training purposes?

Please note that embryos can only be used if the sperm provider has also given his consent.

☐ No
☐ Yes

6 In the event of your death or mental incapacity

As part of your consent, you also need to decide what you would like to happen to your eggs, or embryos created in vitro with your eggs, if you die or lose the ability to decide for yourself (become mentally incapacitated). Please note that if you consent to your eggs or embryos being used in the event of your death or mental incapacity, your consent to their storage may also be required.

6.1 Do you consent to your eggs being used for training purposes?

If you die		If you become mentally incapacitated	
☐ No	☐ Yes	☐ No	☐ Yes

6.2 Do you consent to embryos (already created in vitro with your eggs) being used for training purposes?

Please note that embryos can only be used if the sperm provider has also given his consent.

If you die		If you become mentally incapacitated	
☐ No	☐ Yes	☐ No	☐ Yes

Other uses for your eggs or embryos

If you wish your eggs or embryos to be used for the treatment of others ▸▸ Please complete ***Your consent to the use and storage of your donated eggs*** (WD form), ***Your consent to the use of your donated embryos*** (ED form) or ***Your consent to the use and storage of your eggs or embryos for surrogacy*** (WSG form).

However, if you do not give your consent in this section or on one of the forms mentioned above, **the eggs or embryos must be allowed to perish in the event of your death or mental incapacity.**

Page declaration

Your signature ✗ Date D D M M Y Y

For clinic use only Patient number

7 Declaration

Please sign and date the declaration

Your declaration

- I declare that I am the person named in section 1 of this form.
- I declare that:
  - before I completed this form, I was given information about the different options set out in this form, and I was given an opportunity to receive counselling,
  - the implications of giving my consent, and the consequences of withdrawing this consent, have been fully explained to me, and
  - I understand that I can make changes to or withdraw my consent at any point until the time of embryo transfer, use of eggs or embryos in research or training or the eggs or embryos have been allowed to perish.
- I declare that the information I have given on this form is correct and complete.
- I understand that information on this form may be processed and shared for the purposes of and in connection with the conduct of licensable activities under the Human Fertilisation and Embryology Act 1990 (as amended) in accordance with the provisions of that Act.

Your signature ✗

Date D D M M Y Y

If signing at the direction of the person consenting

If the person consenting is unable to sign for herself because of physical illness, injury or disability, someone else representing the person can sign the form at her direction. There must also be a witness confirming that the person consenting is present when the representative signs the form.

Representative's declaration

- I declare that the person named in section 1 of this form is present at the time of signing this form and I am signing it in accordance with her direction.

Representative's name

Representative's signature ✗

Relationship to the person consenting

Date D D M M Y Y

Witness's name

Witness's signature ✗

Date D D M M Y Y

For clinic use only Patient number

WT page 4 of 4
Version 3 (12/05/10)

Appendix 2: Interview Schedule

Section 1

This section is concerned with your reproductive treatment experience

1. How many full treatment cycles have you had? [ ]

2. How many frozen embryo transfer cycles have you had? [ ]

3. Throughout your treatment, how many treatment cycles have resulted in a pregnancy? [ ]

4. How many children do you have?

   Conceived through assisted reproduction [ ]

   Conceived without assisted reproduction [ ]

5. Are you satisfied with the number of children you have?

   Definitely satisfied [ ]

   Would have liked more [ ]

   Would have liked fewer [ ]

6. How likely is it that you will undergo another treatment cycle?

(Circle the appropriate number)

1 2 3 4 5 6 7

definitely not definitely will

Section two

This section is concerned with embryos storage and the options couples have with respect to surplus embryos

1. Have you had frozen embryos in storage as a result of your involvement in assisted reproductive treatment?

YES [ ]

NO [ ]

Please answer the next question if you answered **"yes"** to question 1

2. What happened to those embryos? (You can tick more than one box)

Used in treatment [ ]

Destroyed [ ]

Donated for research [ ]

Donated to another couple [ ]

Still in storage [ ]

3. **Do you currently have frozen embryos?**

YES [ ]

NO [ ]

Please answer the following questions if you answered **"yes"** to question 3

4. **How many embryos do you have in storage?** [ ]

5. **How long have the embryos been in storage?**

.....

6. **Do you think of the embryos as siblings to your children?**

1 2 3 4 5 6 7

definitely not **definitely**

7. **How often do you think about your embryos?**

1 2 3 4 5 6 7

almost never **often**

The following is a list of the options available to you with respect to your frozen embryos. Please consider each option and tick the appropriate box.

Option 1: Use the embryos ourselves in future treatment

Very unlikely [ ]

Possible [ ]

Probable [ ]

Option 2: Donate the embryos to another couple who we know

Very unlikely	[ ]
Possible	[ ]
Probable	[ ]

Option 3: Donate the embryos to another couple anonymously

Very unlikely	[ ]
Possible	[ ]
Probable	[ ]

Option 4: Donate the embryos for medical research

Very unlikely	[ ]
Possible	[ ]
Probable	[ ]

Option 5: Give consent for the embryos to be destroyed

Very unlikely	[ ]
Possible	[ ]
Probable	[ ]

8. When do you expect to make a decision about the embryos?

Within a year	[ ]
Within 3 years	[ ]
Put off as long as possible	[ ]

Please use the remainder of this page to add any comments you would like to about the issues covered in this section

Appendix 3: Embryo Disposition Survey

Needs assessment in infertility patients with cryopreserved embryos

Study description

During in vitro fertilisation (IVF) usually more embryos are created than can be transferred to the uterus in a single treatment cycle. Therefore, people are given the option to freeze their embryos in order to be able to use them in subsequent cycles. Some people may not want to make use of the embryos for further treatment, and thus, they have to make a decision about what to do with their embryos. The four common options include thawing of the embryos, donation to research, donation to an infertile couple, or continuation of storage.

The aim of the present survey is to find out more about how people make this decision, what their information and decisional needs are, and to learn more about couples' experience with embryos and the decision-making process. If you decide to participate, you will be asked about your current social situation (age, marital status, etc.), your history of infertility including your experience in regard to your embryos, e.g., how you view your embryos, how often you think about them, and how that makes you feel. The survey will take about 15 minutes to complete. All your answers will remain anonymous so that it is impossible to trace your information back to you individually. At the end of the study we will post a summary of the study results on this webpage.

We will not be able to trace any responses to individual participants. Note, however, that as with any online transaction there is a possibility that the data could be intercepted on the way to us, but this risk is negligible.

The study has received ethical approval from the School of Psychology, Cardiff University. If you have any questions about this study then please contact the principal investigator Dr Jacky Boivin at Boivin@Cardiff.ac.uk.

You are free to withdraw from the study at any time by closing the window.

If you are 18 or over, understand the statement above and freely consent to participate in this study click YES. If you do not want to complete the questionnaire please close the window.

YES

Next

0% complete

About you

How old are you?

What is your ethnic background? White ○ Black ○ Asian ○ Latin-American ○

Other:

What is your country of residence?

What is your highest level of education? Primary School ○ Secondary School ○ Post-Secondary School/College ○ University ○

Other:

Do you have a partner? Yes ○ No ○

If yes, how long have you been together? Years Months

Do you have any children (including step- and adopted children)?

Yes ○ No ○ If yes, how many?

Back Next

7% complete

About your fertility history

How long have you been trying to become pregnant? Years ____ Months ____

Have you ever had the following?
(please indicate all that apply by stating the number of times it happened to you)

miscarriage	ectopic pregnancy	abortion	live birth	adoption

If you and your partner had problems getting pregnant do you know why? Yes ○ No ○

If yes, please indicate all that apply

- ☐ Normal or unexplained
- ☐ Endometriosis
- ☐ Do not ovulate
- ☐ Other hormonal problem
- ☐ Tubes blocked
- ☐ Problem with sperm
- ☐ Previous tubal sterilisation
- ☐ Previous vasectomy
- ☐ My or my partner's age
- ☐ Social reasons (lesbian, gay)
- ☐ I do not have a partner
- ☐ Other ____

Have you ever had fertility treatment? Yes ○ No ○

Are you currently having fertility treatment? Yes ○ No ○

If yes, how long have you been in treatment? years ____ months ____

Back Next

14% complete

About your current mood

A number of statements which people have used to describe themselves are given below. Read each statement and then click on the appropriate button to the right of the statement to indicate how you feel right now, that is at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	Not at all	Somewhat	Moderately	Very much
I feel calm	○	○	○	○
I feel tense	○	○	○	○
I feel relaxed	○	○	○	○
I feel content	○	○	○	○
I feel worried	○	○	○	○

Back Next

21% complete

About your experience with embryos

During invitro fertilisation (IVF) usually more embryos are created than can be transferred to the uterus in a single treatment cycle. Therefore, people are given the option to freeze their surplus embryos in order to be able to use them in subsequent cycles.

Have you ever had surplus frozen embryos? ○ Yes ○ No

If yes, number of embryos: _____

Do you currently have surplus frozen embryos? ○ Yes ○ No

If yes, number of embryos: _____

What was the reason for creating embryos?

- ☐ Problems getting pregnant
- ☐ Preimplantation genetic diagnosis
- ☐ Cancer
- ☐ Other _____

Do you receive letters from the clinic where your embryos are stored?

○ Yes ○ No ○ I don't know

If yes, how often do you receive these letters?

○ Once every 6 months ○ Once a year ○ Less often than once a year ○ I don't know

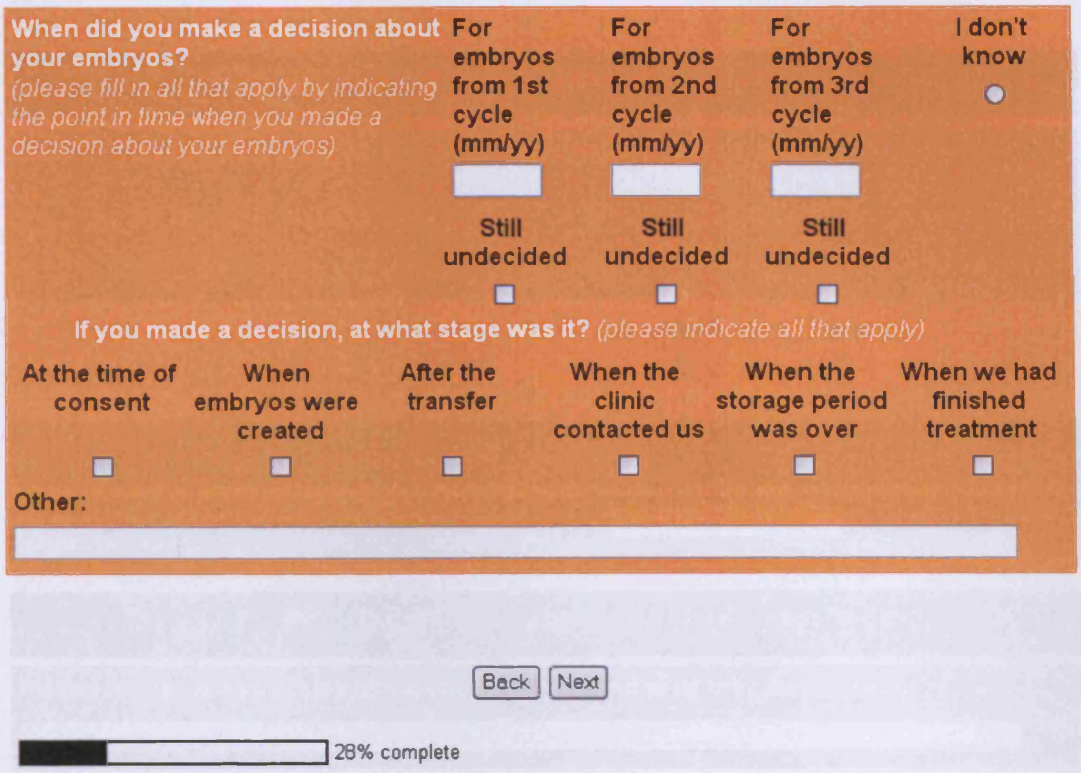
Do you respond to these letters? ○ Yes ○ No

If no, why do you not respond? _____

In how many cycles did you have the opportunity to freeze embryos? _____

When were your embryos frozen? *(please fill in all that apply by indicating the start of storage)*	For embryos from 1st cycle (mm/yy)	For embryos from 2nd cycle (mm/yy)	For embryos from 3rd cycle (mm/yy)

When does the storage period end? *(please fill in all that apply by indicating the end of storage)*	For embryos from 1st cycle (mm/yy)	For embryos from 2nd cycle (mm/yy)	For embryos from 3rd cycle (mm/yy)	I don't know
				○


When did you make a decision about your embryos?
(please fill in all that apply by indicating the point in time when you made a decision about your embryos)
For embryos from 1st cycle (mm/yy)
For embryos from 2nd cycle (mm/yy)
For embryos from 3rd cycle (mm/yy)
I don't know
Still undecided
Still undecided
Still undecided
If you made a decision, at what stage was it? (please indicate all that apply)
At the time of consent
When embryos were created
After the transfer
When the clinic contacted us
When the storage period was over
When we had finished treatment
Other:
Back
Next
28% complete

About the outcome of your IVF treatment(s)

Have you had a live birth using any of your embryos? *(please indicate all that apply)*

- ☐ Yes, as a result of a fresh transfer
- ☐ Yes, as a result of a frozen transfer
- ☐ No

Do you intend to have another treatment cycle using your surplus embryos? Yes ○ No ○

About family size

How many children would you like to have?

About how you view your embryos

Please tell us how you think about your embryos and what they mean to you:

Back Next

35% complete

About how you view your embryos (continued)

In the following section we would like to know how you view your surplus embryos. Please indicate on the scale how much you agree with each statement by clicking the appropriate button

My frozen surplus embryos are:

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
like a brother or sister to my existing children	○	○	○	○	○
a bunch of cells	○	○	○	○	○
like a child	○	○	○	○	○
a symbol of my infertility	○	○	○	○	○
a human being	○	○	○	○	○
part of my family	○	○	○	○	○
completely different from children	○	○	○	○	○
cells that could replace a child if something happens	○	○	○	○	○
Other:					
	○	○	○	○	○

How often do you think about your surplus embryos?	Never	Sometimes	Often	All the time
	○	○	○	○

If you think about them, how does it make you feel?

Back Next

42% complete

Making a choice about your surplus embryos

What options have been offered to you?
(please indicate all that apply)

- ☐ Donation to research
- ☐ Donation to another couple
- ☐ Thawing/discard
- ☐ To continue storage
- ☐ To use in a future cycle
- ☐ To transfer at a time when pregnancy is unlikely
- ☐ None

Other:

What is your preferred role in making this decision?
(please indicate all that apply)

- ☐ I would like to make the decision myself or with my partner
- ☐ I would like my partner to make the decision for us
- ☐ I would like the clinic to make the decision for us
- ☐ I don't want anyone to make this decision
- ☐ I would like fate or God to make this decision for us

Other:

We would like to know what your opinion is about your disposition options at present. If the clinic asked you right now to make a choice about your embryos, please indicate where you would be on the scale below by clicking on one of the buttons.

Donation of the embryos to research

No, I don't want to donate -7 -6 -5 -4 -3 -2 -1 0 1 2 3 4 5 6 7 Yes, I want to donate

Donation of the embryos to another couple

No, I don't want to donate -7 -6 -5 -4 -3 -2 -1 0 1 2 3 4 5 6 7 Yes, I want to donate

Thawing and disposal of the embryos

No, I don't want to thaw/discard -7 -6 -5 -4 -3 -2 -1 0 1 2 3 4 5 6 7 Yes, I want to thaw/discard

Continuation of storing the embryos

No, I don't want continue storage -7 -6 -5 -4 -3 -2 -1 0 1 2 3 4 5 6 7 Yes, I want to continue storage

Now that you have indicated your preferences, could you please let us know which option looks best to you?

Option:

Why is this currently the best option for you?

Back Next

50% complete

Considering the embryo options you prefer, please answer the following questions:

	strongly agree	agree	neither agree or disagree	disagree	strongly disagree
I know which options are available to me	○	○	○	○	○
I know the benefits of each option	○	○	○	○	○
I know the disadvantages of each option	○	○	○	○	○
I am clear about which benefits matter most to me	○	○	○	○	○
I am clear about which disadvantages matter most to me	○	○	○	○	○
I am clear about which is more important to me (the benefits or disadvantages)	○	○	○	○	○
I have enough support from others to make a choice	○	○	○	○	○
I am choosing without pressure from others	○	○	○	○	○
I have enough advice to make a choice	○	○	○	○	○
I am clear about the best choice for me	○	○	○	○	○
I feel sure about what to choose	○	○	○	○	○
The decision is easy for me to make	○	○	○	○	○

About the difficulty of what to do with surplus embryos

Are there any reasons that keep you from making the decision?

Back Next

57% complete

About the difficulty of what to do with surplus embryos (continued)

(please indicate how much you agree with each of the following statements)

	strongly agree	agree	neither agree or disagree	disagree	strongly disagree
I am afraid that I might regret the decision later	○	○	○	○	○
I feel too worried right now in order to be able to make a decision	○	○	○	○	○
I prefer to keep the situation as it is (that means, keeping the embryos frozen)	○	○	○	○	○
I am afraid that I might blame myself later on for having made the wrong decision	○	○	○	○	○
I wish to avoid an irreversible decision	○	○	○	○	○
I am afraid that my partner (or someone important to me, for example family) might blame me later on for having made the wrong decision	○	○	○	○	○
I dread the decision	○	○	○	○	○
I am uncertain about which option to choose	○	○	○	○	○
I feel too fearful right now to make a decision	○	○	○	○	○
I thought a better option might become available in the future	○	○	○	○	○
I find it difficult to choose the best option	○	○	○	○	○
I am not sure if I want to try for more children	○	○	○	○	○
I feel too anxious right now to make a decision	○	○	○	○	○
My partner and I do not agree on which option to choose	○	○	○	○	○
I am afraid to lose the embryos	○	○	○	○	○
Other:					

Back Next

64% complete

About your values

In this section we are interested in your personal values. Please indicate to what extent the following aspects are important to you when making a decision about your embryos.

How important is your financial situation?	Not at all important	Very important
How important is the size of your family?	Not at all important	Very important
How important are your personal values (e.g. your religious beliefs)?	Not at all important	Very important
How important is how you view your embryos?	Not at all important	Very important

-7 -6 -5 -4 -3 -2 -1 0 1 2 3 4 5 6 7

What other factors are important to you when making a decision about your embryos?
(Please specify any factor that you have considered and rate their importance)

Factor 1:

Factor 2:

Factor 3:

Not at all important ... Very important

-7 -6 -5 -4 -3 -2 -1 0 1 2 3 4 5 6 7

Back Next

71% complete

About your decision and information needs for embryo disposition

What kind of support would help you make the decision?
(please indicate all that apply)

Advice from doctor	Counselling	Talking to others in the same situation	Talking to my partner	Talking to my family/friends
☐	☐	☐	☐	☐

☐ Other

What kind of information would you like to receive?

1. **Information on procedures involved in each option (e.g. how embryos are thawed)**

I have received it already ○ I would like to receive this ○

When having received it already, how helpful has it been?

not at all	a little	moderately	very much	extremely
○	○	○	○	○

2. **Information on the potential consequences of each option**

I have received it already ○ I would like to receive this ○

When having received it already, how helpful has it been?

not at all	a little	moderately	very much	extremely
○	○	○	○	○

3. **Information on and the likelihood of each option (e.g., what is the likelihood that donation will result in a healthy baby?)**

I have received it already ○ I would like to receive this ○

When having received it already, how helpful has it been?

not at all	a little	moderately	very much	extremely
○	○	○	○	○

4. **Information on other people's experience with making the choice**

I have received it already ○ I would like to receive this ○

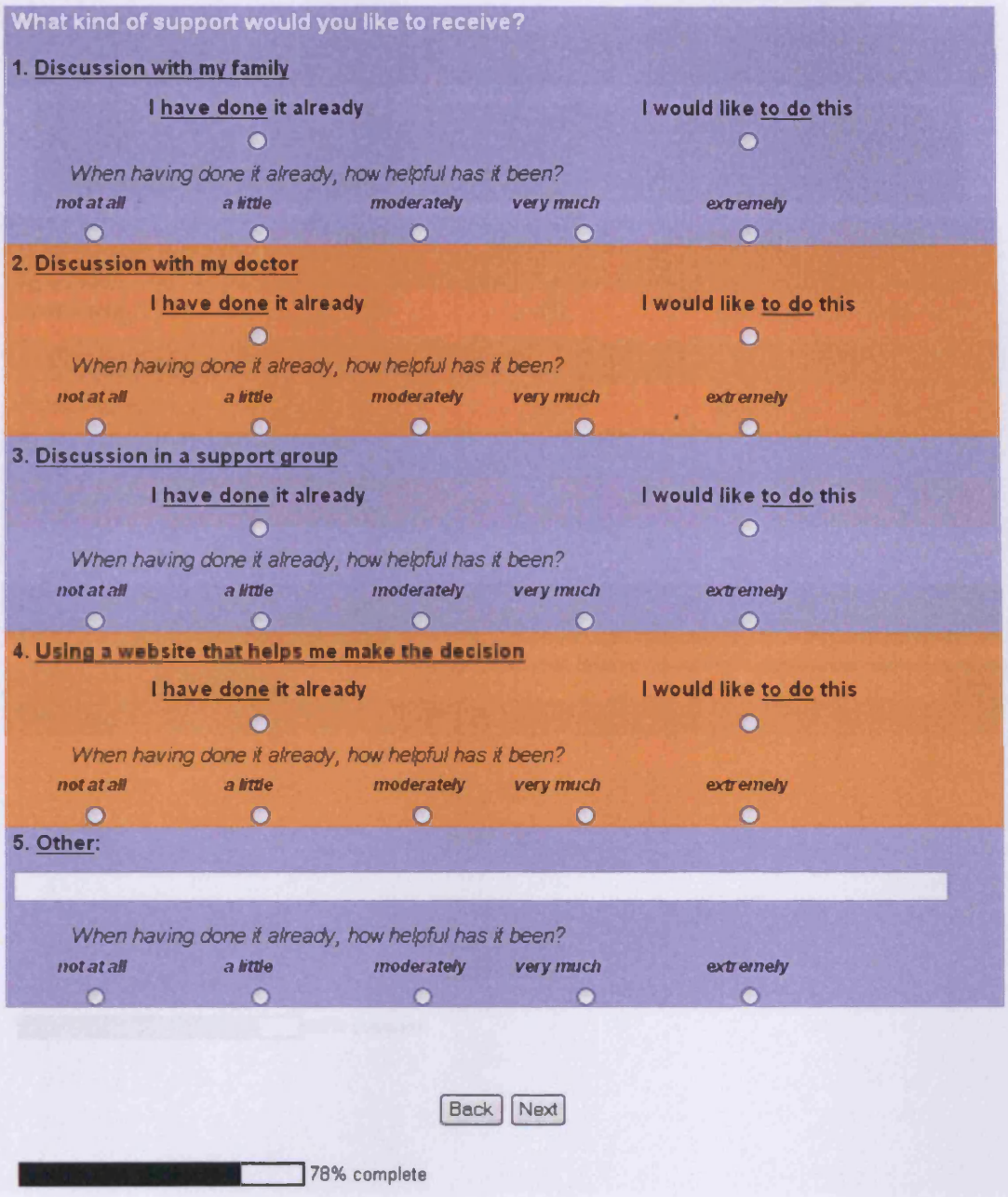
When having received it already, how helpful has it been?

not at all	a little	moderately	very much	extremely
○	○	○	○	○

5. **Other** *(please describe)*:

When having received it already, how helpful has it been?

not at all	a little	moderately	very much	extremely
○	○	○	○	○


What kind of support would you like to receive?
1. Discussion with my family
I have done it already
I would like to do this
When having done it already, how helpful has it been?
not at all
a little
moderately
very much
extremely
2. Discussion with my doctor
I have done it already
I would like to do this
When having done it already, how helpful has it been?
not at all
a little
moderately
very much
extremely
3. Discussion in a support group
I have done it already
I would like to do this
When having done it already, how helpful has it been?
not at all
a little
moderately
very much
extremely
4. Using a website that helps me make the decision
I have done it already
I would like to do this
When having done it already, how helpful has it been?
not at all
a little
moderately
very much
extremely
5. Other:
When having done it already, how helpful has it been?
not at all
a little
moderately
very much
extremely
Back
Next
78% complete

About your current mood

Again, we would like to know how you feel right now, that is at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	Not at all	Somewhat	Moderately	Very much
I feel calm	○	○	○	○
I feel tense	○	○	○	○
I feel upset	○	○	○	○
I feel relaxed	○	○	○	○
I feel content	○	○	○	○
I feel worried	○	○	○	○

About how you found us

Where did you find this questionnaire?

Thank you very much for your time in completing this survey

Back Next

85% complete

Thank you very much for helping us with this important study.

We would be very grateful if you would let us know your thoughts and feelings about this survey, any questions you found difficult and any topics you feel we left out.

We would like to reassure you that all the information you provided is anonymous and cannot be traced back to you. However, if you would like to receive an update of our results and are interested in participating in future studies, **please provide us with your contact details** (e.g., name and email address) in the box below.

Below is some more information about our study

Although many couples reach a final decision about what to do with their frozen embryos at some point, there is also a substantial number of women and men who fail to do so. The online survey you completed will help us better understand what kind of beliefs and attitudes people hold towards their embryos and what factors influence decision-making in regards to the embryos. This research will help us to develop and evaluate decision support tools to aid people with frozen embryos and their health professionals make a decision about the embryos.
It was important to ask you a range of personal questions about your infertility treatment experience. If you have any concerns as a result of your participation in this study please contact Dr Jacky Boivin (see below for contact details), your GP or family doctor or consult the following infertility websites, which provide advice and help for people who have undergone fertility treatment.

If you have any further questions about this research then please contact the principal investigator:

Dr Jacky Boivin
School of Psychology, Cardiff University
Psychology Building, Park Place
Cardiff, Wales
CF10 3AT
Boivin@Cardiff.ac.uk

Dr Jacky Boivin is interested in the psychosocial aspects of reproductive health. She has conducted many studies in this area on issues such as the link between stress and fertility, differences between men and women in emotional reactions to fertility problems, whether counselling helps people cope with fertility problems, how children conceived with fertility treatment develop, and much more. This research has been carried out with the help of women from many countries worldwide. You can see some of the published reports of this work and information on current projects at **www.fertilitystudies.cardiff.ac.uk**

Back Submit

92% complete

Appendix 4: Interaction Effects in Moderated Regression (Chapter 4)

Table 4.9 continued

Summary statistics for interaction effects in moderated regression analysis on correlates of decisional conflict (n=118)

Predictors	Beta	SE B	sr^2 (%)	t
Block 2: Interaction effects				
Number of live births * intention personal use	-.14	.53	.20	-.69
Discrepancy between number of children wished for and current number of children * intention personal use	-.15	.64	.20	-.81
Number of currently stored embryos * intention personal use	-.07	.37	.10	-.50
Years since last cycle with frozen embryos * intention personal use	-.24	.63	0.30	-.93
Live birth as result of frozen transfer * intention personal use	-.00	1.08	.0	-.01
Human concept scale * intention personal use	-.37	.40	1.90	-2.37*
Frequency of thinking about embryos * intention personal use	.08	.49	.10	.40
Embryo Disposition Apprehension scale * intention personal use	-.04	.62	.0	-.18
Point in time when decision was made: at the time of consent * intention personal use	-.11	.88	.0	-.56
Point in time when decision was made: when finished with treatment * intention personal use	-.09	1.62	.30	-.88
Need for information and support * intention personal use	-.24	.48	.60	-1.29
Discrepancy between the STAI short form post and pre questionnaire assessment * intention personal use	.18	.35	.40	1.14

* $p < .05$

multiple $R^2 = .684$; Adjusted $R^2 = .598$; $F(25,117) = 7.95$, $p < .001$

Appendix 5: Embryo Scale Evaluation Survey

Survey on embryo perceptions

Men and women who have stored frozen embryos as part of infertility treatment have been reported to have various emotional reactions to them and to view their embryos diversely with some seeing them as potential children whereas others having a more medical point of view. These views and emotions are important to how people come to make a final decision about what to do with their embryos when they no longer need the embryos for their own family needs. In order to continue investigating the embryo disposition decision we need to have a good way of measuring these emotions and views.

The aim of the present survey is therefore to find out emotions and views about stored embryos and this information will be used to develop and evaluate an embryo affect and embryo perception scale.
If you decide to participate, you will be asked about your current social situation (age, partnership status), embryo history (e.g., how many embryos you have), your intended use of your embryos, how you feel about your embryos and your view of your embryos. The survey will take about 10 minutes to complete. All your answers will remain anonymous so that it is impossible to trace your information back to you individually. At the end of the study we will post a summary of study results on our website www.cardifffertilitystudies.com .

We will not be able to trace any responses to individual participants. Note, however, that there is a possibility that someone could intercept your responses on the way to us but this risk is negligible.

The project has received ethical approval from the School of Psychology, Cardiff University (UK). If you have any questions about this project then please contact the principal investigator Dr Jacky Boivin at Boivin@Cardiff.ac.uk.

You are free to withdraw from the study at any time by closing the window.

If you are 18 or over, understand the statement above and freely consent to participate in this study then click 'YES'. If you do not want to complete the questionnaire please close the window.

Yes

Next

0% complete

Part I. About you

Are you:

- male
- female

How old are you?

(state in years)

What is your highest level of education?

- Primary school
- Secondary school
- Post secondary/ College
- University
- Other

Please state other:

What is your country of residence

What is your marital status?

Are you currently

- Single
- Married and/or living with partner
- Separated/divorced
- Widowed

Do you have children? (including adopted and step-children)

- No
- Yes

If yes: number of children:

How many children do you intend to have in total?

(please state a number)

Next

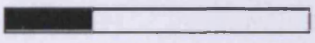
14% complete

Part II. About your current mood

In the following section various emotions are listed. Please rate the extent to which you experienced each one of these emotions in the past 24 hours in terms of whether and to what extent the symptom occurred by ticking the appropriate box.

	Not at all	A little	A moderate amount	Very much	An extreme amount
Confident	○	○	○	○	○
Anxious	○	○	○	○	○
Positive	○	○	○	○	○
Content	○	○	○	○	○
Uncomfortable	○	○	○	○	○
Encouraged	○	○	○	○	○
Disappointed	○	○	○	○	○
Hopeful	○	○	○	○	○
Discouraged	○	○	○	○	○
Uncertain	○	○	○	○	○
Nervous	○	○	○	○	○
Happy	○	○	○	○	○
Worried	○	○	○	○	○
Relieved	○	○	○	○	○
Tense	○	○	○	○	○
Hesitant	○	○	○	○	○
Unsure	○	○	○	○	○
Angry	○	○	○	○	○
Fulfilled	○	○	○	○	○
Uneasy	○	○	○	○	○
Sad	○	○	○	○	○
Doubtful	○	○	○	○	○
Bothered	○	○	○	○	○

Next



Part III. About your experience with embryos

In how many cycles of previous treatments were you able to freeze embryos? (please state a number)

How many embryos did you freeze in total? (please state a number)

How many of your embryos are still in storage? (please state a number)

Have you had a live birth using any of your embryos?

- ☐ Yes, as a result of a fresh transfer
- ☐ Yes, as a result of a frozen transfer
- ☐ No

How likely are you to choose any of the following options for your frozen embryos when you have decided you no longer intend to use them for yourself?

Donation of the embryos to research

I do not want to donate — I am unsure — I want to donate

Donation of the embryos to another infertile couple

I do not want to donate — I am unsure — I want to donate

Thawing and disposal of the embryos

I do not want to thaw and dispose — I am unsure — I want to thaw and dispose

Please state any other option you have considered:

I do not want to choose this option — I am unsure — I want to choose this option

Next

42% complete

Part IV. About how you feel about your embryos

The following table lists emotions that people may or may not experience about their frozen embryos. Please rate the extent to which you experience each one of these emotions if you think about your frozen embryos now.

My frozen embryos make me:

	Not at all	A little	A moderate amount	Very much	An extreme amount
Content	○	○	○	○	○
Worried	○	○	○	○	○
Guilty	○	○	○	○	○
Tense	○	○	○	○	○
Pleased	○	○	○	○	○
Uncertain	○	○	○	○	○
Frustrated	○	○	○	○	○
Sad	○	○	○	○	○
Nervous	○	○	○	○	○
Positive	○	○	○	○	○
Anxious	○	○	○	○	○
Hopeful	○	○	○	○	○
Happy	○	○	○	○	○
Relieved	○	○	○	○	○
Upset	○	○	○	○	○
Optimistic	○	○	○	○	○
Confused	○	○	○	○	○
Glad	○	○	○	○	○
Depressed	○	○	○	○	○
Helpless	○	○	○	○	○
Undecided	○	○	○	○	○
Pressured	○	○	○	○	○
Lucky	○	○	○	○	○
Conflicted	○	○	○	○	○
Comforted	○	○	○	○	○
Concerned	○	○	○	○	○
Tentative	○	○	○	○	○
Stuck	○	○	○	○	○
Curious	○	○	○	○	○

Next

57% complete

Part V. About how you view your embryos:

Please indicate to what extent you agree or disagree with each of the following statements if you think about your frozen embryos now

My frozen embryos:	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
are like children	○	○	○	○	○
are my/our genetic makeup	○	○	○	○	○
are like unborn children	○	○	○	○	○
are important to me	○	○	○	○	○
are my/ our children	○	○	○	○	○
are future opportunities for another child	○	○	○	○	○
are like family members	○	○	○	○	○
are options for having children in the future	○	○	○	○	○
are already babies	○	○	○	○	○
are valuable to me	○	○	○	○	○
are human life	○	○	○	○	○
are hope for (more) children	○	○	○	○	○
are a form of life	○	○	○	○	○
could be used for stem cell therapy in case of illness	○	○	○	○	○
are miniature versions of our children	○	○	○	○	○
are a possibility of having a(nother) child	○	○	○	○	○
are protection if fertility problems persist in the future	○	○	○	○	○
are living organisms	○	○	○	○	○
are special to me	○	○	○	○	○
are family	○	○	○	○	○
are our children in the future	○	○	○	○	○
are stem cell sources	○	○	○	○	○
are precious	○	○	○	○	○
belong to me	○	○	○	○	○
are hope for having our own (biological) children	○	○	○	○	○
are a back-up if something happens to my/our child(ren)	○	○	○	○	○
mean the world to me	○	○	○	○	○
are a chance to have a baby	○	○	○	○	○
are genetically related to me (and my partner)	○	○	○	○	○
are my responsibility	○	○	○	○	○
hopefully become my children someday	○	○	○	○	○
are clusters of cells	○	○	○	○	○

Below are additional statements about embryos. As before please indicate to what extent you agree or disagree with each of the following statements if you think about your frozen embryos now.

	Strongly disagree	disagree	Neither agree nor disagree	Agree	Strongly agree
I am protective towards my frozen embryos	○	○	○	○	○
I own my frozen embryos	○	○	○	○	○
I would never have abandoned my frozen embryos	○	○	○	○	○
The life of my frozen embryos depends on me	○	○	○	○	○
I am emotionally attached to my frozen embryos	○	○	○	○	○
My frozen embryos should be given a chance at life	○	○	○	○	○
I love my frozen embryos	○	○	○	○	○
My frozen embryos should be respected	○	○	○	○	○

Please indicate which question if any were unclear and why?

Are there other important feelings and views regarding your frozen embryos that were not included in this questionnaire?

Part V. About where you found us?

Where did you find this questionnaire?

Next

71% complete

Thank you very much for helping us with this important study.

We would be very grateful if you could let us know your thoughts and feelings about this survey, any questions you found difficult and any topics you feel we left out.

We would like to reassure you that all the information you provided is anonymous and cannot be traced back to you. However, if you would like to receive an update of our results and are interested in participating in future studies, please provide us with your contact details (e.g., email address) in the box below.

Below is some more information about this study

Many couples find making a final decision about what to do with their frozen embryos demanding and this challenge has been linked to how people view and emotionally react to their embryos. In order to continue investigating why the embryo disposition decision is demanding for men and women we need to have a good way of measuring these emotions and views. The online survey you completed will help us achieve the goal to develop an embryo specific affect and perception scale and thereby help to better understand embryo disposition decision-making.
It was important to ask you a range of personal questions about your embryo history and view of your embryos. If you have any concerns as a result of your participation in this study please contact Dr Jacky Boivin (see below for contact details), your GP or family doctor.

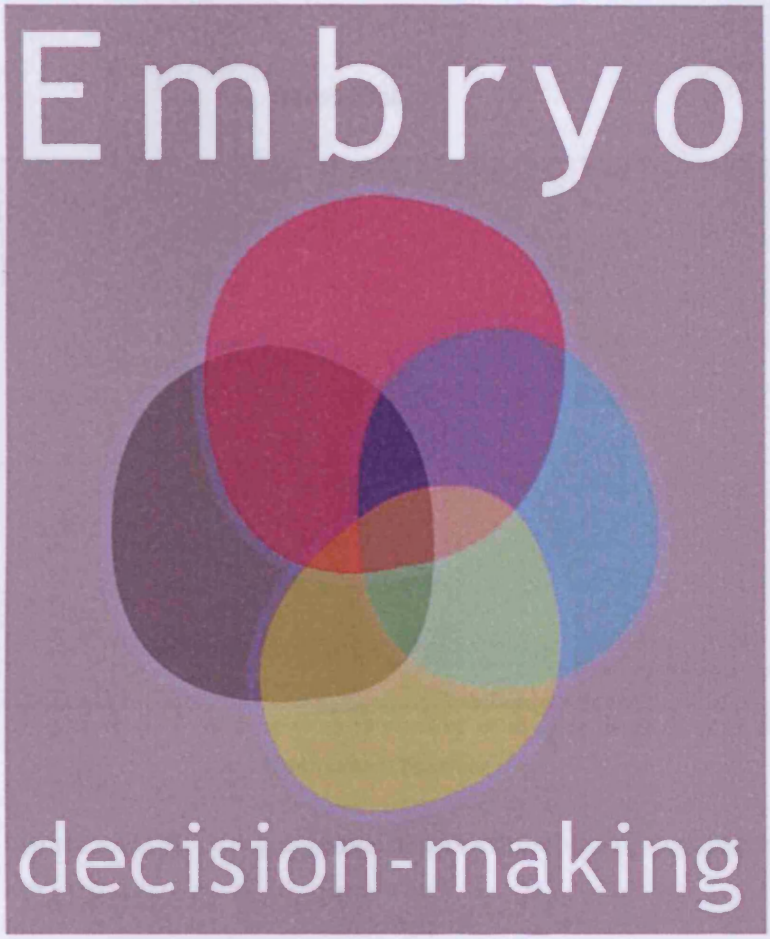
If you have any further questions about this research then please contact the principal investigator:
Dr Jacky Boivin
School of Psychology, Cardiff University
Psychology Building, Park Place
Cardiff, Wales
CF10 3AT
Boivin@Cardiff.ac.uk

Dr Jacky Boivin is interested in the psychosocial aspects of reproductive health. She has conducted many studies in this area on issues such as the link between stress and fertility, differences between men and women in emotional reactions to fertility problems, whether counselling helps people cope with fertility problems, how children conceived with fertility treatment develop, and much more. This research has been carried out with the help of women from many countries worldwide. You can see some of the published reports of this work on the Cardiff Fertility Research Group at **www.cardifffertilitystudies.com .**

Submit

85% complete

Appendix 6: Embryo Disposition Logo Used for Advertisement of the Scale Evaluation Survey



This is a 10 minute survey on what embryos mean (or meant) to you that will be used to improve patient support.

Appendix 7: Scree Plot of Principal Component Analysis on CAER Scale for Group PES

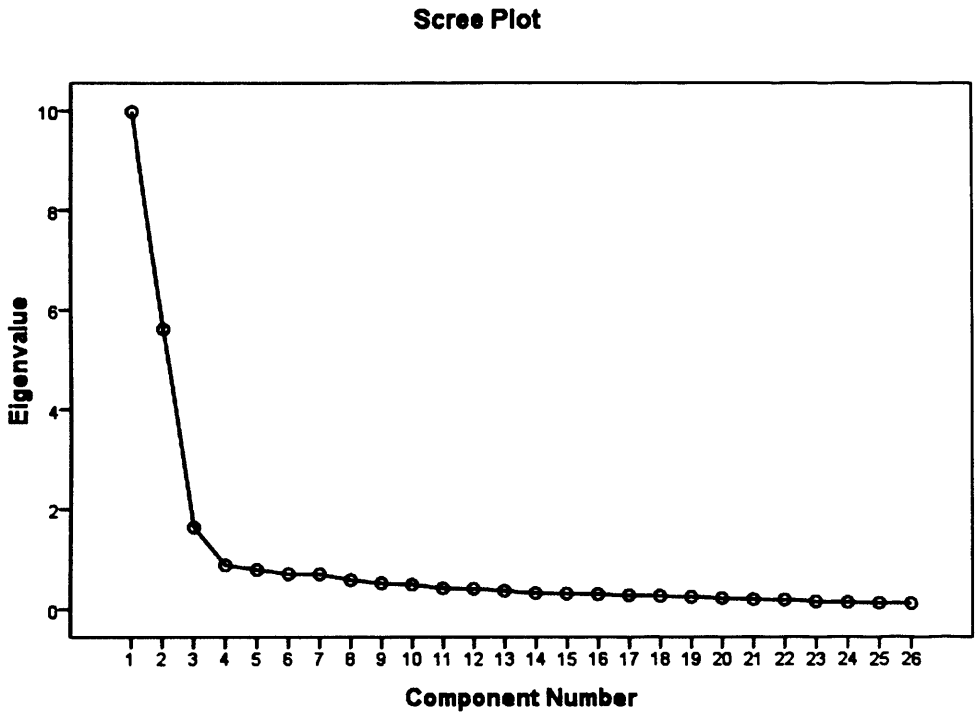


Figure 5.2: Scree plot showing eigenvalues as a function of component of the CAER scale for group PES.

Appendix 8: Scree Plot of Principal Component Analysis on CAER Scale Group CES

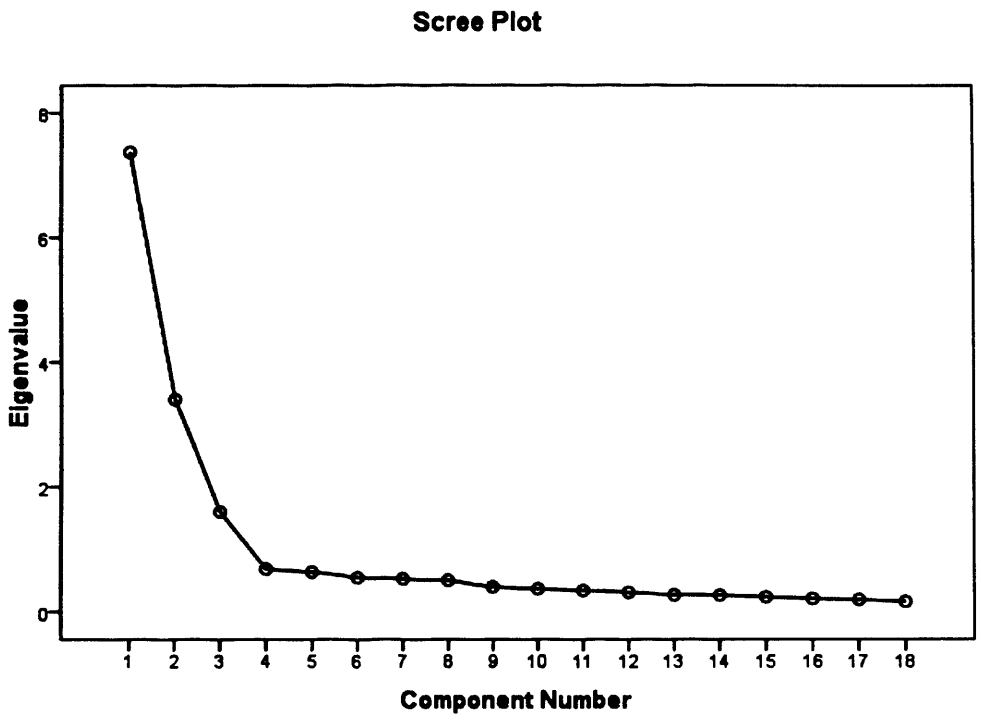


Figure 5.3: Scree plot showing eigenvalues as a function of component of the CAER scale for group CES.

Appendix 9: Scree Plot of Principal Component Analysis on CCER Scale for Group PES

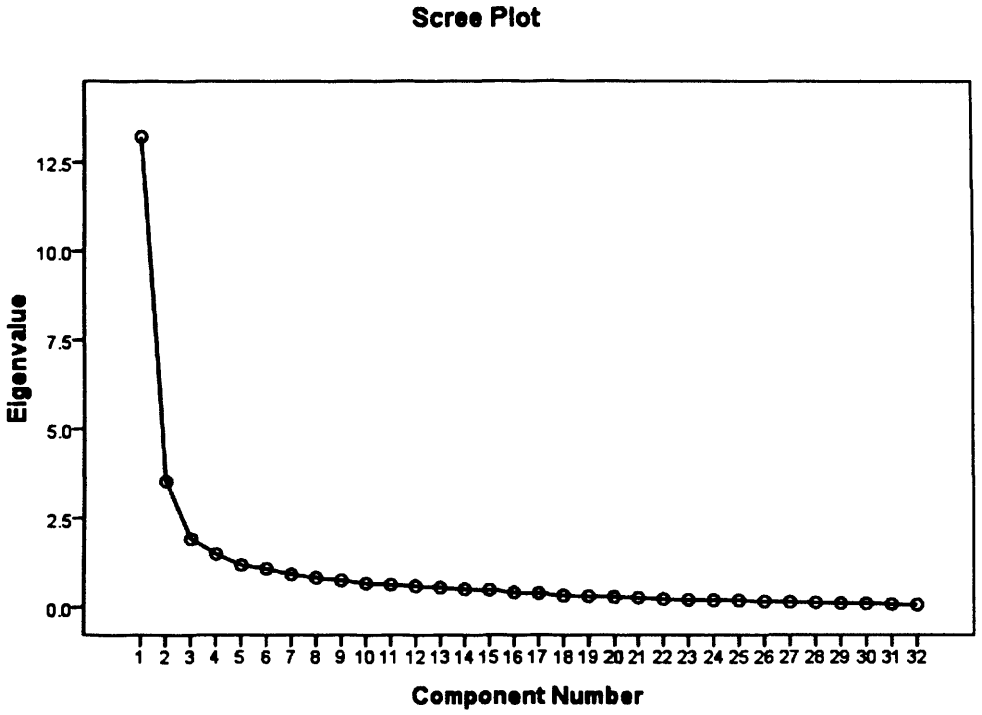


Figure 5.5: Scree plot showing eigenvalues as a function of component of the CCER scale for group PES

Appendix 10: Scree Plot of Principal Component Analysis on CCER Scale for Group CES

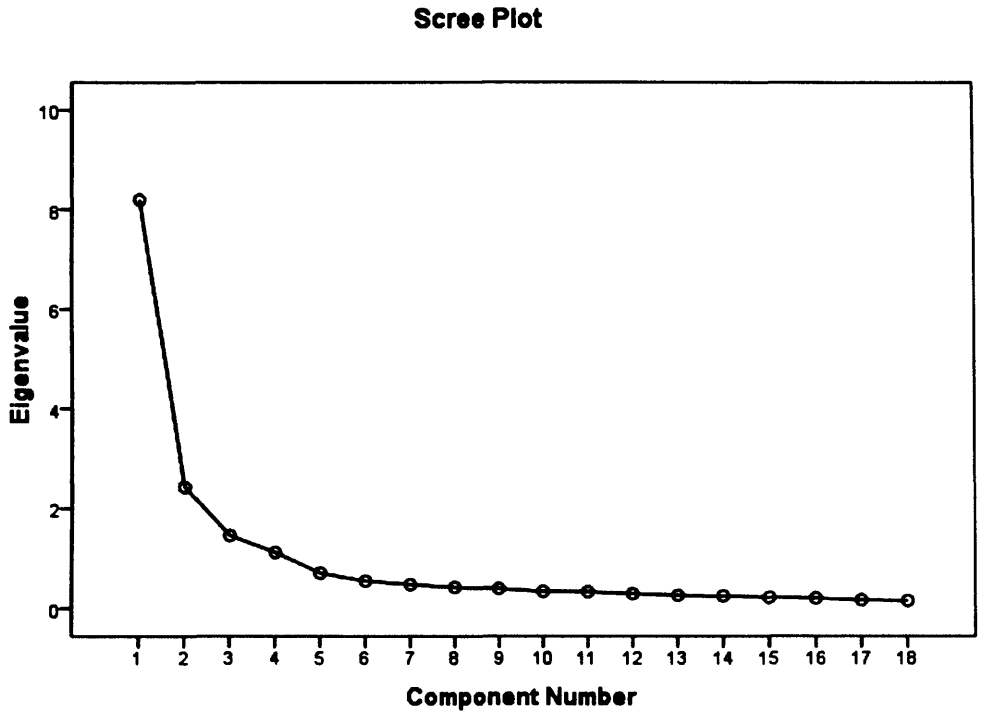


Figure 5.6: Scree plot showing eigenvalues as a function of component of the CCER scale for group CES

Appendix 11 Part I: Questionnaire Used in Clinic Study Presented in Chapter 6

(Time 1)

Participant code: Version 1.1, March 2010

Survey on embryo perceptions
Study Part I

Part I. About you

Are you male ☐
female ☐

How old are you? [ ] (state in years)

What is your highest level of education?

Primary school ☐
Secondary school ☐
Post secondary / College ☐
University ☐
Other [ ]

What is your marital status?

Are you currently:

Single ☐
Married and/or living with partner ☐
Separated/divorced ☐
Widowed ☐

Do you have children? (including adopted and step-children)

Yes ☐ If yes: number of children: [ ]
No ☐

How many children to you intend to have in total? [ ] (state a number)

Part II. About your current mood

In the following section various emotions are listed. Please rate the extent to which you experienced each one of these emotions in the past 24 hours in terms of whether and to what extent the symptom occurred by ticking the appropriate box.

	Not at all	A little	A moderate amount	Very much	An extreme amount
Confident					
Anxious					
Positive					
Content					
Uncomfortable					
Encouraged					
Disappointed					
Hopeful					
Discouraged					
Uncertain					
Nervous					
Happy					
Worried					
Relieved					
Tense					
Hesitant					
Unsure					
Angry					
Fulfilled					
Uneasy					
Sad					
Doubtful					
Bothered					

Part III. About your experience with embryos

Have you ever had embryos?

No ☐ If no: please go to section IV on the next page

Yes ☐

In how many cycles of previous treatments were you able to freeze embryos?

[ ] (please state a number)

How many embryos did you freeze in total?

[ ] (please state a number)

How many of your embryos are still in storage?

[ ] (please state a number)

Have you had a live birth using any of your embryos? (please indicate all that apply)

Yes, as a result of a fresh transfer ☐

Yes, as a result of a frozen transfer ☐

No ☐

Part IV. About what you want to do with your extra embryos.

If your treatment today results in extra embryos, what do you intend to do with your extra embryos after the upcoming transfer?
(Please indicate where you would be on the scale below by placing a tick in one of the boxes.)

1) If you get pregnant

I do not want to use my embryos for further treatment	I am unsure	I want to use my embryos for further treatment

2) If you do not get pregnant

I do not want to use my embryos for further treatment	I am unsure	I want to use my embryos for further treatment

If your treatment today results in extra embryos, how likely are you to choose any of the following options for your extra embryos when you have decided you no longer intend to use them for yourself?

1) Donation of the embryos to research

I do not want to donate	I am unsure	I want to donate

2) Donation of the embryos to another infertile couple

I do not want to donate	I am unsure	I want to donate

3) Thawing and disposal of the embryos

I do not want to thaw and dispose	I am unsure	I want to thaw and dispose

4) Please state any other option you have considered: [ ]

I do not want to choose this option	I am unsure	I want to choose this option

Part V. About how you think and feel about your extra embryos

The following table lists emotions that people may or may not experience about their extra embryos. Please rate the extent to which you experience each one of these emotions when you think about your extra embryos that may be created as part of your treatment today.

The prospect of having extra embryos makes me:	Not at all	A little	A moderate amount	Very much	An extreme amount
content					
worried					
guilty					
tense					
pleased					
uncertain					
frustrated					
sad					
nervous					
positive					
anxious					
hopeful					
happy					
relieved					
upset					
optimistic					
confused					
glad					
depressed					
helpless					
undecided					
pressured					
lucky					
conflicted					
comforted					
concerned					
tentative					
stuck					
curious					

Part VI. About how you view your extra embryos

Please indicate to what extent you agree or disagree with each of the following statements when you think about the extra embryos that may be created as part of your treatment today.

Extra embryos:	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
are like children					
are my/our genetic makeup					
are like unborn children					
are important to me					
are my/ our children					
are future opportunities for having another child					
are like family members					
are options for having children in the future					
are already babies					
are valuable to me					
are human life					
are hope for (more) children					
are a form of life					
could be used for stem cell therapy in case of illness					
are miniature versions of our children					
are a possibility of having a(nother) child					
are protection if fertility problems persist in the future					
are living organisms					
are special to me					
are family					
are our children in the future					
are stem cell sources					
are precious					
belong to me					
are clusters of cells					
are hope of having our own (biological) children					
are a back-up if something happens to my/our child(ren)					
mean the world to me					
are a chance to have a baby					
are genetically related to me (and my partner)					
are my responsibility					
hopefully become my children someday					

Below are additional statements about embryos. As before please indicate to what extent you agree or disagree with each of the following statements when you think about your frozen embryos that may be created as part of your treatment today.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I am protective towards my extra embryos					
I own my extra embryos					
I would never abandon my extra embryos					
The life of my extra embryos' depends on me					
I am emotionally attached to my extra embryos					
My extra embryos should be given a chance at life					
I love my extra embryos					
My extra embryos should be respected					

Please indicate which items in this survey, if any, were unclear and why?

_____

_____

Are there other important feelings and views regarding your extra embryos that were not mentioned in the survey?

_____

_____

Thank you for taking part in this study

Appendix 11 Part II: Questionnaire Used in Clinic Study Presented in Chapter 6 (Time 2)

Participant code: Version 1.1, March 2010

Survey on embryo perceptions
Part II

Part I. About your current mood

In the following section various emotions are listed. Please rate the extent to which you experienced each one of these emotions in the past 24 hours in terms of whether and to what extent the symptom occurred by ticking the appropriate box.

	Not at all	A little	A moderate amount	Very much	An extreme amount
Confident					
Anxious					
Positive					
Content					
Uncomfortable					
Encouraged					
Disappointed					
Hopeful					
Discouraged					
Uncertain					
Nervous					
Happy					
Worried					
Relieved					
Tense					
Hesitant					
Unsure					
Angry					
Fulfilled					
Uneasy					
Sad					
Doubtful					
Bothered					

Part II. About your experience with embryos

Do you have any extra embryos (whether frozen or not) that were not transferred today?

Yes ☐ If yes: number of extra embryos: [ ]
No ☐

Part III. About what you want to do with your extra embryos.

What do you intend to do with your extra embryos after today's transfer?
(Please indicate where you would be on the scale below by placing a tick in one of the boxes.)

1) If you get pregnant

I do not want to use my embryos for further treatment	I am unsure	I want to use my embryos for further treatment

2)If you do not get pregnant

I do not want to use my embryos for further treatment	I am unsure	I want to use my embryos for further treatment

How likely are you to choose any of the following options for your extra embryos when you have decided you no longer intend to use them for yourself?

1) Donation of the embryos to research

I do not want to donate	I am unsure	I want to donate

2) Donation of the embryos to another infertile couple

I do not want to donate	I am unsure	I want to donate

3) Thawing and disposal of the embryos

I do not want to thaw and dispose	I am unsure	I want to thaw and dispose

4) Please state any other option you have considered: [ ]

I do not want to choose this option	I am unsure	I want to choose this option

Part IV. About how you think and feel about your extra embryos

The following table lists emotions that people may or may not experience about their extra embryos. Please rate the extent to which you experience each one of these emotions when you think about your extra embryos that have been created as part of your current treatment.

My extra embryos make me:	Not at all	A little	A moderate amount	Very much	An extreme amount
content					
worried					
guilty					
tense					
pleased					
uncertain					
frustrated					
sad					
nervous					
positive					
anxious					
hopeful					
happy					
relieved					
upset					
optimistic					
confused					
glad					
depressed					
helpless					
undecided					
pressured					
lucky					
conflicted					
comforted					
concerned					
tentative					
stuck					
curious					

Part V. About how you view your extra embryos

Please indicate to what extent you agree or disagree with each of the following statements when you think about your extra embryos that have been created as part of your current treatment.

My extra embryos:	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
are like children					
are my/our genetic makeup					
are like unborn children					
are important to me					
are my/ our children					
are future opportunities for having another child					
are like family members					
are options for having children in the future					
are already babies					
are valuable to me					
are human life					
are hope for (more) children					
are a form of life					
could be used for stem cell therapy in case of illness					
are miniature versions of our children					
are a possibility of having a(nother) child					
are protection if fertility problems persist in the future					
are living organisms					
are special to me					
are family					
are our children in the future					
are stem cell sources					
are precious					
belong to me					
are clusters of cells					
are hope of having our own (biological) children					
are a back-up if something happens to my/our child(ren)					
mean the world to me					
are a chance to have a baby					
are genetically related to me (and my partner)					
are my responsibility					
hopefully become my children someday					

Below are additional statements about embryos. As before please indicate to what extent you agree or disagree with each of the following statements when you think about your extra embryos that have been created as part of your current treatment.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
I am protective towards my extra embryos					
I own my extra embryos					
I would never abandon my extra embryos					
The life of my extra embryos' depends on me					
I am emotionally attached to my extra embryos					
My extra embryos should be given a chance at life					
I love my extra embryos					
My extra embryos should be respected					

Please indicate which items in this survey, if any, were unclear and why?

_____

_____

Are there other important feelings and views regarding your extra embryos that were not mentioned in the survey?

_____

_____

We would be grateful if you could let us know your thoughts and feelings about this survey, any questions you found difficult and any topics you felt we left out.

Thank you for taking part in this study

Appendix 12: Consent Form for Clinic Study Presented in Chapter 6

Version 1.2, March 2010

Participant code:

CONSENT FORM

Study title: Perception of extra embryos

Name of researcher: Prof Jacky Boivin

Please initial box

1. I confirm that I have read and understood the information sheet dated.....for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that the anonymised research data that I provide will be used by researchers and the study group and may be looked at by regulatory authorities. I give permission for these individuals to have access to my anonymised research data. ☐

4. I agree to take part in the above study. ☐

Appendix 13: Letter of Access for Research in the NHS

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board

Ysbyty Athrofaol Cymru
University Hospital of Wales

Heath Park, Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838
Minicom 029 2074 3632

Parc Y Mynydd Bychan, Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 2074 3838
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Workforce and OD Directorate

12th May 2010

Amended letter

Mareike Stiel

Dear Mrs Stiel

Letter of access for research

This letter confirms your right of access to conduct research through Cardiff and Vale University Local Health Board for the purpose and on the terms and conditions set out below. This right of access commences on 12th May 2010 and ends 31st October 2010 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at Cardiff and Vale University Local Health Board has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Cardiff and Vale University Local Health Board. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Cardiff and Vale University Local Health Board, you will remain accountable to your place of study at Cardiff University, School of Psychology, but you are required to follow the reasonable instructions of the Principal Lead for the study in this organisation or those given on his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with Cardiff and Vale University Local Health Board policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Cardiff and Vale University Local Health Board in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Cardiff and Vale University Local Health Board premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

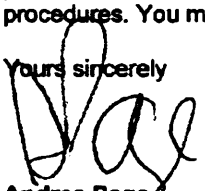
You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Cardiff and Vale University Local Health Board will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely



Andrea Page
Recruitment Manager
Workforce and OD Directorate

cc: R&D office, Cardiff and Vale University Health Board

2

Appendix 14: Ethical Approval by the Research & Development Department for Research in the NHS

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board

Ysbyty Athrofaol Cymru
University Hospital of Wales

Heath Park, Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838
Minicom 029 2074 3632

Parc Y Mynydd Bychan, Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 2074 3838
Minicom 029 2074 3632

Eich cyf/Your ref
Ein cyf/Our ref
Welsh Health Telephone Network 1872
Direct line/Llinell uniongyrchol

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

From: Professor JI Bisson
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

20 April 2010

Dr Jacky Boivin
School of Psychology
Cardiff University
Park Place
Cardiff
CF10 3AT

Dear Dr Boivin

Project ID : 10/RPM/4824 : The Impact Of Treatment Experience, Treatment Intentions and Dissonance on Perception of Cryopreserved Embryos

Thank you for your recent communication regarding the above project, which was reviewed on 20 April 2010 by the Chair of the Cardiff and Vale Research Review Service (CaRRS).

Documents submitted for review were:

Document	Version	Date
NHS RD Form	-	-
SSI Form	-	-
Protocol	1.4	March 2010
Patient Information Sheet	1.2	March 2010
Patient Consent Form	1.2	March 2010
Questionnaire (Survey)	1.1	March 2010

I am pleased to inform you that the Chair of the Panel had no objection to your proposal. You have informed us that Cardiff University will act as research Sponsor under the Research Governance Framework for Health and Social Care.

Cardiff & Vale University Local Health Board approval is therefore subject to:

- Evidence of favourable opinion from the relevant NHS Research Ethics Committee
- Honorary research contracts/letters of access being issued

Once the above are in place, Cardiff and Vale UHB will be happy for the project to begin.

May I take this opportunity to wish you success with the project and remind you that as Principal Investigator you are required to:

- Ensure that all members of the research team undertake the project in accordance with ICH-GCP and adhere to the protocol as approved by the Research Ethics Committee
- Inform the R&D office if any external or additional funding is awarded for this project in the future
- Inform the R&D office of any amendments relating to the protocol, including personnel changes and amendments to the actual or anticipated start and end dates
- Complete any documentation sent to you by the R&D office or University Research and Commercial Division regarding this project
- Ensure that adverse event reporting is in accordance with the UHB adopted Cardiff and Vale NHS Trust Policy and Procedure for Reporting Research-Related Adverse Events (refs 164 & 174) and Incident Reporting and Investigation (ref 108)
- Ensure that the research complies with the Data Protection Act 1998
- Ensure that arrangements for continued storage or use of human tissue samples at the end of the approved research project comply with the Human Tissue Act 2004 (for further information please contact Sharon Orton, HTA Coordinator (OrtonS@cf.ac.uk).

Yours sincerely,

Professor Jonathan I Bisson
Chair of the Cardiff and Vale Research Review Service (CaRRS)

CC Chris Shaw, Research and Commercial Division, Cardiff University
CC R&D Lead Prof Alison Fiander
CC Mrs Mareike Stiel

Appendix 15: Ethical Approval by the South East Wales Research Committee Panel B for Conducting Research in the NHS

GIG CYMRU NHS WALES | Canolfan Gwasanaethau Busnes / Business Services Centre

South East Wales Research Ethics Committee Panel B
Telephone: 02920 376823
Facsimile: 02920 376835
Email: Carl.phillips@bsc.wales.nhs.uk

Dr Jacky Boivin
Reader, Cardiff University
School of Psychology
Cardiff University
Park Place
CF10 3AT

23 April 2010

COPY FOR YOUR INFORMATION

Dear Dr Boivin

Study Title:	**The impact of treatment experience, treatment intentions and dissonance on perception of cryopreserved embryos**
REC reference number:	**10/WSE02/31**
Protocol number:	**1.4**

The Research Ethics Committee reviewed the above application at the meeting held on the 21 April 2010.

The Committee was most grateful to Mrs M Stiel for attending the meeting to discuss the study.

Ethical opinion

The Committee noted that this was a single site study which involved administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology.

The Committee noted that the study aimed to establish whether patients modified their perception of their frozen embryos as they progress through infertility treatment.

The Committee noted that the study was being undertaken as an educational project in part fulfilment of a PhD in Health Psychology.

Canolfan Gwasanaethau Busnes
Ty Churchill
17 Ffordd Churchill
Caerdydd, CF10 2TW
Ffôn: 029 20 376820 WHTN: 1809
Ffacs: 029 20 376826

Business Services Centre
Churchill House
17 Churchill Way
Cardiff, CF10 2TW
Telephone: 029 20 376820 WHTN: 1809
Fax: 029 20 376826

rhan o Bwrdd Iechyd Lleol Addysgu Powys / part of Powys Teaching Local Health Board

The Committee in noting that the study was being undertaken in part fulfilment of a PhD also noted that the National Research Ethics Service (NRES) advised applicants that where a project was being undertaken as part of a PhD or other doctorate, the student should normally be named as the Chief Investigator (CI).

Unless there was a good reason for doing otherwise, the PhD student must be named as the CI and members asked that this be borne in mind for future applications.

The Committee in noting that the study was sponsored by Cardiff University also noted that evidence of indemnity to cover any potential liability arising from the research had been provided as required by *Section 1.46* of the *Standard Operating Procedures for Research Ethics Committees version 4.0 dated April 2009,* issued by the *National Research Ethics Service.*

The Committee noted that the sponsor's representative had declared that an appropriate process of scientific critique had demonstrated that this research proposal was worthwhile and of high scientific quality.

The Committee noted that the statistical aspects of the research had been reviewed by the educational supervisor.

The Committee noted that the study would involve 165 participants who would be identified and initially approached by a member of the team directly involved in their care. Members also noted that no identifiable personal information would be passed on to the research team outside of the clinical team.

The Committee noted that the study would not involve adults unable to consent for themselves through physical or mental incapacity.

The Committee noted that the study involved the completion of a questionnaire on two occasions approximately one week apart. Completion of the questionnaire would take approximately 10 minutes.

The Committee noted that potential participants would be provided with written information about the purpose of the study, why they had been invited to participate, who was conducting the research, how the data would be used and what participation would be required of them. They would also be given the opportunity to ask any questions about the study. Written consent would be obtained prior to participation in the study and it was made clear that participation was entirely voluntary and that those taking part could withdraw at any point for any reason.

The Committee noted that participants would have as much time as was required in which to decide whether or not to take part in the study.

The Committee noted that if a participant, who had given informed consent, lost capacity to consent during the study then that participant would be withdrawn. Non identifiable data might be retained.

The Committee noted from *section A43* of the *application form* that personal data would be stored for between 6 -12 months after the study had ended.

The Committee pointed out that it was the responsibility of the Chief Investigator to be up to date and to comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- The Committee noted an apparent typing error in the last sentence of the first paragraph of the section of the Information Sheet headed "What is the purpose of the study". The sentence currently read "*This decision has been shown to be linked to how couples perception and feelings about their frozen embryos*", when presumably it should read "*This decision has been shown to be linked to how couples perceive and feel about their frozen embryos*".

- Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

- For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

- Sponsors are not required to notify the Committee of approvals from host organisations.

- It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

3

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
REC application	IRAS 2.5	29 March 2010
Protocol	1.4	01 March 2010
Investigator CV	M Stiel	01 April 2010
Investigator CV	J Boivin	01 April 2010
Participant Information Sheet	1.2	01 March 2010
Participant Consent Form	1.2	01 March 2010
Evidence of insurance or indemnity	Zurich Municipal	30 July 2009
Letter from Sponsor	Cardiff University	18 January 2010
Questionnaire: Survey on Embryo Perceptions	1.1	01 March 2010
Questionnaire: Survey on Embryo Perceptions	1.1	01 March 2010

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/WSE02/31	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Mrs A Dowden
Chair, Panel B
South East Wales Research Ethics Committees

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers" SL-AR2

Copy: R&D office for Cardiff University

R&D office for Cardiff & Vale University Health Board

Mrs Mareike Stiel, School of Psychology, Cardiff University, Park Place, Cardiff, **CF10 3AT**

5

South East Wales Research Ethics Committee Panel B

Attendance at Committee meeting on 21 April 2010

Committee Members:

Name	Profession	Present	Notes
Dr A Bayer	Consultant Physician	No	
Ms G Bennett	Lay Member	No	
Dr I Doull	Vice Chair & Consultant Respiratory Paediatrician	No	
Mrs A Dowden	Chair and Lay Member	Yes	
Dr N A Drage	Consultant Dental Radiologist	Yes	
Dr P Evans	Consultant Physician	No	
Professor N Frude	Consultant Psychologist	Yes	
Dr N Jamil	Consultant Psychiatrist	Yes	
Dr I J Kerby	Consultant Oncologist	Yes	
Mrs S J Kotecha	Research Dietician	No	
Mr P Lindsay	Consultant Obstetrician & Gynaecologist	No	
Mrs J Matthews	Pharmacist	Yes	
Mr J Owen	Lay Member	Yes	
Dr M D Page	Consultant Physician	No	
Mrs S Warrell	Alternate Vice-Chair & Lay Member	No	
Mr Paul Williams	Lay Member	Yes	

6

Appendix 16: Frequency Distributions

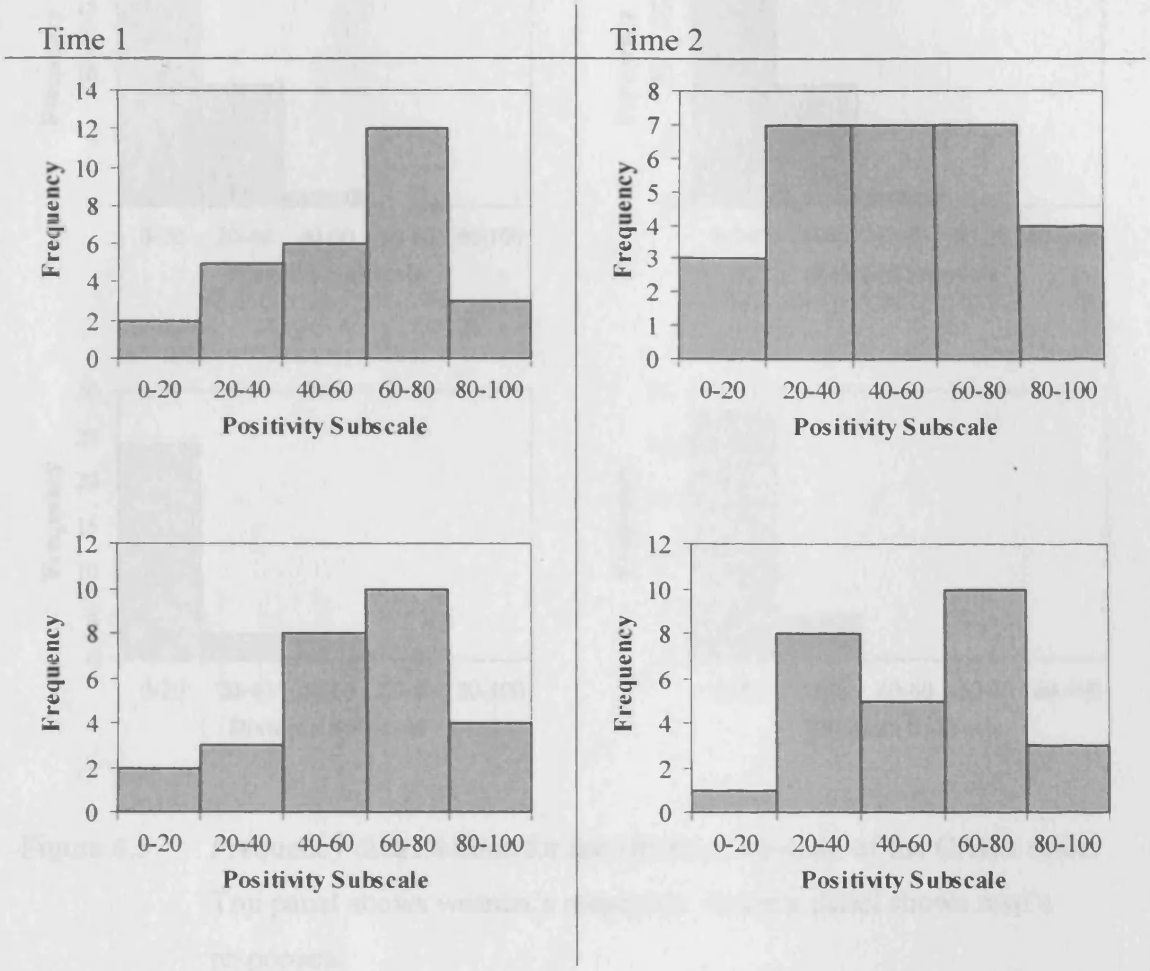


Figure 6.4: Frequency distributions for the *Positivity* subscale of the CAER scale. Top panel shows women's responses, bottom panel shows men's responses.

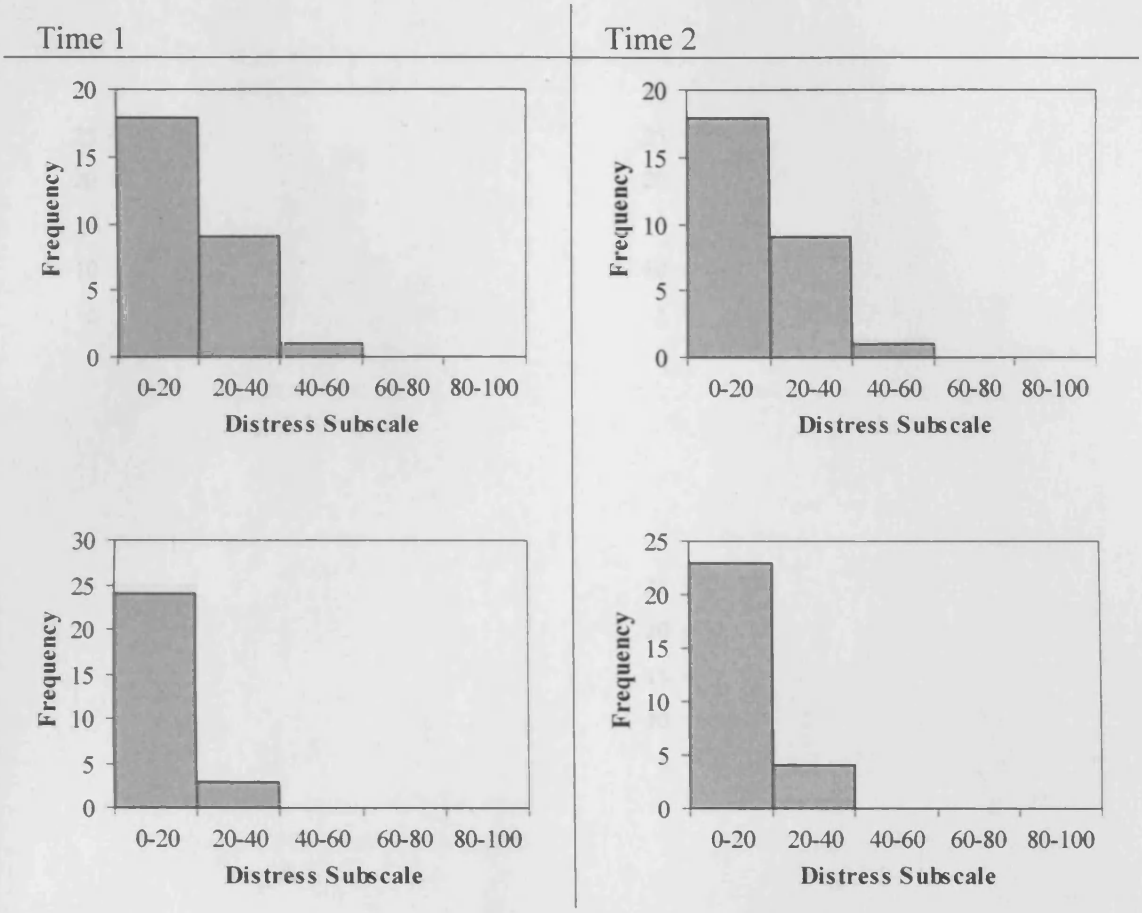


Figure 6.5: Frequency distributions for the Distress subscale of the CAER scale. Top panel shows women's responses, bottom panel shows men's responses.

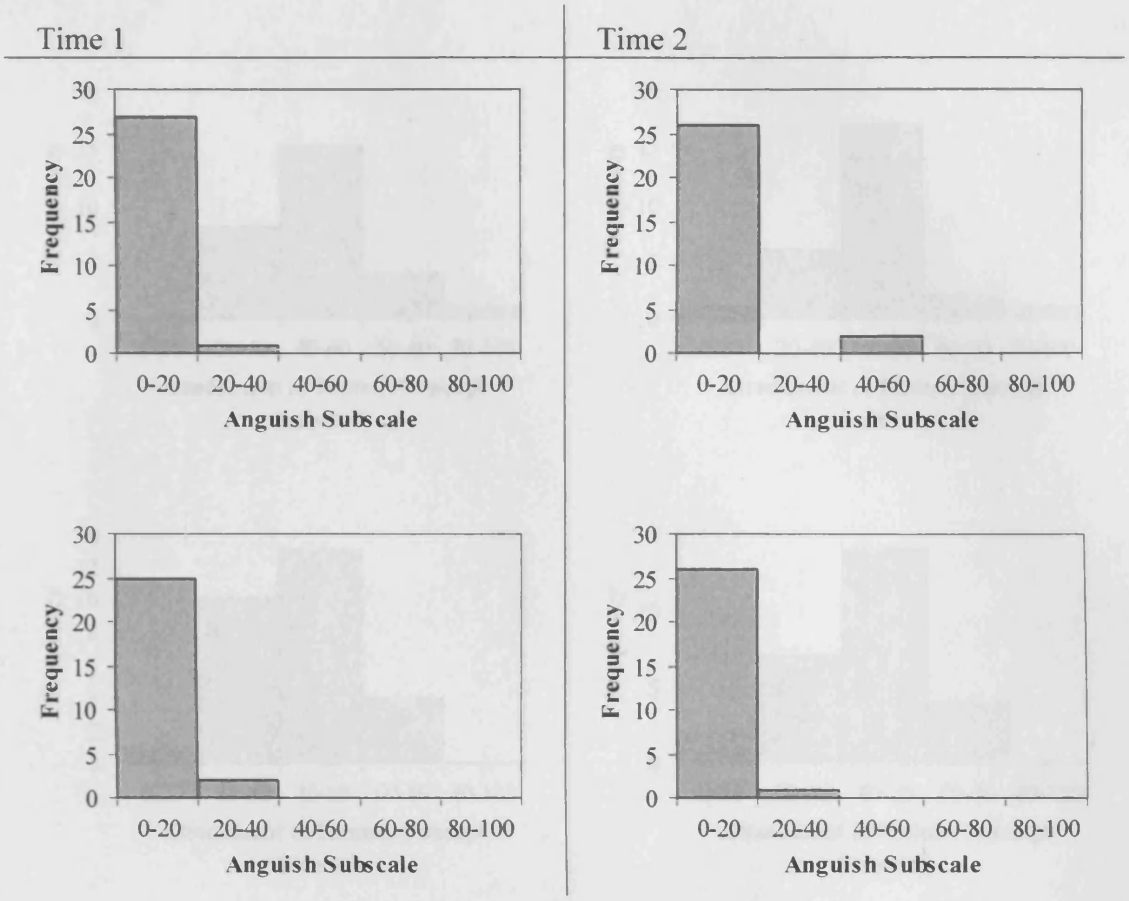


Figure 6.6: Frequency distributions for the Conflict subscale of the CAER scale. Top panel shows women's responses, bottom panel shows men's responses.

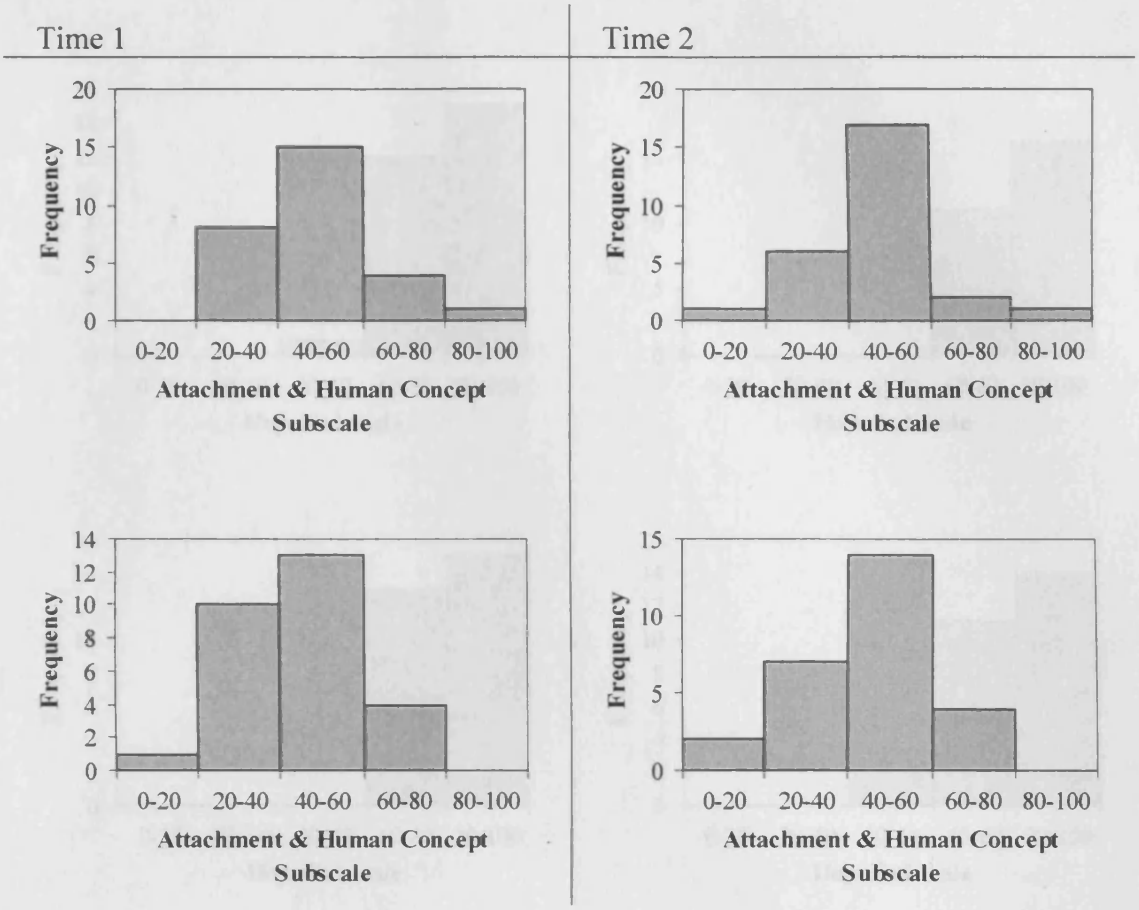


Figure 6.7: Frequency distributions for the Attachment & Human Concept subscale of the CCER scale. Top panel shows women's responses, bottom panel shows men's responses.

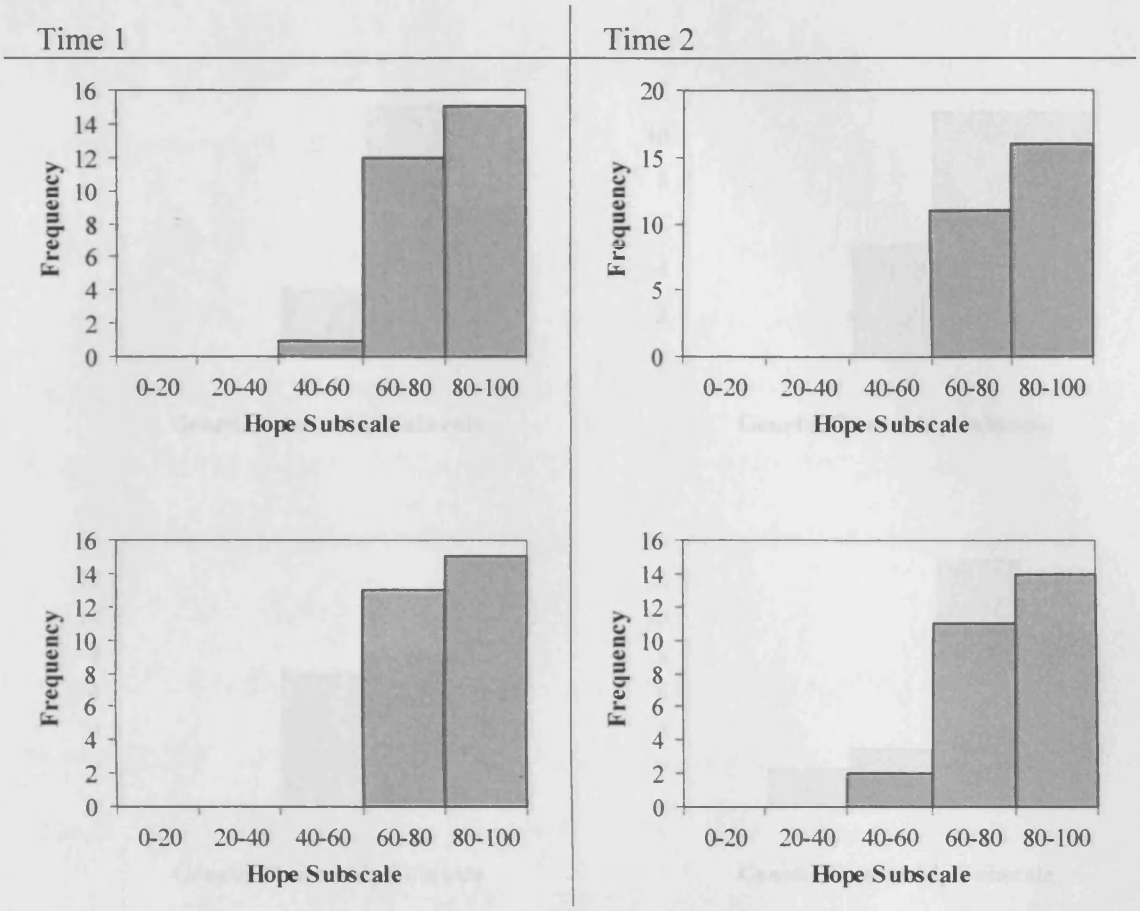


Figure 6.8: Frequency distributions for the Hope subscale of the CCER scale. Top panel shows women's responses, bottom panel shows men's responses.

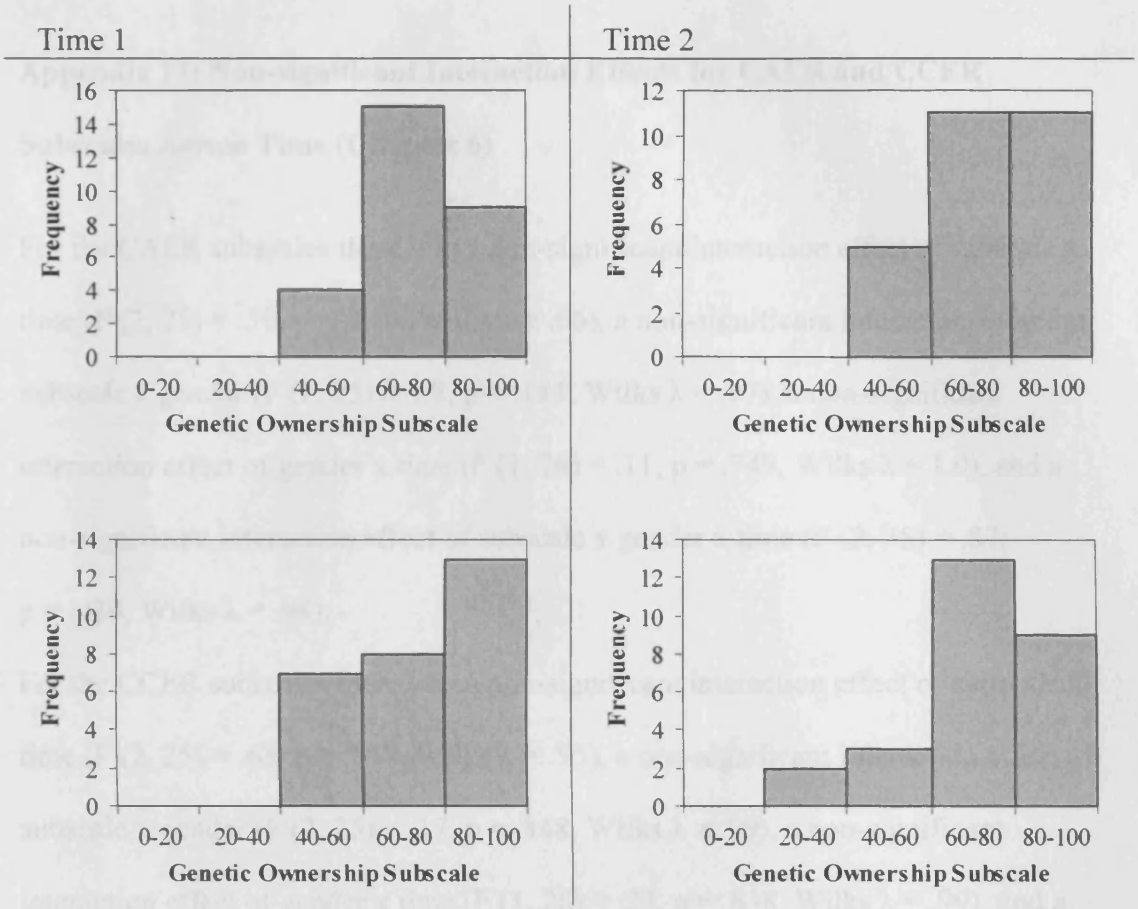


Figure 6.9: Frequency distributions for the Genetic Relation & Ownership subscale of the CCER scale. Top panel shows women's responses, bottom panel shows men's responses.

Appendix 17: Non-significant Interaction Effects for CAER and CCER Subscales Across Time (Chapter 6)

For the CAER subscales there was a non-significant interaction effect of subscale x time ($F(2, 25) = .50$, $p = .610$, Wilks $\lambda = .96$), a non-significant interaction effect of subscale x gender ($F(2, 25) = 1.8$, $p = .185$, Wilks $\lambda = .97$), a non-significant interaction effect of gender x time ($F(1, 26) = .11$, $p = .749$, Wilks $\lambda = 1.0$), and a non-significant interaction effect of subscale x gender x time ($F(2, 25) = .87$, $p = .430$, Wilks $\lambda = .94$).

For the CCER subscales there was a non-significant interaction effect of subscale x time ($F(2, 25) = .68$, $p = .517$, Wilks $\lambda = .95$), a non-significant interaction effect of subscale x gender ($F(2, 25) = .17$, $p = .848$, Wilks $\lambda = .99$), a non-significant interaction effect of gender x time ($F(1, 26) = .23$, $p = .638$, Wilks $\lambda = .99$), and a non-significant interaction effect of subscale x gender x time ($F(2, 25) = .96$, $p = .395$, Wilks $\lambda = .93$).

Appendix 18: Interaction Effects for the Relation between CAER and CCER Subscales (Chapter 6)

Table 6.6

Interaction effects with gender as a moderator for the relation between affective and cognitive embryo representations (N = 29)

Variables	*Attachment & Human Concept* T2	*Hope* T2	*Genetic Relation & Ownership* T2
Positivity T1 x gender	B = 0.02, t (47) = 0.12, p = 0.904	B = 0.13, t (47) = 0.48, p = 0.631	B = 0.26, t (47) = 1.09, p = 0.283
Distress T1 x gender	B = 0.02, t (47) = 1.26, p = 0.214	B = - 0.14, t (47) = - 0.53, p = 0.539	B = 0.10, t (47) = 0.53, p = 0.601
Conflict T1 x gender	B = 0.14, t (47) = 0.74, p = 0.460	B = - 0.16, t (47) = - 0.58, p = 0.564	B = - 0.01, t (47) = - 0.04, p = 0.971

Appendix 19: Publication of Data in Chapter 3

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Pre-birth characteristics and 5-year follow-up of women with cryopreserved embryos after successful *in vitro* fertilisation treatment

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Abstract

Many patients do not make a decision about the disposition of their surplus embryos until they are compelled to do so by statutory limits. In the current study, the characteristics of women who had conceived through *in vitro* fertilisation (IVF) and who still had embryos stored (E-S; $n = 26$) 5 years after IVF were compared to a cohort comparison group (C-C; $n = 40$). At time 1 (T1, 28 weeks pregnant) women completed questionnaires on personality traits (anxiety, locus of control and dependency) and participated in an interview on socio-demographic characteristics, family composition and stored embryos. At T2 (5 years later) women were re-interviewed and asked about beliefs about the embryos. Women in the E-S group were significantly younger, had been married or living with their partner for fewer years and had had more children than the C-C group. Further, women in the E-S group were more likely to have an external locus of control and a dependent personality than women in the C-C group. Almost all women in the E-S group (88.5%) thought of their embryos as siblings to existing children, and reported thinking about the embryos occasionally (61.5%) or frequently (34.6%). The personality differences identified may suggest that women who still have embryos after the end of fertility treatment may be in need of decision support.

Keywords: *Surplus embryos, embryo disposition, patient characteristics, long-term effects of ART, decision making*

Introduction

In August 2001 the Human Fertilisation and Embryology Authority (HFEA) changed their policy by reducing the number of embryos that may be transferred in a single *in vitro* fertilisation (IVF) treatment cycle from three to two. However, usually more than two embryos are created in a single cycle of ovarian stimulation, and as a consequence surplus embryos are created. Most couples opt to cryopreserve these embryos for potential future use. In many countries storage of cryopreserved embryos is limited to 5–10 years [1,2] and at the end of this period patients must decide what to do with surplus embryos, which can include: (1) use for future pregnancy attempts, (2) donation to another infertile couple, (3) donation to research, or (4) destruction of the embryos. There is much evidence to suggest that the embryo disposition decision is a difficult one and influenced by many factors [3–11]. Many patients delay making the decision [7,12,13] and between 25% and 60% of couples do not reply to clinic letters requesting a decision [14–16] which means, in effect, that the assisted reproductive technology (ART) clinic makes the decision for them and typically destroys the embryos [13,17]. A delay in decision-making about embryos has also been associated with finding the decision difficult [8,18], further treatment stressful [19] and a wish to avoid an irreversible decision [13] that could cause distress [3]. Aside from distress, demographic, social and family characteristics also influence decision-making though associations are not always consistent. In some studies [20] age is positively related to decision-making, but others report no relationship [19,20]; prior treatment success has been linked to a greater response to clinic letters [16,20,21] but lower likelihood of claiming

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surplus embryos [19]. Beliefs about the embryos have been reported to influence decision-making in that embryos were frequently described as human beings [17,22,23] that should either not be destroyed [22] or had to be destroyed in order to avoid dilemmas associated with donation to other couples [7,8]. Long-term distress caused by the infertility itself has also been associated with longer storage times [8,15] and greater worry about the embryos [3].

While overall this research provides good evidence for the difficulty of the embryo decision-making context there are two main limitations. First, personality and relational variables identified as relevant to decision-making have not yet been investigated in the embryo decision-making context. In other contexts, personality traits, for example, dispositional anxiety is associated with risk avoidant decision-making [24] as is low self-efficacy, which incorporates fear of being unable to make a good decision [25]. An external locus of control is also associated with lower preference for active involvement in the decision-making process [26,27]. Relational variables have also received comparatively little attention even though research suggests that couples who were not in complete agreement about the disposition decision found it more difficult to make the decision and took longer to do so (2.7 years *versus* 2.1 years) [7,8]. Second, studies have mainly used a cross-sectional design making it impossible to identify whether the psychosocial variables under investigation were predictors of longer storage times, a consequence of delayed decision-making or both. Personality factors such as locus of control, dependency and anxiety have been shown to be constructs stable over time [28–31]. This is particularly important for the purpose of the current study where it was aimed to identify such predictors in order to inform the design of decision-support interventions (DSI) tailored to the embryo disposition context and identifying for whom they might be most useful. DSIs support decision-making through information provision, value clarification and deliberation exercises [32] in order for people to be able to make choices consistent with their values and beliefs.

In this paper we investigate more broadly the association between psychosocial factors and embryo disposition. We compared personality and relational variables assessed at the start of IVF treatment (time 1, T1) between women who still had embryos 5 years after treatment (time 2, T2) to a cohort who had achieved a pregnancy through IVF at the same time but who did not have embryos at T2.

Method

Participants and procedures

All women in this study were participants in a larger longitudinal Australian study of couples conceiving by IVF who were recruited over a period of 18 months from an IVF unit. At the time of assessment women were 28 weeks pregnant (T1). Women in both groups met the following inclusion criteria: primiparous, singleton or twin pregnancy, 28 years or older, living with the father of the child, and English-language skills sufficient to complete the questionnaires and interviews. Additionally, both parents had to be genetically related to the child. The response rate was 80% of those invited into the study. The original study set out to examine adjustment during the transition to parenthood and was the first to follow IVF couples prospectively from pregnancy. At the 12 month follow-up unanticipated stress emerged among some parents regarding their stored frozen embryos and we decided to further examine decision making and concerns regarding embryos at child age 5 years (T2), but were constrained by our original IVF sample size and numbers retained in the study ($N = 66$; 81.5% of original sample). Thus, the present study should be taken as a preliminary report.

At both T1 and T2 women completed independent batteries of questionnaires. At T2 women were given the questionnaires as part of a face-to-face semi-structured interview. For further details about the larger study see McMahon et al. (1999, 2002). At the time of assessment the Australian legislation allowed storage for a maximum of 10 years [33,34]. Couples received a letter after 3 years, asking them to make a decision and annual reminders thereafter. An annual storage fee was paid for continued embryo storage. The study received ethical review and approval from relevant institutional Ethics Committees.

Study groups

In this study the experiences of women who had embryos in storage 5 years after initiating treatment (T2) were compared with a cohort of women who started treatment and achieved a pregnancy at the same time (T1), but who did not have embryos at the 5-year follow-up assessment. At T2, 26 women who still had embryos in storage were assigned to the Embryo-Storage group ('E-S': 39.4% of $n = 66$). The remaining 40 women either originally had embryos in storage, but had used them ($n = 19$; 28.8%) or did not report ever having had surplus embryos ($n = 21$; 31.8%). There were no differences between the latter two groups on any study variables and they were therefore collapsed and assigned to the cohort comparison group ('C-C' group: 60.6% of $n = 66$).

Materials

At T1 treatment information was collected from medical records and participants completed questionnaires on personality characteristics. Trait anxiety

was measured using the 20-item Trait Anxiety Inventory [35] that assesses feelings of tension, nervousness, worry and apprehension. The manual reports good test–retest reliability of the Trait anxiety scale ($r = 0.77$), and low test–retest reliability for the State scale ($r = 0.33$). However, the latter coefficient is expectable given the transitory nature of state anxiety. The manual also provides evidence for construct validity of both scales. The 17-item Locus of Control of Behaviour Scale [36] was used to measure the extent to which individuals perceived events as being a consequence of their own behaviour and therefore being under their personal control, where high scores indicate an external locus of control. The scale was shown to have satisfactory internal reliability and construct validity, correlating substantially with Rotter's I-E General Expectancy Scale ($r = 0.67$) [28].

The 10-item Dependency and Relatedness subscale [37] of the Depressive Experiences Questionnaire (DEQ) [38] measured the extent to which individuals are externally directed in regard to their interpersonal relationships. Items addressed concerns about abandonment, feeling helpless, a need to be close to and dependent upon others, and a fear of separation, loss and rejection [37]. The internal reliabilities of the DEQ have been reported to be adequate, with α coefficients ranging from 0.78 to 0.86 for the two main factors (Viglione, 1990). Construct validity was demonstrated to have test–retest correlations of 0.89 and 0.81 for dependency, and 0.83 and 0.75 for self-criticism [39]. These scales are widely used and have been shown to have content, criterion-related, and construct validity and internal reliability (Cronbach's $\alpha = 0.96$).

Interview

At T2 women were interviewed regarding their reproductive experiences between T1 and T2, details of further treatment (e.g., number of treatment cycles), subsequent pregnancies and births (naturally or with IVF), current family composition, satisfaction with family size and future childbearing intentions. We used a semi-structured interview because of the exploratory nature of our design and the personally and emotionally sensitive topic. In addition, semi-structured interviews gave us the flexibility and sensitivity necessary to capture the range of possible responses.

Women were also asked if they viewed their surplus embryos as a sibling to an existing child, and how frequently they thought about their embryos with response options 'not at all', 'occasionally', and 'preoccupied'. Women indicated the likelihood of various disposition options (donate to research or other couples, use themselves or discard), and whether they would postpone the embryo decision with options including 'no postponement', 'will decide soon', and 'postpone as long as possible'.

Data analysis

Data were analysed using univariate and multivariate analyses. At a univariate level non-parametric categorical and nominal variables were examined using χ^2-tests (using Fisher's exact probability where appropriate) whereas parametric interval data was examined using t-tests. In light of the multiple tests we used two approaches to minimise the risk of alpha inflation. First we carried out multivariate analyses of variance (MANOVA) on related sets of variables (i.e., demographic characteristics, relational variables, personality variables) and examined univariate tests only when the multivariate test was significant according to the method of Tabachnik & Fidell [40]. Second, where MANOVA was inappropriate we used Bonferroni adjusted probability values. A standard discriminant analysis was then computed using those predictor variables that showed univariate significance or marginally significant differences between the E-S and C-C groups. The subject to variable ratio in the discriminant analysis was 10:1 which is acceptable for this type of analysis [40]. Discriminant analysis summarises the pattern of intercorrelations among predictor variables by extracting independent dimensions that maximally differentiate between the groups. In the case of two groups only one dimension can be extracted and loadings on this dimension are an indication of the strength of association between an individual predictor and the dimension that differentiates the group after controlling for all other factors. As such the loadings act as effect size measures and loadings above 0.30 are considered significant [40]. The level of significance was $p < 0.05$ though trends were also examined ($p < 0.10$).

Results

Table I shows the demographic characteristics of the E-S and C-C groups. The MANOVA was significant (multivariate F (2, 63) = 7.4, $p < 0.001$). Follow-up univariate F-tests showed that women in the E-S group were significantly younger (F (2, 63) = 12.4, $p < 0.001$) and had been married or living with their partner for fewer years, F (2, 63) = 3.85, $p < 0.05$, than the C-C group. In the E-S group 3.8% ($n = 1$) of women were 37 years or older whereas 32.5% in the C-C group were in this age group. Groups differed on maternal education, χ^2 (3) = 7.93, $p = 0.047$; with more women in the ES group having a diploma or university degree (76%). Groups did not differ on ethnic origins, $\chi^2(11) = 11.47$, $p = 0.41$, with the majority being born in either Australia or Great Britain (78.8%).

Reproductive and treatment experiences

The groups did not differ on time trying to get pregnant with their first child, number of treatment cycles or percentage of singleton (81.8%) *versus* twins (18.2%) (χ^2 (1) = 2.20, $p = 0.14$) (see Table II).

The MANOVA on reproductive and treatment variables showed a significant result (multivariate F (4, 56) = 2.84, $p = 0.032$). Follow-up univariate F-tests showed that women in the E-S group had significantly more children at T2 than the C-C group (F (4, 56) = 7.99, $p = 0.006$). More women in the C-C than E-S group expressed dissatisfaction with their family size (45.7% *versus* 30.8%, respectively) in that they would like to have more children, but the difference was not significant (χ^2 (1) = 1.40, $p = 0.24$). The E-S group had an average of 5.27 (SD = 3.16, range = 1–13) embryos currently in storage (see Table II).

The majority of E-S women reported thinking about their embryos occasionally (61.5%, $n = 16$) and 34.6% reported thinking frequently about their embryos ($n = 9$). Almost all women in this group, 88.5% ($n = 23$), considered the embryos as potential siblings to existing children. Overall 42.3% ($n = 11$) of E-S women indicated that it was possible or probable that they would donate to research, and 26.9% ($n = 7$) considered donation to other couples. A total of 42.3% ($n = 11$) planned to use embryos in subsequent treatment and 30.8% ($n = 8$) wanted to discard the embryos (options were not mutually exclusive). Only 34.6% ($n = 9$) of women in the E-S group indicated they would make a final disposition shortly, with 65.4% ($n = 17$) reporting they would postpone the decision as long as possible.

Table I. Demographic characteristics of the E-S and C-C groups.

Demographics	Still have surplus embryos 'E-S' ($n = 26$)	Cohort control 'C-C' ($n = 40$)	Test statistics
Age women	32.35 ± 2.04	34.83 ± 3.19	3.522**
Age men	35.73 ± 5.56	37.55 ± 5.6	1.293
Years married	5.89 ± 2.89	8.47 ± 6.3	1.964*

Values are means ± SD; *$p < 0.05$. **$p < 0.001$.

Table II. Reproductive and treatment experiences at T2 according to E-S and C-C groups.

Fertility treatment experiences	Still have surplus Embryos 'E-S' ($n = 26$)	Cohort Control 'C-C' ($n = 40$)	Test statistics
Number of children	2.15 ± 0.88	1.68 ± 0.73	2.46*
Total number of pregnancies	2.12 ± 1.03	1.73 ± 1.45	1.17
Total number of treatment cycles (T1–T2)†	4.96 ± 5.29	5.18 ± 4.68	0.17
Time in months to fall pregnant	11 ± 12.28	11.29 ± 7.04	0.06
Number of currently frozen embryos	5.27 ± 3.16	n/a	n/a

Values are means ± SD; *$p < 0.05$.
†Treatment cycles include only IVF (using fresh and frozen embryos).

Personality traits (T1)

A MANOVA was computed on personality characteristics and was marginally significant (F (3,51) = 2.31, $p = 0.087$) with women in the E-S group showing a more externally oriented locus of control compared to the C-C group as shown in Table III. The E-S group also showed higher dependency scores on the Blatt et al. (1995) questionnaire. The groups were similar on trait anxiety.

Factors differentiating E-S and C-C groups

We next examined to what extent the T1 variables that differentiated the E-S and C-C groups represented unique influences using discriminant analysis (see Table IV). Based on the univariate results the variables entered into the discriminant analysis were: female age, years living with partner, number of children at T2, locus of control and dependency (variables showing significant or marginally significant between-group differences). Table IV shows the pooled within-groups correlations (i.e., loadings) for the significant discriminant function (χ^2 (9) = 15.51, $p < 0.017$). As shown, all variables remained

Table III. Personality characteristics according to E-S and C-C groups.

Personality variables	Still have surplus embryos 'E-S' (n = 26)	Cohort control 'C-C' (n = 40)	Test statistics
Locus of control	29.8 ± 7.39	25.28 ± 9.01	2.07*
Trait anxiety	37 ± 9.74	34.52 ± 8.79	1.047
Dependency	36.08 ± 5.79	32.94 ± 4.26	2.419*

Values are means ± SD; *$p < 0.05$.

Table IV. Pooled within-groups correlations coefficients (loadings).

Fertility treatment experiences	Loading
Demographic	
Female age	−0.717*
Years living together	−0.428*
No. of children at T2	0.46*
Psychological	
Locus of control	0.496*
Dependency	0.466*

Only loadings > 0.30 were considered significant [40].

significant when considered as a group, and together these explained 27.1% of the between-group variance. Group centroids showed that the E-S group scored significantly higher (centroid = 0.722) on the discriminant function than did the C-C group (centroid = −0.497). The loadings showed that a higher score on the function that discriminated the groups was associated with younger age, fewer years living together, more children at T2, a more external locus of control and higher dependency.

Discussion

Five years after a successful IVF treatment cycle, 39% of women still had embryos in storage and a significant proportion of these women were preoccupied with their embryos and wanted to further postpone decision-making about their fate. The secondary analysis of our prospective data demonstrated that retaining embryos could be indicative of decisional avoidance, which in turn, could be ascertained from demographic factors and personality traits assessed at the start of treatment. Our results demonstrate a need for decisional support in women undergoing IVF.

Our exploratory analyses show that those who had embryos in storage at the 5-year assessment depicted a different demographic and psychological profile. This group of women were at an earlier reproductive life stage in that they were younger. As such women may have been more hesitant to make decisions about embryos that they could (in theory) use for further family building even if they did not necessarily want more children, as was shown (i.e., more children and less family-size dissatisfaction than C-C group).

Women who still had embryos in storage also showed a more externally oriented personality profile. People with an external locus of control indicated by high scores on the Locus of Control Behaviour Scale perceive themselves as having little control over their behaviour, for example they tend to think they cannot control their problems. Thus it may be that women in the E-S group generally relied more on external support provided by physicians, family and friends when coping with a health decision, and this tendency would extend to the disposition decision context. Together our findings suggest that the embryo-disposition decision is not just dependent on identifying the best option (e.g., donation to research, donation to another couple, or discard), but also dependent on reproductive life stage and personality traits.

Reproductive life stage and personality traits were shown to independently differentiate the E-S group from the remaining women who started treatment at the same time and these factors may influence decision-making about surplus embryos via different pathways. Younger couples may not yet have achieved their desired family size, and their age would allow them to extend their family further. Family size was also found to be an important determinant in other studies where patients who had a successful delivery [21] or who had completed their family [19] were more likely to not claim their surplus embryos. In our sample E-S women already had an average of two children and were generally satisfied with their family size, nevertheless 40% stated they would consider using surplus embryos in further treatment. The juxtaposition of earlier reproductive life stage in the E-S group, but concurrent satisfactory family composition may make the decision to use (or discard) embryos particularly difficult because it would require women to close off the possibility to have more children when it was still biologically possible, though not necessarily desired. In addition, the burden of continued fertility options may have been lesser in the C-C group where 30% of women were more than 37 years old.

Personality traits may exert their influence through factors that have the potential to influence any life decision. People who experience decisional conflict in other contexts, for example whether or not to use contraception [41–43] or deciding to seek fertility treatment when problems arise [44] have been shown to share similar characteristics to the profile found in the E-S group. For example, past research has found that people with an external locus of control are less likely to use contraceptives [41], whereas those with an internal locus of control are less likely to seek fertility treatment when problems arise [44]. Our findings would concur with these general observations in that those who still had embryos many years after treatment were more externally oriented.

Results from the two personality scales are suggestive of individual differences in autonomy and assertiveness. Items on the dependency measure, for example, assess the extent to which individuals are concerned about abandonment, and inclined to feel helpless and want to be dependent upon others for their well-being [37]. Similarly, an external locus of control indicates a tendency to view events as controlled by external rather than internal causes. Autonomy and assertiveness may facilitate decision-making in challenging situations so that individuals who are less autonomous and assertive may be more inclined to postpone decision-making, and be in greater need of external guidance and support. In our sample we found that age and dependency [r (60) = −0.318, p = 0.013] were negatively correlated so that maturational factors may also play a part.

Another factor that may influence decision-making is attitude towards the embryo. Our results were consistent with previous studies demonstrating that people conceptualise their embryos as siblings to

their already existing children [7,8,45]. This type of conceptualisation was evident in the E-S group where 88.5% of patients referred to their embryos as real persons, which has been suggested to be important when a disposition decision is made, to be associated with discarding or freezing the embryos indefinitely [46] and to make the decision-making process more difficult [22]. Although we cannot ascertain from the design of this study whether such factors were pivotal in decision making, our results are consistent with previous studies showing that conceptualisation of the embryo as a potential child or sibling is associated with long storage duration [17,22].

The strengths of this study included the prospective design so that personality variables were measured prior to the birth of the first child and actual embryo decision time. The participation rate was high (80%) and the attrition rate over the 5-year follow-up period was relatively low (20%) so that the final sample can be considered representative of the cohort of women conceiving with IVF. The multifactorial assessment battery included both reliable and valid questionnaires and face-to-face interviews. A further strength was the homogeneity of the sample with respect to parity, education, and time to conceive the first child.

There were several substantial limitations. First the small sample size, which meant less than ideal power to detect group differences. A second important limitation was the composition of the cohort comparison group which included women who had started treatment at the same time as the E-S group, but was comprised of both women who had previously made an embryo disposition and women who had never had surplus embryos. These groups were combined because they did not show marked differences on target variables and because pooling increased power for group comparisons and the participant-to-variable ratio for our multivariate analysis. We acknowledge, however, that more fine-grained comparisons with the individual groups could allow for stronger conclusions to be drawn and that the current approach can only allow general statements to be made about women who still had embryos many years after the end of fertility treatment. However, we feel that the prospective data in this exploratory study provides a useful starting point for future studies on the embryo disposition context and for the development of a DSI.

Conclusion

In conclusion, women who still have embryos many years after fertility treatment may have a psychosocial profile suggestive of decisional avoidance. We propose that the most crucial differentiating factors are reproductive life stage, autonomy and assertiveness and to a lesser extent, conceptualisation of the embryo. Thus, women who have already satisfied their family building needs, have dependent personality traits and who conceptualise their embryos as siblings to their children may have a more difficult time making the embryo disposition decision. Consequently, this group may be in greater need of external support. In the context of embryo disposition, external support is commonly provided within the infertility clinic by health professionals (consultants, embryologists, infertility nurses). By identifying characteristics that are unique to patients who retain embryos many years after treatment we make an important step towards informing the development of a DSI tailored to the specific needs of patients in the embryo disposition context. These interventions could subsequently be used by infertility clinics to support patient consultations and become part of their routine practice, i.e., as part of the annual disposition request and information letter that is commonly sent out to patients.

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Current knowledge on this subject

- Increasingly more research is suggesting that the embryo disposition decision is a difficult one and influenced by many factors.
- Many patients postpone the decision about their cryopreserved embryos until they are compelled to do so by statutory limits resulting in thousands of embryos remaining in storage (currently 52,000 in the UK and 92,500 in Australia and New Zealand).
- A delay in decision making has been associated with socio-demographic characteristics, fertility history, and embryo conceptualisation (such as age, treatment success, and beliefs about the embryo) as well as finding the decision difficult and a wish to avoid an irreversible decision that could cause distress.

What this study adds

- Depicts a different demographic and personality profile in those women who have embryos in storage 5 years after treatment in comparison to a cohort control group. Women who still had embryos were at an earlier reproductive life stage in that they were younger, and they showed a more externally oriented and dependent personality profile.
- This suggests that the embryo-disposition decision is not just dependent on identifying the best option but also dependent on reproductive life stage and personality traits.
- Retaining embryos could be indicative of decisional avoidance.
- There is need for decisional support in women undergoing IVF.