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**EXPLORING THE LIVED EXPERIENCES OF EGG SHARE  
DONORS: CAN WOMEN CONSENT TO SHARE THEIR EGGS?**

**BERENICE JANE GOLDING**

**A thesis submitted to the University of Huddersfield in partial fulfilment of  
the requirements for the degree of Doctor of Philosophy**

**University of Huddersfield**

**April 2011**

## DEDICATION

Brenda Margaret Golding.

*My much loved mum, who is so dearly missed.*

## **ABSTRACT**

The thesis explores the 'lived experiences' of egg share donors in the United Kingdom (UK) and in particular, has examined the extent to which they are able to consent to becoming an egg share donor. Specific emphasis was given to exploring the factors that motivated their decision-making in view of the criticism egg sharing schemes have met with since their emergence in the early 1990s.

Egg sharing provides women who are themselves undergoing assisted reproduction treatment (ARTs) with the opportunity to share their eggs with up to two recipients(s). The donor's treatment costs are subsidised by the recipient(s). Thus some women are able to access cheaper, expeditious treatment. Advocates perceive the schemes as 'win-win'. Conversely, critics challenge egg sharing on both psychosocial and ethical grounds.

The thesis conveys the accounts provided by a self-selected sample of seventeen women recruited via two online infertility support websites and a charitable organisation. Hermeneutic phenomenology and the voice-centered relational method (VCRM) of analysis were employed to assess women's motivations to donate and their ability to provide informed consent. Four asynchronous e-mail interviews and data collected from an online self-completion questionnaire were utilised in order to enable the experiences of egg share donors to be revealed.

Drawing extensively upon philosophical, social anthropological, social philosophical, sociological, and social psychological literature, the study demonstrates the complexities associated with the decision to egg share within the context of the UK regulatory framework for ART provision. This includes existing empirical accounts of egg sharing.

The thesis describes how it is one of the first to examine the experiences of egg share donors since the removal of donor anonymity in the UK in 2005. Significantly, it makes an original contribution to current understandings of the experiences, motivations, ability to consent, and post-treatment implications for egg share donors.

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## CONTENTS

<b>DEDICATION</b> .....	1
<b>ABSTRACT</b> .....	2
<b>COPYRIGHT STATEMENT</b> .....	3
<b>ACKNOWLEDGEMENTS</b> .....	4
<b>CONTENTS</b> .....	6
<b>LIST OF TABLES</b> .....	11
<b>LIST OF FIGURES</b> .....	13
<b>CHAPTER ONE Introduction</b> .....	14
My journey to doctoral studies .....	14
My biography: its influence on choice of research area .....	16
My biography: the emergence of similarities with the study .....	17
Background to the study.....	18
The need for the study .....	19
Aims and objectives of the study .....	19
Explaining terminology .....	20
Integrating informants' accounts.....	20
Organisation of the thesis.....	21
<b>CHAPTER TWO Egg sharing: a critical appraisal</b> .....	25
The medicalisation of reproduction.....	25
Early pioneers.....	26
Defining infertility .....	28
Assisted reproduction treatments (ARTs) .....	28
Intrauterine insemination.....	28
In vitro fertilisation.....	28
Third party ARTs .....	29
Donor insemination.....	29
Egg donation .....	29
Known and known anonymous egg donation .....	30
Non patient or 'paid' egg donation .....	30
Third party ARTs and family formation .....	31
Egg sharing: the UK context.....	32
Egg sharing: the global context .....	33
Regulating reproduction .....	34
UK regulation of egg sharing .....	35
Reviewing existing empirical studies and literature on egg sharing .....	38
Searching for literature.....	38
Studies undertaken by clinical pioneers.....	39
Promoting egg sharing schemes.....	39
Other studies and literature pre 2005 .....	42
The egg share donor's perspective .....	42
Motivations to egg share.....	43
Egg sharing and access to IVF treatment .....	44
Concerns about egg sharing .....	44
Empirical concerns .....	44
Ethical concerns .....	46
Egg sharing and informed consent.....	47
Psychosocial implications of egg sharing .....	48
Recent developments: new variants of egg sharing .....	49
Chapter review .....	49



<b>CHAPTER THREE Methodological approach</b> .....	50
Making sense of the research process .....	50
Ontological and epistemological foundations.....	51
Adopting a phenomenological approach.....	53
Foundations of the phenomenological approach .....	54
Heideggerian (existential) phenomenology .....	56
Hermeneutic phenomenology .....	58
Interpretive versus descriptive phenomenology .....	60
A hermeneutic methodology .....	61
Data collection using hermeneutic phenomenology.....	64
Data analysis using hermeneutic phenomenology.....	65
Introducing the voice-centered relational method (VCRM) in the e-interviews .....	66
On sensitivity, reflexivity and emotion work .....	67
Chapter review .....	69
<b>CHAPTER FOUR Methods – the original study</b> .....	71
Researching a sensitive topic.....	71
Approaching the study sensitively .....	72
The original study .....	74
Gaining ethical approval.....	75
Developing the original study .....	75
Semi-structured interviews.....	75
Designing the interview schedule.....	76
Gaining access to participants .....	81
The impact of gatekeepers .....	84
Chapter review .....	86
<b>CHAPTER FIVE Methods – the revised study</b> .....	88
Background to the revised study .....	88
Researchers and the Internet.....	89
The asynchronous e-mail interview .....	90
Recruiting participants.....	92
Managing the e-interviews.....	93
Piloting.....	93
Netiquette .....	94
Introducing the study .....	94
Semi-structured e-interviewing.....	95
Reflexivity, emotion work and the e-interview .....	96
E-interview timescales .....	97
Data collection .....	98
Dealing with the lack of non-verbal communication.....	98
Developing rapport .....	100
Transcription.....	101
Advantages and disadvantages of the e-interview.....	101
Rationale for further revisions to the design: the online survey .....	103
Revisiting my philosophical framework .....	103
A mixed methods approach .....	103
Designing the self-completion survey .....	104
Bristol online surveys (BOS) .....	105
Formatting questions .....	106
Data analysis .....	107
Poster development .....	107
Contacting clinics.....	107
Chapter review .....	108

<b>CHAPTER SIX</b>	<b>Developing ethical research: special considerations</b>	110
Planning ethically responsible research		110
Gaining ethical approval: the original study		111
Gaining access		112
Confidentiality and anonymity		112
Obtaining informed consent		113
Planning ethically responsible Internet research		113
Gaining ethical approval: the revised study		114
Obtaining informed consent		114
Completing the consent form		116
Managing the consent process		116
Maintaining confidentiality		117
Anonymity		117
Identity verification		118
Debriefing		120
Participant safety		121
Researcher safety		121
Ethical considerations: the online survey		123
Chapter review		123
<b>CHAPTER SEVEN</b>	<b>Analysing the data</b>	125
Analysing the self-completion surveys		125
Locating associations		127
Background to e-interview analysis		127
The voice-centered relational method (VCRM)		128
Reading one: responding to the donors' shared experiences		129
Reading two: locating 'I' within the context of donors' experiences		130
Reading three: revealing relationships within the context of egg sharing		131
Reading four: egg sharing within social and cultural contexts		132
Producing case studies		132
Constructing the 'I' poems		133
Thematic coding of the data		133
Data validity		135
Establishing data validity		135
Sensitivity to context		135
Commitment and rigour		136
Coherence and transparency		137
Impact and importance		138
Peer debriefing		138
Member checks		139
Data triangulation		140
Chapter review		141
<b>CHAPTER EIGHT</b>	<b>Findings from the online survey</b>	142
Section 1: demographic data		142
Age and its relationship to access to treatment		142
Ethnicity		143
Relationship status		144
Geographical location		144
Education level		145
Onset of fertility problems		146
Beginning fertility treatment		146
Section 2: about their treatments		147
Access to NHS treatment		147
Treatments prior to egg sharing		148

Section 3: about becoming an egg share donor .....	149
Finding out about egg sharing.....	149
Initial reactions to egg sharing .....	150
Choosing egg sharing.....	151
Combined decision-making .....	152
Impact of information on the final decision to egg share.....	153
Section 4: experiences of egg sharing.....	154
Cycles of egg sharing completed.....	154
Treatment outcomes.....	155
Knowledge of recipients' treatment.....	156
Giving informed consent.....	157
Discussing donor anonymity.....	159
Information about donor anonymity.....	160
Donor anonymity and decision-making.....	160
Additional experiences shared.....	161
Commentary upon these findings.....	163
Chapter review.....	163
<b>CHAPTER NINE E-interviews: egg sharing stories, 'I' poems and emergent theory.....</b>	<b>165</b>
Case studies .....	165
Charlotte's story.....	166
Emmeline's story .....	167
Emmeline's update.....	170
Florence's story .....	170
Jayne's story.....	174
Jayne's update.....	176
Case studies: revealing interrelationships and interdependence .....	176
The 'I' poems.....	177
Charlotte's poem.....	178
Emmeline's poem .....	179
Florence's poem .....	181
Jayne's poem .....	182
Egg sharing: the emergence of theory.....	183
On the ethics of informed consent.....	184
Women as autonomous thinkers .....	186
On decision-making.....	188
Rational decision-making.....	189
Moral decision-making.....	189
Analysing the gift relationship.....	190
Affect theory of social exchange.....	191
Developing a feminist perspective .....	192
Chapter review .....	193
<b>CHAPTER TEN Egg sharing: putting the donor's accounts together.....</b>	<b>195</b>
Combining the data from phases one and two.....	195
The sample population .....	196
Motivation to egg share .....	196
Access to NHS treatment.....	198
The only option .....	200
Financial considerations .....	201
A helping relationship .....	202
Altruism and empathy .....	203
Reproductive 'gift' giving .....	205
Egg sharing: a complex, psychosocial treatment option .....	209

Giving informed consent .....	210
Dissociation .....	211
Psychosocial impact .....	216
Egg sharing as no control and being controlled .....	219
Reproductive control .....	219
Pressure to produce .....	221
Egg sharing as motherhood .....	222
Potential children .....	224
Genetic links .....	226
The 'knock on the door' scenario .....	227
Reality of egg sharing .....	229
Chapter review .....	230
<b>CHAPTER ELEVEN Egg sharing: a psychosocial and ethical discussion ..</b>	<b>231</b>
Returning to the beginning... ..	232
Aims and objectives revisited: integrating theory .....	234
Revisiting the gift relationship: helping as opposed to gifting .....	235
Locating affect social exchange theory .....	237
Egg share donor decision-making .....	238
Utilitarian decision-making and egg sharing .....	240
Altruism and empathy-altruism.....	242
Egg sharing as dissociation .....	243
Informed consent within the context of egg sharing .....	244
Reconceptualising informed consent.....	246
Revisiting my feminist development .....	249
The ethical and psychosocial implications of egg sharing.....	250
Egg sharing and new family formation .....	250
Policy implications .....	251
My biography and its impact on my analysis of participants' stories .....	253
Chapter review .....	256
<b>CHAPTER TWELVE Concluding comments .....</b>	<b>232</b>
Can women consent to share their eggs? .....	258
Informed consent and egg share donors .....	258
Returning to the research questions.....	258
Main findings .....	261
What this study adds .....	263
Providing informed consent .....	263
Advancing asynchronous e-interview methodology.....	264
Limitations of the study.....	265
Recommendations for future research.....	266
<b>GLOSSARY .....</b>	<b>269</b>
<b>REFERENCES.....</b>	<b>270</b>
<b>APPENDICES .....</b>	<b>296</b>
APPENDIX ONE .....	297
Overview of relevant literature .....	297
APPENDIX TWO.....	300
Egg sharing for research.....	300
Egg sharing for 'social' reasons .....	300
APPENDIX THREE .....	302
Prompts for interviews .....	302
APPENDIX FOUR.....	303
E-interview protocols .....	303

Prompts for e-interviews .....	304
APPENDIX FIVE .....	305
Website information .....	305
APPENDIX SIX .....	306
Study information .....	306
APPENDIX SEVEN .....	308
Survey questions .....	308
APPENDIX EIGHT .....	316
Recruitment poster .....	316
APPENDIX NINE .....	318
Ethics application documentation .....	318
9.1 Pro forma ethics application .....	318
9.2 Risk analysis form .....	321
9.3 Letter seeking collaboration .....	323
9.4 Research proposal for clinics .....	325
9.5 Participant information leaflet .....	330
9.6 Participant reply slip .....	333
9.7 Interview Schedule .....	335
9.8 Participant consent form .....	338
9.9 Transcriber consent form .....	340
APPENDIX TEN .....	341
Revised ethics application and risk analysis form .....	341
APPENDIX ELEVEN .....	346
Online consent form .....	346
APPENDIX TWELVE .....	347
Pseudonym list .....	347
APPENDIX THIRTEEN .....	348
Analysis: brief sample of some of my responses to reading one .....	348
APPENDIX FOURTEEN .....	350
Complete 'I' poems .....	350
I poem - Charlotte .....	350
I poem - Florence .....	352
I poem - Jayne .....	354
I poem - Emmeline .....	356

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## LIST OF TABLES

<b>Table 3.1</b> Methodological structure of hermeneutic research.....	62
<b>Table 5.1</b> Advantages and disadvantages of the e-interview.....	102
<b>Table 8.1</b> Ethnicity of Respondents.....	143
<b>Table 8.2</b> Relationship status.....	144
<b>Table 8.3</b> Geographical location.....	145
<b>Table 8.4</b> Educational level.....	146
<b>Table 8.5</b> Onset of fertility problems.....	146
<b>Table 8.6</b> Beginning fertility treatment.....	147
<b>Table 8.7</b> Access to NHS treatment.....	147
<b>Table 8.8</b> Prior treatments.....	149
<b>Table 8.9</b> Finding out about egg sharing.....	149
<b>Table 8.10</b> Choosing egg sharing.....	152
<b>Table 8.11</b> Combined decision-making.....	153
<b>Table 8.12</b> Information about egg sharing.....	153
<b>Table 8.13</b> Decision-making.....	154
<b>Table 8.14</b> Cycles of egg sharing.....	155
<b>Table 8.15</b> Treatment success.....	155
<b>Table 8.16</b> Recipient(s) results.....	156
<b>Table 8.17</b> Giving informed consent.....	157
<b>Table 8.18</b> Understanding informed consent.....	158
<b>Table 8.19</b> Information providers about the consent process.....	158
<b>Table 8.20</b> Discussing donor anonymity.....	159
<b>Table 8.21</b> Being told about donor anonymity.....	160
<b>Table 8.22</b> Impact of information provision.....	161

## LIST OF FIGURES

<b>Figure 9.1</b> The reality of egg sharing: the creation of visible and invisible interrelationships and interdependence.....	177
<b>Figure 10.1</b> Motivations to egg share.....	197
<b>Figure 10.2</b> From independence, to dependence, resulting in the concept of mutual interdependence.....	200
<b>Figure 10.3</b> A helping relationship.....	203
<b>Figure 10.4</b> Egg sharing: a complex psychosocial treatment choice.....	210
<b>Figure 10.5</b> Egg sharing as no control and being controlled.....	219
<b>Figure 10.6</b> Egg sharing as motherhood.....	223
<b>Figure 10.7</b> The more complex interdependence and interrelationships that emerge if two recipients are involved.....	226
<b>Figure 10.8</b> The creation of interdependence and interrelationships between the donor, the recipient, offspring, and the wider familial network.....	228

## CHAPTER ONE

### Introduction

*The views and experiences of those most personally affected by egg sharing remain silent voices in current debates. This omission should not be perpetuated.*  
(Blyth & Golding, 2008, p.470)

The purpose of this thesis is to provide an empirical contribution to the existing social science research base on 'egg-sharing' in the United Kingdom (UK). This base is currently limited to empirical studies by Rapport (2003) and Blyth (2004). Both studies examined egg sharing from the perspectives of the egg share donor using qualitative methodology.

As the opening quotation suggests, the 'voices' of those personally involved in egg sharing have remained silent in more recent years. The work in the thesis is my attempt to give 'voice' to the experiences of some of those people; the egg share donors. This has been undertaken to overcome the omission of egg share donor experiences in current literature.

The thesis will provide the reader with an account of my research into egg sharing from the donor's perspective. The account focuses upon the moral, psychosocial, and ethical debates regarding egg sharing. More specifically, it focuses upon the ethical debates surrounding the provision of 'informed consent' and the 'decision-making processes' experienced by egg share donors. To date these issues have largely been commented upon, rather than subject to extensive empirical research. Apart from the studies cited above the only other empirical evidence available about egg sharing is based largely on the reports of the pioneers of egg sharing. They tend to provide more favourable accounts of the treatment than the evidence provided in the aforementioned studies (Ahuja et al., 1996; 1997; 1998a; 2000; Simons & Ahuja, 2005). They also attempt to address the concerns raised by critics of egg sharing. Critics of egg sharing contest the ability of egg share donors to provide informed consent (Shenfield & Steele, 1995; Johnson, 1997; 1999; English, 2005; Lieberman, 2005).

#### **My journey to doctoral studies**

My decision to pursue egg sharing as the basis of doctoral research was multifaceted. This stemmed initially from the completion of my first degree in 2005, but included a number of other factors, namely, my first insight into academic life.



I commenced my academic career at the University of Huddersfield in 2001, when I embarked upon the Women into Technology and Science (WITS) Access course. I had made enquires about training as a social worker a couple of years earlier. However, I decided not to pursue enrolment on the course and chose instead to start a family. Nevertheless, this did not detract from the fact that I was interested in learning and developing a new career path. Hence, I returned to education at a later date, as an access course student, and by this time, as a lone parent.

Successful completion of the access course provided me with the inspiration and confidence I required to undertake further studies. However, not for a moment did I envisage that this would lead to my registration as a PhD student. In fact, this is something that I did not even consider until the completion of my undergraduate degree in Health with Community Studies for which I gained First Class Honours.

During my studies I was fortunate to be taught by some outstanding lecturers who both inspired and encouraged me. This resulted in me developing a keen interest in social research and the benefits that it can have in terms of societal understandings about the health and well-being of populations, an interest that developed as a direct result of the research I undertook for my final year undergraduate dissertation. This took the form of a literature review that explored whether public health sun safety campaigns were developed in a manner that would encourage parents of mixed race children to practice safe sun behaviours. The rationale underpinning this topic choice resulted from my work as a nursery nurse, having witnessed first-hand sun safety practices that I deemed to be unsatisfactory. However, on the basis of insufficient research upon which to support my own perceptions I could do little other than be an observer. Nevertheless, this observation remained with me, and thus influenced my choice of research topic. What ensued from this research endeavour was an interest in undertaking further research.

However, at that point in time (mid 2005) undertaking a PhD was not feasible. This was because I had just missed the recent round of studentships and there was no way that I could manage to self-fund a programme of research. However, at this time I had successfully gained some part-time research work with Professor Sue White to undertake a literature review which investigated the experiences of carers who were involved in caring for someone in receipt of palliative care. Successful completion of this work led to me being offered the opportunity to be involved in another study exploring the needs of South Asian carers.

Whilst undertaking this work I continued to ponder my options for the future, knowing that ultimately I wanted to pursue further studies. I also began to appreciate the roles of the inspirational lecturers by whom I had been taught. This made me realise that my pursuit of educational attainment was not restricted to my own personal development. I believed that my own enjoyment of the learning experience was something that I could share with others. Hence, my next decision was to pursue a teaching certificate. I gained a place on the Postgraduate Certificate in Education (PGCE) course and my successful acquisition of this certificate made me realise that a career in academia was something which I wished to strive towards.

### **My biography: its influence on choice of research area**

Having maintained contact with staff on my undergraduate degree, in particular Professor Peter Bradshaw, it was not long before the opportunity to pursue a PhD became a possibility. Midway through my PGCE I found out that a new set of studentships were available. Having previously been put in contact with Professor Eric Blyth we had discussed the idea of me pursuing a PhD under his tutelage. Subsequent meetings led us to highlight an area in the field of infertility which required further empirical research, a treatment known as egg sharing. Under normal circumstances I may have turned down the study due to a lack of knowledge and understanding of the field and the issues which it raises. However, events within my circle of friends coincided with this research opportunity.

It was this coincidence which increased my knowledge of what it meant to be unable to have children naturally. This was compounded further by the patient information which I had read, and the subsequent discussions with friends about their experiences and personal journeys towards parenthood. For me this was the catalyst that motivated me to undertake this research. A decision not made in isolation to the events occurring around me; instead, it was done because of these life events. Thus, I felt that if I could increase my own knowledge of the issues faced by infertile couples, this knowledge would then equip me to better understand, and to be of support to the people I knew. I also viewed it as a beneficial way to contribute to current understandings of egg sharing, from the perspective of those who know: the egg share donors. However, what I had not envisaged were the similarities that emerged with regards to my own biography and the data collected from informants. These similarities became evident due to the reflexive approach that I applied in the research (see pages 253-256); similarities that I discuss in this introductory chapter, so as to enable the reader to

understand how my personal biography unexpectedly, became relevant to the work undertaken in the study.

### **My biography: the emergence of similarities with the study**

Born the oldest of four girls to an English mother and a Jamaican father I have always known that I had a half-brother and a half-sister, both of whom were older than me. With regards to my half-sister, this was just as well, because, to know me is to know my big sister. Living in the same town it would be difficult for our familial connection not to be recognised, in some way, by someone. My half-brother lived in the Cayman Islands and we developed a relationship with him when we lived in Jamaica for a few years. Sadly, my brother passed away some years ago – the first real loss that I faced in adulthood. Over the years I have kept in touch with my older half-sister though I have never had the same type of relationship with her that I have with my full sisters (which is a shame).

When I embarked on the study this aspect of my life, my genetic links, was something about which I had not given a great deal of thought. Indeed, it only occurred to me during the latter stages of thesis completion (see pages 223-227 and 253-256). On reflection, I admit that my experience of growing up knowing that I had half-siblings never really concerned me. To this day my immediate family is signified by the patriarchal figure of my father, and the matriarchal figure of my mother, who had my sisters and me.

My relationship with my father is somewhat distant these days. He and my mother divorced when I was about 17 and I have had no real contact with the man I call my father since I was 15 years old. Nevertheless, this has never caused me any consternation as I always had my mother to depend upon, until she passed away in 2000. My mother's death left a void in my life, a gaping hole that can never be filled. This loss meant I had to re-construct my life, not only as a daughter, but as a mother. It is this unbearable loss (that has abated a little over the years) that brought me closer, I think, to the participants in the study.

I embarked on my PhD shortly before my 37<sup>th</sup> birthday and I had no inkling that as I approached my 40<sup>th</sup> birthday I would begin to yearn for that which I believed was lost – my own reproductive capacity, which was degenerating the older I got. I was also acutely aware of my social location in relation to that of my participants. I was a mother who had conceived naturally and this weighed heavily on my mind as I interacted with

participants in the study (see pages 72-74 and 121). Having read extensively about the issues infertile women faced, I wanted to be able to do justice to the area of investigation. What I did not realise at the beginning was just how emotionally challenging the study would prove to be (see pages 96-97). However, being cognisant of the existing literature pertaining to egg donation, egg sharing and the creation of new family formation (see pages 25-49) meant that I was able to more fully appreciate the impact that this research might have upon me. This insight enabled me to navigate these issues in order to see the research through to completion.

### **Background to the study**

Pioneered in the early 1990s by Simons and Ahuja, 'egg sharing' was promoted and developed as a self-help scheme that enables women, who are themselves undergoing assisted conception procedures, the opportunity to 'share' their eggs with up to two recipients (Simons & Ahuja, 2005). In exchange the donor is able to access lower-cost treatment; the cost of her treatment is subsidised by the recipient. It is reported that the scheme was developed when patients at a clinic suggested that "if someone else would pay for our treatment, we could give up some of our eggs in return. We might be lucky" (Simons, 2008, p.11). Commenting further, Simons asserts that egg sharing represented a viable opportunity to enable women to access private treatment that they might otherwise be unable to afford. He states that:

This was one way in which we in private practice – which was then responsible for 90% of all IVF<sup>1</sup> in Britain – could extend IVF to those who couldn't afford it. So here we had a source of donor eggs which took coercion away and meant that people who couldn't access IVF treatment because of cost now had a chance.

(Simons, 2008, p.11)

By 2005 it was estimated that over 2,000 children had been born to both donors and recipients in the UK as a direct result of egg sharing (Simons and Ahuja, 2005). Furthermore, egg sharing provides the biggest source of donor eggs in the UK – approximately two thirds of the UK totals (Human Fertilisation and Embryology Authority (HFEA), 2005a). Recent UK statistics indicate that between 1999 and 2006 there were 5,231 cycles of egg sharing; these resulted in 1,694 live births (HFEA, 2010a). Notwithstanding the apparent ingenuity of the scheme, it has been subject to extensive debate on moral, psychosocial, and ethical grounds.

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<sup>1</sup> In vitro fertilisation – an overview of this treatment is provided in Chapter Two to contextualise the study.

The thesis documents my research into egg sharing. It utilises egg share donors' accounts of their assessments of their ability to make informed choices. It examines their awareness and understandings about the constraints within which their decisions may have been made. It describes the factors that impacted on their decision-making and the range of alternative options that were available to them prior to becoming egg share donors. More generally, the emphasis has been upon establishing whether, as suggested by critics of egg sharing, the practice is unethical because a donor cannot give freely, informed consent. The suggestions are that consent is fettered by the inducements of reduced cost and/or quicker treatment (Johnson, 1997; 1999; Blyth, 2002; English, 2005; Lieberman, 2005).

### **The need for the study**

As mentioned, there is a limited research evidence base that has examined the impact of egg sharing on donors who had proceeded with treatment. In light of the concerns which have been raised about the treatment, the study has focused specifically on the motivations of egg share donors. In doing so, it has examined the moral, psychosocial and ethical debates surrounding egg sharing since the scheme was first promoted in the UK.

### **Aims and objectives of the study**

The overall aims of the study were to investigate egg share donors' understanding of informed consent within the context of their decision to participate in an egg sharing arrangement. As discussed, limited evidence exists that has elucidated the lived experiences of egg share donors. Moreover, research that has focused specifically upon the ability of women to consent to becoming egg share donors is limited to the work of two authors. However, both studies pre-date the 2005 change in UK legislation removing donor anonymity. More specifically, the objectives of the study were to:

- 1) Explore the views and experiences of women who have become egg share donors regarding involuntary childlessness;
- 2) Examine whether they had considered alternative treatments prior to deciding to become an egg share donor;
- 3) Analyse their understanding of egg sharing and the implications it may have for them;
- 4) Assess what implications, if any, their decision to egg share had had on other members of their family;
- 5) Examine what motivated them to become an egg share donor; and to

6) Gain an insight into their perceptions and understanding of informed consent within the context of the decision to egg share.

### **Explaining terminology**

In the study a number of key terms are used. I explain the key terminology in order to familiarise the reader.

For the purpose of the thesis, the term 'egg share donor' signifies the woman donating her eggs; I also occasionally use the term 'donor'. This is used in reference to the egg share donor unless specified otherwise. In my discussion of data collection I introduce a number of terms; these are: participants, respondents, and informants. These are used to refer to the egg share donors who took part in the study but whose data were captured in different ways. The term 'participant' refers to those women who took part in the asynchronous e-mail interview; the 'respondents' are those women who completed the self-completion survey; and my use of 'informants' refers to the collective sample population that underpinned the findings provided later in the study. The rationale for making these distinctions is based on the phases used in the study. In phase one I utilised e-mail interviews; in phase two I used the online survey to capture data for analysis.

Additionally, throughout the study, I use a number of medical terms. For this reason I have provided a glossary of terms to explain their meaning. The need to refer to the glossary is denoted in the text where necessary with a footnote. I have also chosen to use the term 'eggs', as opposed to the more clinical terms of 'ova', 'ovum' or 'oocytes'. My belief is that the use of the term 'eggs' provides a more personable approach to the discussions provided in the thesis (see pages 211-216 and 243-244).

### **Integrating informants' accounts**

In the study I utilise informants' accounts to demonstrate how these contributed to the findings presented in the thesis. Verbatim quotations from the accounts provided by informants are included in the study. Hence, in some instances, they may contain grammatical idiosyncrasies or typing errors which have purposefully been left *in situ*. This in no way affects the quality of the accounts provided by informants. Rather, it uses the data in the way that they were conveyed by those taking part in the study. This includes the use of bold or italics. The rationale for this approach is linked to the feminist concept of being true to my informants. It also serves to illustrate my

development as a researcher with a feminist leaning and with the underpinning methodological approach employed in the study (see pages 66-69).

### **Organisation of the thesis**

In Chapter two I critically examine what is currently known about egg sharing. I draw on existing literature, and provide a comprehensive account of the emergence of egg sharing in the UK. The analysis contextualises the debates surrounding egg sharing, focusing upon arguments in favour of egg sharing and, conversely, those that question egg sharing on moral, psychosocial, and ethical grounds.

The chapter commences by locating egg sharing within the wider context of the medicalisation of reproduction and the treatment of primarily female factor infertility. It describes the emergence of assisted reproduction treatments (ARTs) in the UK. This historical account charts the birth of the world's first 'test-tube baby', through to the emergence of egg sharing in the UK. An account of the global prevalence of egg sharing is included. Specific attention is given to the regulation of egg sharing. In locating egg sharing within its medical, clinical, ethical, and historical contexts I acknowledge that much of the underpinning evidence is largely Eurocentric. Consequently, the study is somewhat confined within the parameters of European regulation, legislation, and the provision of ARTs.

The chapter draws extensively on the work of Blyth (2002; 2004), and Rapport (2003) in my examination of egg sharing from the donors' perspective. It uses the debates presented in the literature, for and against the provision of egg sharing, that enable egg sharing to be conceptualised within the context of the regulatory framework of ART provision in the UK. The literature is then used to analyse the provision of egg sharing and the potential longer-term implications for egg share donors. Thus, it enables egg sharing to be located within wider theoretical contexts.

In Chapter Three I introduce the methodological framework that was used in the study. I document how methodological decisions undertaken during the development of the study aided the progression of the research. I also demonstrate how and why I chose to integrate hermeneutical (interpretive) phenomenology (Gadamer, 1975; 1996) into the study as a means of eliciting the 'lived experiences' of the egg share donors who took part. In doing so, I make evident how this philosophical approach underpinned the development of the methods employed in the study. I also introduce the reader to the

voice-centered relational method (VCRM) approach to data analysis. I then justify the rationale underpinning the integration of this approach to the analysis in the study.

This is followed in Chapter Four with a discussion of the study, as originally planned. The reader is guided through the developmental stages employed in the preparation of the study prior to embarking upon data collection. I then provide an explanation as to why the original study, as planned, was not conducted. This focuses upon the issues and problems encountered when I attempted to gain access to a sample population via collaborating ART clinics.

In Chapter Five I draw extensively on the discussions provided in chapter four, in order to justify the revisions made to the methods employed in the study. This enables the reader to observe the wider philosophical and methodological thinking that facilitated the change in methods. In doing so, I exemplify how a serendipitous encounter was influential in the design and scope of the ensuing investigation. It also demonstrates how a study such as this can draw on the 'virtual' realm of the Internet in the research endeavour; a pursuit that if undertaken rigorously has the potential to yield beneficial results. In doing so, the reader is introduced to a method of qualitative data collection using the Internet in the revised study; the asynchronous e-mail interview.

In this chapter I also explain why there was a need to further revise my data collection methods. I describe how reliance on recruiting a self-selecting sample population via the Internet needed to be revisited. I illustrate the rationale underpinning the development of an additional method of data collection using an online self-completion survey. Following this inclusion I provide an explanation as to why this led me to return to the underpinning philosophical framework.

In Chapter Six, special consideration is given to undertaking ethically responsible research. In doing so, I illustrate how the ethical approaches pertinent to the original study were developed. I then describe how these were built upon to meet the needs of the revised study. Although the ethics of e-mail interviewing are not dissimilar to conventional face-to-face methods of data collection, I illustrate how the protocols devised for the original study were developed to encapsulate the specific ethical considerations that apply to e-mail interviewing.

This is followed in Chapter Seven with an extensive account of the methods of analysis employed in the study. The chapter begins with an overview of the methods used to



analyse the online self-completion survey. It describes the decisions made during the analysis of this data set.

The chapter then moves on to describe, in detail, the features of the VCRM approach to data analysis and how these were incorporated into the study. By detailing the processes in this way, the chapter provides the reader with the opportunity to view the logical and transparent approaches undertaken during the analysis of the e-interviews. This puts into context the separate phases of the method and demonstrates how they led to the findings discussed in the thesis.

Chapter Eight draws on the analysis of the self-completion survey and begins to present and contextualise the findings of the study. Thus, it provides the reader with an opportunity to engage with the complex and relational nature of egg sharing as experienced by the respondents who completed the survey.

Chapter Nine introduces the stories of the women who took part in the e-mail interviews. This is where the features of the VCRM approach to analysis become evident. In this chapter I use case studies and 'I' poems to illustrate the accounts given by participants. In doing so, exploratory analysis of the emergent findings of the data is included. This provides the background to the focused analysis of both data sets that takes place in Chapter Ten. An overview of the wider theoretical concepts that underpinned the study from its inception is included. This draws extensively on philosophical, social anthropological, social philosophical, sociological, and social psychological literature to illustrate the application of theory. This further conceptualises the debates regarding the provision of 'informed consent' by women when they become an egg share donor.

The discussion provided locates the study in an ethical context that is governed by the principles of informed consent. This takes into account consequential, utilitarian decision-making and the link it has with the desire to be a parent. It also introduces my leaning towards a feminist position and how this was utilised in the study. I also illustrate how this theoretical positioning led to my determination to remain true to the stories told by participants.

In Chapter Ten I begin by explaining the rationale underpinning the analysis of both data sets. This draws together the emergent findings from both phases of data collection. The discussion is then set alongside the theoretical perspectives

underpinning the study and documents informants' journeys to egg sharing. In constructing the emergent findings the chapter introduces a number of discourses surrounding egg share donor decision-making. These are used to contextualise the debates regarding women's ability to give informed consent within the context of an egg sharing arrangement.

Chapter Eleven gives specific reference to the psychosocial and ethical debates surrounding egg sharing. I document how the research has broader implications than previously envisaged and how it contributes to the critical debate concerning egg sharing. I also demonstrate how I have been able to answer the primary research question that underpinned the study. It describes how the study contributes to current understandings about the experiences of egg share donors. The chapter returns to the theoretical perspectives, described in Chapters Nine and Ten, to demonstrate this. This illustrates how the work undertaken in the study has raised a number of implications for policy that are located within the UK regulatory framework of ART provision and donor remuneration. The chapter concludes by returning to my personal biography and its implications for the interpretation and presentation of the findings in the thesis.

In Chapter Twelve I summarise and provide my concluding comments. The chapter illustrates the complex nature of the research process. It explains how the thesis has enabled a further understanding of egg share donors' post-treatment experiences to be revealed. Finally, I present my recommendations for future research into egg sharing from various perspectives including that of the egg share donor.

## CHAPTER TWO

### Egg sharing: a critical appraisal

*Egg-sharing schemes should be welcomed as a means of enabling people to have children who would not otherwise have this opportunity. The argument that such schemes amount to the selling of gametes does not provide sufficient grounds for not permitting them.*

(McMillan & Hope, 2003, p.584)

In this chapter I critically examine what is currently known about egg sharing. Drawing on existing literature, the chapter provides a comprehensive account of the emergence of egg sharing schemes in the United Kingdom (UK). As the opening quotation indicates, there are contrasting perspectives on egg sharing. This analysis explores arguments that favour egg sharing for the good that it can do and, conversely, those that question egg sharing on moral and ethical grounds.

The chapter begins by locating egg sharing within the context of the medicalisation of reproduction and the treatment of primarily female factor infertility. It explores the emergence of ARTs in the UK, from the birth of the world's first 'test-tube baby', through to the emergence of egg sharing in the UK. This incorporates an account of the global prevalence of egg sharing, and the growing acceptance of third party ARTs using donor eggs prior to the emergence of egg sharing. I then describe the regulation of ART provision. Specific attention is given to the regulation of egg sharing.

Drawing on earlier empirical work, I demonstrate the need for the current study; the justification being that too little is known about egg sharing from the perspectives of women who share their eggs, the egg share donors. I use the arguments presented in the literature for and against the provision of egg sharing, debates that conceptualise egg sharing within the regulatory framework of ART provision in the UK. The literature is then used to analyse the provision of egg sharing and the potential implications for egg share donors.

#### **The medicalisation of reproduction**

Childlessness in both western and non-western countries has been interpreted historically in a negative light: and it is often perceived as a sign of divine punishment or disfavour; with infertile women being treated with contempt whilst suffering from

feelings of isolation and rejection (Heitman & Schlachtenhaufen, 1996). This view is discussed by Johnston who states that:

To earliest man [*sic*] the propagation of the race and its survival was a source of real anxiety: a woman who failed to conceive and carry a pregnancy to term was a source of concern and she regarded her plight as a disgrace.  
(Johnston, 1963, p.21)

This so called plight has attracted much medical attention as new ways of potentially alleviating involuntary childlessness emerged.

### **Early pioneers**

Early accounts of attempts to circumvent involuntary childlessness using, for example, surrogacy, were recorded in the Bible (see for example, Genesis chapters 16 and 30). The first reported form of medically assisted reproduction recorded took place in 1790; this was artificial insemination by the woman's husband (AIH) (Kranz, 2002). In 1884 Dr William Pancoast is reported to have performed the first occurrence of donor insemination (DI) that led to a pregnancy and birth (National Advisory Board on Ethics in Reproduction (NABER), 1996; Blyth with Benward, 2004).

Dr Pancoast, a Philadelphian professor, pioneered the technique after a request from a wealthy couple who were having problems conceiving. It transpired that the husband was infertile, possibly as a result of contracting a sexually transmitted infection (STI). The couple, however, were unaware that Pancoast had discussed their case with a group of his medical students, one of whom suggested that Pancoast should get the 'best looking' student to donate his sperm, which they could then use to treat the couple (Daniels, 1998; Kranz, 2002). Thus, it was the student's donated sperm, and not the sperm of the husband, that Pancoast used to impregnate the woman. The woman remained unaware that the procedure had taken place, as she had been previously anaesthetised and apparently was not told of Pancoast's intentions. The deception might not have become evident were it not for the fact that, as the child grew; it began to resemble the sperm donor. At this point Pancoast made the decision to inform the husband about his use of donor sperm – he asked that the man never tell his wife about the child's true genetic origins (Daniels, 1998; Haynes, 2003). However, it is possible that only Pancoast and the donor himself were aware of their involvement in the child's conception. Consequently, no one would know that the child resembled the donor. Conversely, an alternative account exists whereby Pancoast informed the husband because of his wife's successful conception and not because of the child's

likeness to his donor (Snowden, 2006). However, there are conflicting accounts as to whether the husband was aware of the procedure when it happened, or whether he was only informed after the fact, as previously suggested. Nevertheless, it is noted that the husband was happy with the outcome of the treatment and never informed his wife (Gregoire & Mayer, 1965; Daniels, 1998; Kranz, 2002). Notably, the impact of the child's birth on the sperm donor is omitted in the literature, although there may be a clue to his identity. Some believe that a letter published in *Medical World* in 1909 by Addison Davis Hard, one of Pancoast's former medical students, indicates that Hard was the donor (Gregoire & Mayer, 1965). Significantly, the letter described this early use of DI and followed the contact Hard made with the family, about twenty five years later, out of what has been described as curiosity about how the family had fared (Snowden, 2006).

However, this use of DI was not limited to married couples as other clinicians were experimenting with the technique. In 1934, an editorial in the *New England Journal of Medicine* entitled 'Conception in a Watch Glass' reported on the work of Gregory Pincus, who had used the glass top of his watch to mix the eggs and sperm of a rabbit. He implanted the resultant embryo into a rabbit and was successful in creating offspring. This development, it has been suggested, led to the concept of *in vitro* fertilisation (IVF) first being proposed (Kranz, 2002). However, some criticised the work of Pincus, claiming that there was insufficient evidence to show that conception had occurred *in vitro* rather than *in vivo*<sup>2</sup> (Fishel, 1988). Nevertheless, the manipulation of gametes to create embryos *in vitro* continued as advancements were made in ARTs. Since then pioneers in the field have continued to explore new ways of making babies.

By the end of the twentieth century, scientific and technological advances in fertility treatments had led to a wide range of options becoming available. These advancements led to the development of IVF techniques that resulted in the birth of the world's first 'test-tube baby', Louise Brown, in 1978. Born in Oldham, England, her birth was brought about by the pioneering work carried out by Steptoe and Edwards (Steptoe & Edwards, 1978). This work continues and for the estimated one in seven couples (3.5 million) who experience infertility every year in the UK (HFEA, 2007/2008), there are a range of potential methods available to them as they attempt to circumvent their infertility.

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<sup>2</sup> See Glossary.

### **Defining infertility**

In the UK infertility is defined as a “failure to conceive after frequent unprotected sexual intercourse for 2 years in the absence of known reproductive pathology” (National Institute for Health and Clinical Excellence (NICE), 2004, p.10). Infertility may be caused by a number of factors and either partner may be affected. In women, tubal damage, primary ovarian failure, secondary ovarian failure and polycystic ovary syndrome (PCOS)<sup>3</sup> can contribute to infertility, while male factor infertility may be due to, for example, a low sperm count, or poor sperm motility (Jenkins et al., 2003). Thus, access to ART procedures is largely dependent upon the clinical diagnosis of infertility; this determines whether those affected pursue ARTs using their own gametes or third party ARTs. Since the thesis investigates a specific treatment (egg sharing), I locate the study within the context of third party ARTs. However, I provide a brief overview of treatments available. This enables egg sharing to be contextually located in relation to the provision of ARTs. Moreover, it is pertinent to the study that egg sharing is located within this broader context since, as I demonstrate later in the thesis, egg sharing is rarely, if ever, the first treatment sought.

### **Assisted reproduction treatments (ARTs)**

Having received an infertility diagnosis, a number of ARTs are available to couples. Here I provide a brief overview of ARTs prior to describing third party ARTs.

#### **Intrauterine insemination**

Intrauterine insemination (IUI) is usually the first treatment used by couples who are experiencing unexplained infertility (Rowell & Braude, 2004). IUI was previously known as artificial insemination by husband (AIH) whilst the use of IUI with donor sperm was called artificial insemination by donor (AID). The latter treatment is now conventionally referred to as donor insemination (DI). IUI is the least invasive infertility treatment; it is also a simpler and cheaper treatment in comparison to either IVF or Intracytoplasmic Sperm Injection (ICSI)<sup>4</sup> (Jenkins et al., 2003; Rowell & Braude, 2004).

#### **In vitro fertilisation**

IVF is one of the most popular and widely used treatment options. IVF literally means ‘fertilisation in glass’, hence the popular term of ‘test tube baby’ applied to IVF-conceived infants. It is a treatment that may be used by older women, women who have blocked tubes, have not achieved success with other treatments e.g. IUI, and

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<sup>3</sup> See Glossary.

<sup>4</sup> See Glossary.

women who have received a diagnosis of unexplained infertility (HFEA, 2007/2008, p.22).

In the UK, the latest annual figures published by the HFEA indicated that 36,861 IVF treatment cycles were provided in 2007. This was a 5.8% increase on the previous year. In 2007, 23.7% of IVF treatment cycles resulted in a live birth and 11,091 successful births were recorded. As some of these were twin or triplet births, a total of 13,672 babies were born, an 8.5% increase on the previous year. However, IVF success rates vary by age; for women under the age of 35 the success rate per cycle using fresh eggs was 32.3% in 2007. This figure reduces to a success rate of 3.1% in women over the age of 44 (HFEA, 2009a).

### **Third party ARTs**

Third party ARTs are those procedures that involve the use of donated gametes (sperm and eggs), embryos or use a surrogate (Blyth & Landau, 2004; Venkat & Craft, 2009). The HFEA (2006a, p.1) state that “the donation of sperm, eggs or embryos to help a couple have a child is one of the most generous gifts anyone can give”, a view indicative of altruistic motivation, a concept returned to later in the thesis. In cycles of IVF treatment that rely on the use of donated gametes or embryos, complex relationships evolve, as I demonstrate in Chapters Eight to Eleven, with specific regard to egg sharing.

### **Donor insemination**

DI is a treatment similar to IUI, whereby donor sperm is artificially inseminated into the uterus. The sperm is inserted using a fine plastic tube. Sperm insertion usually coincides with ovulation. DI can be provided as a natural treatment cycle or as a stimulated treatment cycle (Rowell & Braude, 2004). Latest figures in the UK indicate that the number of children born as a result of DI in 2008 was 472 (HFEA, 2009a).

### **Egg donation**

Egg donation is defined as “the giving of eggs (oocytes or ova) by a donor to another woman” (Bryan & Higgins, 1995, p.239). Clinical indicators for women using donor eggs are: if they have had repeated conception attempts using IVF or infertility drugs, if they have had treatment for cancer which caused ovary damage, the absence or removal of ovaries, if they are post-menopausal, are producing too few or low-quality eggs, or if they have experienced recurrent miscarriages. Donor eggs may also be used if there is an increased risk of a serious genetic condition such as Duchennes

Muscular Dystrophy or Haemophilia being passed on to a child (Van Voorhis et al., 1992; Blyth & Golding, 2008; HFEA, no date a). Egg donation programmes vary and, as illustrated below, variance is dependent upon jurisdiction.

### ***Known and known anonymous egg donation***

Known egg donation involves friends or family members. Distinctions can be made regarding family member donation which may involve intergenerational or intra-generational donation. Examples of the former type involves egg donation from a daughter to her mother, or a niece to an aunt (or vice versa – subject to the age of the donor). Examples of intra-generational egg donation include sisters or cousins acting as egg donors (American Society for Reproductive Medicine (ASRM), The Ethics Committee, 2003). Other forms of known egg donation are available, including known anonymous donation. Here, a patient recruits a friend or relative as a donor, but the donor's eggs are donated into a clinic's pool to be used by a recipient who is not known to the donor, while the patient who has recruited the donor is placed higher on the waiting list to receive eggs donated by an unknown donor, who has been recruited by another patient (Ahuja & Simons, 1996).

### ***Non patient or 'paid' egg donation***

Egg donors may donate altruistically with no monetary recompense to themselves. In the UK donors can claim 'reasonable expenses'. In stark contrast to donation policies in the United States of America (USA) which allows payment to donors.

In the USA, some couples or programmes are willing to pay donors up to \$10,000. This, however, is by no means the most that has been offered. There have been reports of figures as high as \$50,000 - \$100,000 being offered for donor eggs (Gurmankin, 2001; Lancet Editorial Staff, 2003; ASRM, The Ethics Committee, 2004). Thus, Rabin (2007) suggests that some women may agree to donate to alleviate debt problems without really considering or evaluating the implications associated with donation. Consequently, it may appear to be a particularly tempting way of raising money.

Critics of the US donor payment system suggest that young female students may choose to donate as a way of meeting tuition costs, thus affecting autonomous decision-making and the ability to give freely informed consent (Papadimos & Papadimos, 2004). At the other end of the continuum, young third world or Eastern



European women do not receive anywhere near this level of payment. This may be due, in part, to the fact that informed consent and autonomy are not well established. It may also be associated with ‘fertility tourism’<sup>5</sup> and the ‘commodification’ of egg donation (Papadimos & Papadimos, 2004), in that eggs become treated as commodities that can be bought and sold.

These aforementioned issues pose moral, ethical and social dilemmas, many of which can only be speculated upon regarding, for example, how a woman may feel in later life, if she herself experiences fertility problems but was a successful donor earlier on in her lifetime (ASRM, The Ethics Committee, 2004). Therefore, the controversies surrounding paid egg donation will continue as long as this practice persists. The debates in the UK are different, as I illustrate throughout this chapter and the thesis.

### **Third party ARTs and family formation**

In the creation of a family using third party ARTs complex relationships evolve. For those using DI, the partner of a woman in a heterosexual relationship would become the father of the child (social and usually legally). For women who choose to become single mothers by choice, parenthood status may be retained by them exclusively, regardless of the fact that the child has both male and female genetic parents. For lesbian couples, the presence of a second woman in the family, who takes on a mothering role, becomes the second parent, thus completing the family unit (Blyth & Landau, 2004).

Family formation through egg donation means that the woman, who provides the eggs or embryos, is the ‘genetic’ mother, and the woman who has a successful pregnancy and birth becomes the ‘gestational’, ‘biological’ and ‘social’ mother (Blyth & Landau, 2004, p.11). In cycles of treatment using IVF and DI, the woman having the treatment is usually the biological and genetic mother of the resultant child. The sperm donor may either be known to the woman or anonymous – there is a higher tendency for anonymous donation (Blyth & Landau, 2004). However, this is jurisdiction dependent. In the UK, donors no longer have the right to anonymity, and thus donor-conceived individuals are able to access donor information (HFEA, 2004), although recipients have no entitlement to access this information. However, as illustrated later in the thesis, a specific characteristic of egg sharing is that family formation may lead to genetically related half-siblings being born within close temporal proximity to each other

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<sup>5</sup> Now conventionally referred to as ‘cross border reproductive care’.

who may also reside in a relatively close geographical location. In order to conceptualise the reality of egg sharing, I explain how egg sharing evolved in the UK and globally.

### **Egg sharing: the UK context**

Current legislation in the UK permits the provision of egg sharing schemes in licensed treatment centres (HFEA, 1998a). Prior to the emergence of these schemes there had been a reliance on altruistic egg donors as a means of alleviating the paucity of donor eggs. However, there is widespread recognition that the demand for donor eggs far exceeds the supply, globally and in the UK (HFEA, 1998a; Groskop, 2007a; Pennings, 2007; Yee, 2007; Blyth & Frith, 2008). This imbalance has been especially acute in countries such as the UK, where overt payment to donors is prohibited.

However, following the first successful use of donated eggs being reported in Australia in 1984 (Lutjen, 1984), the use of egg donation has become commonplace (Pennings, 2007). This contributed to a worldwide demand for donor eggs, as more couples find the use of donated eggs acceptable (Purewal & van den Akker, 2009). It has been noted that many countries worldwide operate a quasi-market or a market basis approach to the provision of ARTs despite their opposition to the commercialisation of ARTs (Blyth & Farrand, 2005).

In their estimations, Blyth & Farrand (2005, p.99) suggest that this situation has arisen primarily because the provision of ARTs is given “low (if any) priority in many publicly funded health services”. Thus, the market principles associated with supply and demand become evident, particularly amongst those seeking donor treatments. Consequently, the restrictions that may be imposed on donor remuneration may contribute to the shortage of donor eggs, which then impacts on waiting lists for treatment using donor eggs. Furthermore, given the fact that female fertility declines markedly from the mid-30s (Bongaarts, 1982), then more rapidly after the age of 40 (Craft, no date), it is possible that “simply waiting one’s turn” for suitable donor gametes to become available is not necessarily a practical option if there is a choice (Blyth & Farrand, 2005, p.99). One response to this issue in the UK was the development of egg sharing schemes as an alternative means of alleviating the paucity of donor eggs.

Pioneered by Simons and Ahuja in 1993 egg sharing was developed as a self-help scheme, representing an opportunity for eligible women under the age of 35<sup>6</sup> - who require IVF treatment – to access cheaper and in some cases, more expeditious, treatment (Ahuja & Simons, 1996; HFEA, 1996; Simons & Ahuja, 2005). It is usual practice for the eggs to be divided equally between the donor and recipient. Policies regarding the allocation of 'extra' eggs are centre-dependent, though extra eggs are usually allocated to the donor (Blyth, 2009).

Egg sharing has been lauded as a treatment that has the potential to achieve a live birth for both donor and recipient. It has also been suggested that it alleviates disparities in access to publicly-funded National Health Service (NHS) treatment in the UK (Ahuja & Simons, 1996; Ahuja et al., 1996; Thum et al., 2003) and is claimed to be supported by an increasing number of doctors because of the shortage of donor eggs and the difficulties of accessing IVF treatment (Ahuja et al., 1998a). However, it has been suggested that if these disparities, the so called 'postcode lottery' of IVF, did not exist, egg sharing may not be seen as a viable treatment option (Blyth, 2002; 2004; Maggs-Rapport, 2001; Rapport, 2003; 2005; Blyth & Golding, 2008).

### **Egg sharing: the global context**

In a review paper, Blyth and Golding (2008) cite a plethora of articles that indicate the existence of egg sharing in various countries: Australia (Ahuja et al., 1998), Belgium (Devroey et al., 1989; Kolibianakis et al., 2003; Pennings & Devroey, 2006), Canada (Press et al., 1995), Greece (Ahuja et al. 1998), Spain (Ahuja et al., 1998), the UK, (Ahuja et al., 1996; 1997; 1998; 2000; Ahuja & Simons, 1998; Blyth, 2002; 2004; Johnson, 1999; Maggs-Rapport, 2001; Rapport, 2003; 2005; Thum et al., 2003; Burrell, 2005; Lieberman, 2005; Simons & Ahuja, 2005) and the USA (Borrero et al., 1989; Check et al., 1992; 1993; 1994; 1995; 1999; 2002; 2005; Fox et al., 2005; Katsoff et al., 2005).

In summarising the global prevalence of egg sharing schemes Blyth & Golding (2008) state that in Italy, egg sharing was offered until legislative changes in 2004 prohibited the use of all forms of third party ARTs (Flamigni et al., 1993; Ferraretti, 2006). Notably, egg sharing is the only legally permitted form of egg donation available in Denmark (European Society for Human Reproduction and Embryology (ESHRE), 2002; Burrell, 2005), Israel (Ben-Nunn et al., 1992; Yaron et al., 1995a; 1995b; Rabinerson et al.,

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<sup>6</sup> In exceptional cases women are able to donate eggs after 35 (HFEA, no date b).

2002) and the People's Republic of China (Heng & Zhang, 2007). However, the global prevalence of egg sharing still remains uncertain as there is anecdotal evidence that suggests the existence of egg sharing in other countries such as Poland and India (Indian Med Guru, no date; McMillan & Hope, 2003).

Nevertheless, in the majority of countries – as currently known – egg sharing is not practiced. Despite egg sharing being permissible in the UK, concerns were raised amongst clinicians, academics, and the regulatory body on moral and ethical grounds (HFEA, 1998a; 1999; Blyth, 2002; Johnson, 1997; English, 2005; Lieberman, 2005). It has also been argued that in the UK, the level of public funding for IVF treatments may affect the context within which egg sharing is practised. That is, restricted access may influence the decision to pursue egg sharing (Rapport, 2003; Blyth, 2004). This is in stark contrast to countries like Belgium, Denmark and Israel that offer generous public funding for fertility treatment (Blyth & Golding, 2008).

### **Regulating reproduction**

Viewed as a medical breakthrough for fertility treatments, IVF was hailed as a 'miracle treatment' and captured world attention (Lasker & Borg, 1987). However, whilst welcomed by many, it was also questioned by many, and still evokes controversy today, as I illustrate later in this chapter. Nevertheless, the ingenuity and subsequent medical advances might be championed because, as Dyson states, "medical science, based on distinguished antecedents" means that it is now "possible for more people to circumvent infertility" (Dyson, 1995, p.27). Indeed, it has been reported that in the UK at least 119,583 children have been born through the use of IVF since the birth of Louise Brown in 1978 (HFEA, 1978-2005).

In the UK, like other countries, there was no established regulatory framework governing the provision of treatments prior to the publication of the Warnock Report in the mid 1980s. Mary Warnock, a British philosopher, had been appointed by the UK Government to chair a committee whose remit was:

To consider recent and potential developments in medicine and science related to human fertilisation and embryology; to consider what policies and safeguards should be applied, including consideration of the social, ethical and legal implications of these developments; and to make recommendations.

(Department for Health and Social Security (DHSS), 1984, p.4)

The committee's report was published in 1984 and proposed the provision of infertility treatments within the framework of regulation and proposed guidance. The Government's response was to implement the Human Fertilisation and Embryology Act in 1990. The Act specified the establishment of a corporate body that would have the responsibility of overseeing the regulation of assisted conception treatment provision. The body, the Human Fertilisation and Embryology Authority, were given the responsibility for licensing and the regulation of centres providing ART procedures (HFE Act, 1990).

### **UK regulation of egg sharing**

When the HFEA began its regulatory work in 1991 it permitted payment to gamete donors of no more than £15 (per sperm or egg donation), plus the reimbursement of reasonable expenses (HFEA, 1991). At the time it set the figure for donor remuneration, egg donation was not practised extensively in the UK and sperm donation was the principal form of gamete donation. Therefore, the decision to peg remuneration for donors was made on the basis of the amount that sperm donors were being paid at that time (Blyth & Golding, 2008). The regulatory framework also provided the scope for women to access cheaper or free treatment, or sterilisation, in exchange for their eggs (HFEA, 1992).

Notably, the HFEA were opposed to any treatment that constituted payment for the donation of gametes (HFEA, 1996) as it was viewed by some as "analogous to paid donation" (Blyth, 2002, p.3254), a practice prohibited in the UK. In an annual report published in 1997 the HFEA announced their intentions to review donor remuneration, and indicated that there was a need to ascertain:

How payment might affect the values associated with a donation, for example, whether donated gametes should be perceived as a gift or a commodity and whether payment could affect this perception.  
(HFEA, 1997, paragraph 7)

In 1997 the HFEA announced plans to phase out payments to donors (Deech, 1998). As part of the consultation process to determine how such phasing out should be accomplished, the HFEA also sought views about egg sharing. During this process, the HFEA set out their own concerns about egg sharing, expressing a preference for altruistic egg donation, and that payment to donors (or the offer of subsidised or free treatment) constituted the commodification of gametes. The HFEA believed that

women who were seeking IVF should be expected to pay for the full cycle of treatment, regardless of whether they were involved in an egg sharing programme. At the same time, the HFEA raised other objections to egg sharing. These were that if egg share donors failed to become pregnant, they may blame their own failure on having given away half of their eggs and would also have to contend with the knowledge that they may have contributed to the birth of a child they will never know. In her discussion of the opposing views, Deech (the then Chair of the HFEA) stated that there were:

Those who say that it is wrong to pay for the building blocks of life, and those who say that if donors are not paid they will disappear, along with treatment services. The HFEA decided that it was opposed to payments for donors in principle as it risked the quality of the consent that was given and was inconsistent with the view that gamete donation should be a gift, freely and voluntarily given.  
(Deech, 1998, p.82)

As with donor payment, the HFEA also stated that egg sharing schemes should be phased out (HFEA, 1997; 1998b). However, the consultation generated considerable opposition to the phasing out of donor payment and failed to secure sufficient endorsement for the HFEA's plans to prohibit egg sharing. As a consequence, not only was modest donor payment retained, but the HFEA also formally acknowledged egg sharing as a licensed treatment in the UK (HFEA, 1998a; Blyth, 2002).

Notably, in formulating its new policy towards egg sharing, the HFEA were initially opposed to donors being able to access information about their recipient's outcome in the belief that this might cause undue psychological harm:

The patient-donor may worry about the outcome for the recipient and whether or not she became pregnant. These concerns may increase if she fails to conceive and then must cope not only with being childless, but also with the possibility that another woman may be bringing up a child which is genetically hers.  
(HFEA, 1998b, p.18)

Thus, the guidance issued to licensed treatments centres stated that information regarding treatment outcome should not be shared with either party (HFEA, 2000). However, this somewhat paternalistic position was challenged (Blyth, 2002), and the HFEA overturned the decision regarding the sharing of information with donors. This made it possible for donors to access this information.

Following the 1998 review, arrangements for reimbursing donors remained unchanged until 2005, when the HFEA reviewed provisions for donor reimbursement to ensure compliance with the European Tissue and Cells Directive (2004). Article 12(1) of the Directive states that:

Donors may receive compensation which is strictly limited to making good the expenses and inconveniences related to the donation. In that case, Member States define the conditions under which compensation is paid.

Following the review, reimbursement was pegged at the amount paid to citizens undertaking jury service, with a total cap of £250 per egg donation cycle, together with reimbursement of 'reasonable expenses' (HFEA, 2005b). Following a further review, the daily level of reimbursement was raised to £61.28 per full day, although the overall cap remains at £250 (HFEA, 2009a).

At the time of writing, the HFEA is undertaking a further review of donor reimbursement by means of a public consultation. This is in order to assess their impact, and to examine donor remuneration policies in the UK more broadly, alongside public perspectives on the payment of donors, and the offer of reduced price treatment associated with egg sharing (HFEA, 2009b).

In justifying its 1998 decision regarding egg sharing, the HFEA noted that it was 'influenced by the argument that egg sharers are not motivated by money, but by the desire for a baby' (HFEA, 1998a, paragraph 3). In providing further justification for permitting egg sharing, they use what Blyth (2002, p.3254) refers to as the "opportunity to provide a more acceptable gloss to the practice, by reconceptualising it as 'compensated' egg sharing". In the concluding advice given to centres, the HFEA stated that "allowing egg-sharing to continue did not mean that the HFEA had given the practice its ethical approval" (HFEA, 1999, cited in Blyth, 2002, p.3254). However, despite expressing these concerns, the HFEA's decision to regulate egg sharing (HFEA, 1998a) and the reporting of favourable outcomes (Ahuja et al., 1998a) led to an increase in the number of centres offering the treatment.

Following the "HFEA's 'green light' for egg sharing" the number of clinics offering egg sharing increased after 1998 (Blyth & Golding, 2008, p.467), rising to 47 in 2007, more than half of the licensed centres in the UK (HFEA, 2007). However, more recently, it appears that the number of clinics offering egg sharing has started to decline. At the

start of the current study in 2008, the number of clinics listed as providing egg sharing had reduced to 42 (HFEA, no date b) and had further declined to 38 clinics at the time of writing (HFEA, no date c). Nevertheless, egg sharing continues to provide a significant source of donated eggs in the UK, as do the controversies surrounding it, and hence the need for this study. Blyth and Golding (2008, p.467) suggest that these can be “distinguished as either empirical or ethical concerns” (see pages 44-49).

### **Reviewing existing empirical studies and literature on egg sharing**

In this section I outline the existing studies pertaining to egg sharing undertaken by its clinical pioneers. Consequently, the reviewed studies present a particular and potentially biased stance towards egg sharing. A comprehensive review of two, more independent, studies is included, in order to qualify the emergent debates regarding egg sharing. Additionally, a critique of existing literature that pre-dates the removal of donor anonymity in 2005 is included.

### **Searching for literature**

The literature review undertaken for the study commenced with a re-visitation of a previous study that explored attitudes towards infertility, infertility treatments, and egg sharing amongst a group of social work lecturers and students at the University of Huddersfield (Golding, 2007). The starting point for the previous research had been the seminal works of Ahuja & Simons (1996; 1998), Ahuja et al (1996; 1997; 1998; 1999; 2000), Simons & Ahuja (2005), and the work of Blyth (2002; 2004), and Rapport (2003).

Further empirical studies were sought that focused on the questions the study has attempted to answer. A range of sources were used in order to locate evidence, reference lists of existing articles were perused to assess whether any articles listed merited inclusion in this review.

Expansion of the existing research base was undertaken using an electronic database search. This was conducted on PUBMED (Medline), Metalib, IngentaConnect and Google Scholar. The key search terms used included ‘egg-sharing’, ‘egg sharing’, ‘informed consent’, ‘egg-sharing and informed consent’, ‘decision-making and informed consent’ and ‘egg sharing, decision-making, informed consent’. Search terms were combined using Boolean logic with AND being the preferred operator used to narrow searches.



The Library catalogue at the University of Huddersfield was also searched for any books that were relevant to the study. A search of subject specific journals was also undertaken. These were either for those which could be accessed via the institution's subscription, via the Athens login, or by signing up for free access to the journals. Journals utilised for the review included *Human Reproduction*, *British Medical Journal*, *Fertility and Sterility*, and *Human Fertility*. In order to keep up to date with developments in the field I signed up to receive table of contents e-mail alerts from some of these journals, in particular *Bionews*<sup>7</sup>, *Human Reproduction*, and *Human Reproduction Update*. A record of the key literature retrieved is located in Appendix One, page 279.

Analysis of the abstracts took place in the first instance before retrieval of full text articles. Cormack (2000, p.97) suggests that this may be a useful method because an abstract, if available, "gives a succinct synopsis of the article".

### **Studies undertaken by clinical pioneers**

Published studies by clinicians that explore egg sharing are primarily reports on surveys to explore the attitudes of egg sharing patients or reports on the clinical outcomes of treatment (see for example, Ahuja et al., 1996; 1997; 1998; 2000; Simons & Ahuja, 2005). Notably, these articles are co-authored by the pioneers of egg sharing, which might question the independence of commentary regarding the merits and efficacy of egg sharing.

### **Promoting egg sharing schemes**

In their promotion of egg sharing the pioneers state the development of egg sharing stemmed from the needs of patients in their clinics (Ahuja et al., 1996; Ahuja & Simons, 1996), prompted by their awareness of the shortage of donor eggs. They state that the logic of the scheme stems from the fact that two 'desperate' groups of infertile women are able to access treatment from which they may otherwise be excluded. In the scheme, donors are required to pay the costs of their initial screening and for their own drugs. The rest of the associated treatment costs are offset by the recipient (Ahuja et al., 1996). It has been noted that this arrangement costs the donor around £600 towards the cost of her single treatment cycle, whereas the recipient will need to pay around £6000 towards the IVF cycle (Templeton, 2008). It has also been claimed that "egg sharing provides a dignified solution for many couples who are unable to afford

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<sup>7</sup> *Bionews* is an online newsletter administered by Progress Educational Trust. It is published on a weekly basis ([www.bionews.org.uk](http://www.bionews.org.uk)).

multiple private treatment cycles” (Wilcox, 2001, p.88). In their continued promotion of egg sharing, Ahuja & Simons suggest it has “great advantages” such as:

- 1) Facilitating treatment for two disadvantaged groups of women who are denied help from the NHS, without recourse to financial inducements or direct personal transactions. Those who are accepted are also spared the frustration of having to wait on long waiting lists for treatment.
- 2) Ensuring compatible matching of donor and recipient by treatment centres and provision of necessary information about both donor and recipient for HFEA records.
- 3) Discreet and dignified monitoring of the process.
- 4) Avoiding the administration of hormonal treatment and associated procedures to otherwise healthy women simply because they are donating eggs, and subjecting such donors to ovarian stimulation treatments and egg retrieval, or to the potential risks that may be associated with the use of gonadotrophins<sup>8</sup> in ovarian stimulation, such as the development of cancer. Infertile donors have fertility difficulties and will require hormonal treatment anyway (Ahuja & Simons, 1996, p.1152; Ahuja et al., 1996; Ahuja & Simons, 1998).

However, although the risk of cancer development amongst egg donors remains unsubstantiated, it is suggested that further detailed investigations are required (Ahuja & Simons, 1996; 1998; Ahuja et al., 1996; 1998; 1999; 2000; International Federation of Fertility Societies (IFFS), 2001; Sauer, 2001; Pearson, 2006; dos Santos Silva, 2009).

Ahuja et al., (1998) also assessed the motivations of egg share donors following a survey of donors’ experiences of egg sharing between 1993 and 1997. The survey explored the following areas: (1) sensibilities about participating in an egg share scheme; (2) motivations to participate in an egg share scheme; (3) sensitivity about ‘mothering’ an unknown child; and (4) reflections on the treatment received (Ahuja et al., 1998, p.2671).

The authors received 114 survey returns from the 274 questionnaires sent out to donors (42% response rate). Of these, 69% had not achieved a pregnancy and 31% had been successful. The authors conclude that donors are not adversely affected emotionally by egg sharing, and that, overall, participants were satisfied with their treatment, and that donors were not marginalised or threatened by the treatment. However, the authors suggest that there was a need for better counselling provision

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<sup>8</sup> See Glossary.

and screening in order to ascertain those most at risk of depressive episodes. The provision and quality of consent was also analysed.

It was reported that “participation in egg sharing is not only intentional but it is completely voluntary” (Ahuja et al., 1998, p.2673). Moreover, the authors assert that “the arbitrary charges of coercion of ‘paid’ egg share donors are not substantiated” (Ahuja et al., 1998, p.2673). In addition, it was suggested that even following unsuccessful treatment, donors, upon reflection, remain confident about the choice they made. Thus, they surmise that any claims regarding psychological distress are unfounded (Ahuja et al., 1998). In qualifying this position they assert that participants in egg sharing schemes find them rewarding. Furthermore, they claim that egg sharing reduces the number of eggs that would be destined for destruction. That is, IVF procedures are naturally wasteful, and egg sharing alleviates this waste. However, they acknowledge that for some women, egg sharing is unattractive, despite the potential for the scheme to meet their family building aspirations.

In illustrating further benefits of egg sharing, evidence is given regarding the background of women willing to participate. The authors conclude that egg share donors are well-informed and educated, with an awareness that they can withdraw from the scheme at any time (Ahuja et al., 1997). Additionally, compensated treatment is not equated with payment for the donor’s assistance or the provision of their eggs. In their espousal of this concept, Ahuja et al., cite Ridley who “describes ‘paid’ egg sharing as ingenious and harmless” [adding that]:

The truth is, as anybody in the real world knows, that pure acts of unrewarded altruism are too rare to base society upon. We would do far better to recognize self interest... if egg donation is right, being paid for it does not make it wrong. If it is wrong, not being paid for it does not make it right.  
(Ridley, 1997 cited in Ahuja et al., 1998, p.2676)

Thus, if such acts are rare, according to Ridley, then one might question the grounds on which the altruism principle rests. As I discuss in Chapter Nine, and return to later in the thesis, the concept of altruism is one that raises conflicting analyses. However, Ahuja et al., do not attempt to assert that egg sharing constitutes unrewarded altruism, rather they state that altruistic donors are few, and that reliance upon a volunteer supply of donor eggs is ‘reprehensible’. In their analysis, they go on to justify their position by stating that cash or the commercialisation of donation would endanger “the

nature of the gift” and “at worst a perspicacious donor would see it as perverse” (Ahuja et al., 1998, p.2677). As such they strongly refute any form of commercialisation. In doing so they liken egg sharing to blood donation, citing Howden-Chapman et al (1996) in support who suggest that voluntary blood donors would not continue to donate if their free gift of blood were to be legally permitted to be traded for cash rewards. Subsequently, Ahuja et al., (1998) suggest that there is a strong case for maintaining the schemes and believe they operate in the best interests both of donors and those in need of donor eggs. Conversely, the authors later assert that “modest financial reward encourages pragmatic and workable altruism” (Simons & Ahuja, 2005, p.116) an opinion that seems inconsistent to their earlier discussions of egg sharing.

### **Other studies and literature pre 2005**

Since the development of egg sharing in the UK, the scheme has sparked extensive debates – on moral and ethical grounds (Johnson, 1997; 1999; Blyth, 2002; 2004, Rapport, 2003; English, 2005; Lieberman, 2005). The main arguments focus upon: (1) the financial remuneration available for gamete donors; and (2) whether this constitutes coercion and whether the payment (in kind) for gametes constitutes the commodification of gametes. Specific attention is given to the provision of informed consent by egg share donors and whether consent is given voluntarily and free from coercion since the provision of subsidised or free treatment may be influential in egg share donor decision-making. The literature is used to illustrate these perspectives.

### **The egg share donor’s perspective**

This study extends the published studies by Blyth (2002, 2004), and Rapport (2003), that were based on patients attending specific clinics and were therefore living in a relatively circumscribed geographical locality. Participants in this study were a geographically dispersed population. Thus, I illustrate later in the thesis the constraints within which women find themselves in their attempts to access publicly-funded NHS treatment that may influence their decision to become an egg share donor, echoing a theme in the work of Rapport (2003) and Blyth (2004) (see Chapters Eight, Nine, Ten and Eleven).

Blyth investigated potential and actual egg share donors’ constructs, the aim being to provide an empirical assessment of “the experiences of women (and their partners)” (Blyth, 2004, p.157), who were considering egg sharing. Other than the published work of Rapport (2003), research into egg sharing in the UK, from the perspective of the egg share donor had been missing (Blyth, 2004), although Blyth had previously provided a

policy analysis of the emergence of subsidised egg sharing schemes in the UK (Blyth, 2002). Rapport's (2003) work also analysed the motivations of egg share donors, and unlike the study by Blyth (2004), Rapport focused upon the motivations of potential rather than actual egg share donors. I use the analysis of their findings as the basis of the arguments proposed later in the thesis (see Chapter Ten).

### **Motivations to egg share**

As noted above, Ahuja et al., (1997; 1999) suggested that women pursue egg sharing for altruistic reasons rather than because of financial inducements. However, the studies reviewed in the thesis indicate that the motivation to egg share is complex. This is compounded by the inability to access NHS treatment and the consequences associated with proceeding with treatment. So, whilst women in the studies expressed a 'genuine' desire to help someone in a similar situation to themselves, motivation also stems from the ability to access treatment that they otherwise could not afford. Blyth (2004) acknowledges that for two couples, the decision-making process was more closely aligned to financial motivations, as the couples cited this as their primary reason for choosing egg sharing. However, Blyth notes also that a total of six couples cited financial motivations as a primary or initial factor alongside the desire to help someone else when deciding to egg share. Blyth quotes a participant to illustrate the impact of financial motivation upon the decision to egg share:

“...Against my better judgement at the time, I thought I would do it for the money, because I wanted a baby so much that I thought I would just do it for money reasons. Not for anything else, just by thinking that money came into it. I did think that's a terrible decision to base it on, but my need for a child was so great and I thought if that is the only way that we are going to be able to afford IVF I'll do it...”  
(Blyth, 2004, p.158)

This response illustrates that decision-making within the context of proceeding with egg sharing is not straightforward, while Rapport (2003, p.40) states categorically that “equating egg sharing with altruism is ill-advised until a firmer understanding of women's motivations to donate is achieved”. I would suggest that the motivation to share eggs is potentially linked to the fact that the procedure is perceived to be a way to circumvent infertility. Both Rapport (2003) and Blyth (2004) report that participants referred to the concept of 'time ticking away'. Thus, there was an awareness of biological status and reproductive ability being compromised by lengthy waiting lists for treatment. Furthermore, Blyth (2004, p.158) suggests that “time and speedy access to

treatment may be an important theme for those contemplating egg sharing as much as financial motives”, especially when combined with the fact that egg sharing as a potential treatment option emerges long after the initial engagement with assisted conception treatments.

Clearly, a better understanding of egg share donors’ motivations to donate is required, hence the significance of the current study.

### **Egg sharing and access to IVF treatment**

In Blyth’s study, access to NHS treatment was a key theme in participants’ experiences. Significantly, Blyth states that each couple in the study had experienced problems accessing NHS treatment for a number of reasons. These included: being ineligible for treatment because of already having a child/children, having to go on a waiting list or having to pay for treatment, lack of treatment on the NHS in their area, or having used their entitlement to NHS treatment (Blyth, 2004).

Rapport (2003) discusses similar findings. Ten of the 11 women whom she interviewed had either investigated, or had received, NHS treatment prior to considering egg sharing. Participants’ experiences of NHS treatment were expressed both financially and temporally. Participants indicated that lengthy waits for NHS treatment were important and were linked to their decision to consider egg sharing, in that the length of time (often years) spent attempting to circumvent infertility plays a pivotal role in their decision-making. Additionally, participants expressed financial aspects as impacting on their decision-making. Notably, the inability to obtain the funds required to pay for private treatment; or having made unsuccessful applications for NHS treatment.

### **Concerns about egg sharing**

As discussed earlier in this chapter, a number of concerns have arisen with regards to egg sharing. These concerns can be expressed as either empirical or ethical (Blyth & Golding, 2008). They also include the psychosocial implications of egg sharing. This includes being an identifiable donor and the impact of information regarding the recipient’s treatment outcome.

### **Empirical concerns**

Empirical concerns arise with regards to the aforementioned scenarios. Additionally, donors may be subject to stronger stimulation treatments in order to maximise the production of sufficient eggs. This may increase their risk of ovarian hyperstimulation

syndrome (OHSS<sup>9</sup>) (HFEA, 2005a). Egg distribution may work in favour of the paying recipient, thus compromising the outcome of treatment for the donor (Johnson, 1999). Donors may be emotionally affected if they know the outcome of the recipient's treatment (HFEA, 1998a; English, 2005).

A factor cited as potentially aggravating this situation was the UK legislative changes to donor anonymity in 2005. Before 2005 donors were assured of their anonymity (HFEA, 2004). However, the changes meant that donor anonymity was no longer permitted. Subsequently, gamete donors were to provide identifying information that could be requested by donor offspring once they reach the age of 18. Critics of the change highlighted potentially problematic situations in the case of egg sharing:

A woman who is infertile who is unsuccessful but who donates eggs to someone who is successful and a child then potentially might want to visit that poor infertile woman some 20 years down the track.  
(Kennedy, 2005, p.12)

Similar concerns were raised by Ahuja (cited in Henderson, 2004), Craft (2008 cited in Templeton, 2008), Winston (2006), and by the British Medical Association (BMA, 2006). Michael Wilks, Chair of the BMA Ethics Committee, said that the committee were worried about women for whom IVF does not work and who remain childless but who may be contacted in the future by people born following their egg donation" (Wilks, 2005 cited in *BioNews*, 2005, paragraph 6). Similar views were expressed by the BMA in response to the Department of Health review of the Human Fertilisation and Embryology Act in 2005. They state that whilst they:

Recognize that there are compassionate reasons for supporting egg sharing... they believe it puts unacceptable pressure on women who are unable to afford IVF treatment, to agree to egg sharing.  
(BMA, 2006, cited in People Science & Policy Ltd, p.33)<sup>10</sup>

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<sup>9</sup> See Glossary.

<sup>10</sup> In 2007, the BMA reviewed their position regarding egg sharing and stated that they had withdrawn their opposition to it (BMA Ethics, 2009), although this reversal of opinion is not reflected elsewhere.

However, Blyth & Golding (2008, p.467) note that a “self-evident shortcoming of empirical concerns relates to the lack of evidence to support (or indeed to confound) them”. This study attempts to address this lack of empirical evidence.

### **Ethical concerns**

Concerns raised by critics of egg sharing on ethical grounds focus upon the provision of informed consent by egg share donors, donor decision-making, and the commercialisation of reproductive material (Shenfield & Steele, 1995; Johnson, 1997; 1999; Blyth, 2002; 2004; Rapport, 2003; English, 2005; Lieberman, 2005; Craft, 2008).

With regards to the provision of consent, English outlined the then current view of the BMA that:

For those who desperately want children but cannot afford to pay for treatment, egg sharing represents their only option. Where there is such a large inducement to donate eggs, questions must be raised about the validity of the consent and whether it meets the requirement that, in order to be valid, consent must be given voluntarily and free from pressure.  
(English, 2005, paragraph 3)

The Chair of BMA Ethics Committee, Michael Wilks, said that the committee felt that egg sharing “places unacceptable pressure on women who cannot afford IVF treatment to donate their eggs” and that, given the restrictions faced by those attempting to access publicly-funded NHS treatment:

The offer of free or reduced price treatment, worth thousands of pounds, is a very large inducement which could affect the validity of the woman's consent.  
(Wilks, 2005 cited in Bionews, 2005, paragraph 6)

It has been suggested that altruistic egg donation programmes are the most acceptable, on moral and ethical grounds (Yee, 2007). However, it has been difficult to ascertain whether egg sharing is an altruistic programme or whether the scheme constitutes a non-altruistically motivated choice. In my analysis of egg sharing, I illustrate the main concerns pertaining to egg sharing. As discussed, the concerns raised about egg sharing are on empirical and ethical grounds, the main ethical concern being the validity of egg share donors' consent.



### ***Egg sharing and informed consent***

Complex debates surround egg sharing and the opinion that consent provision is affected by external influences. As discussed, the provision of informed consent caused great concern when egg sharing first emerged. Supporters of women's ability to consent; for example, Ahuja and colleagues, believe that:

Access to counselling and informed consent are pivotal, and provided these are available, it cannot be argued that women of reproductive age and their partners are incapable of making rational and informed decisions.  
(Ahuja et al., 1996, p.1129)

Their analysis asserts that egg share donors are not adversely affected psychologically by unsuccessful treatment or the knowledge that the recipient was successful. They conclude that donors' distress following unsuccessful treatment may be eased by the knowledge that the recipient may have been successful and state that:

Many who are prepared to donate some of their eggs in return for less expensive fertility treatment regard it as recompense and an acceptable compromise: much more acceptable than being content with no treatment at all.  
(Ahuja et al., 1996, p.1129)

Simons & Ahuja later state that past criticisms of egg sharing are not supported by evidence, and that "the suspected dilution of women's consent due to subsidised or free IVF has been vigorously examined" (Simons & Ahuja, 2005, p.113).

Herein lays the contentious nature of egg sharing. Ahuja and colleagues advocate that the negative perceptions regarding a woman's ability to give informed consent are not warranted. This has been contested by other commentators in this area (Johnson, 1997; 1999; Brazier, 2003; English, 2005).

Brazier (2003, p.296), for example, questions whether egg sharing subjects a potential donor to a "nigh on unbearable pressure to agree because otherwise she may have no chance at all of treatment by IVF" and questions how the donor might "feel if the recipient has a successful pregnancy and she does not?" Thus, she and others argue that consent, and the ability to give it freely, may be affected because elements of implicit coercion may exist. Consequently, the reality is that for women excluded from, or who have used their entitlement to, NHS treatment, or who cannot afford expensive

private treatment, egg sharing offers the only solution available to them. Therefore, egg sharing becomes a pragmatic option in the quest to overcome involuntary childlessness. However, as Blyth & Golding suggest:

The monetary value of the subsidized treatment cycle is indubitably an inducement to a potential egg sharer, as indeed, is any 'feel good' factor that may derive from the ostensibly altruistic donation.  
(Blyth & Golding, 2008, p.469)

Subsequently, decision-making might be affected by these external motivations. Significantly, Lockwood (2007, p.144) concludes that egg sharing "is just a more acceptable form of coercion than the usual ones". Additionally, it has been suggested that:

Women, motivated by an intense life crisis over infertility, are manipulated by this situation into full and total support of any technique which will produce those desired children, without consideration of the implications of doing so.  
(Rowland, 1987, p.75)

### **Psychosocial implications of egg sharing**

Drawing on psychological literature pertaining to decision-making, the study illustrates the potential psychosocial implications associated with becoming an egg share donor. Fielding et al (1998, p.274) in their promotion of the fusion between psychological and social factors within the context of known egg donation note that, "the psychological consequences for families with such complex relationships have not been documented, neither have risk factors been fully explored". This opinion is applicable to egg sharing, since, following the abolition of donor anonymity in the UK, a woman whose treatment is unsuccessful may find that her donation resulted in a successful outcome for the recipient and expose her to the "knock on the door in 18 years time" scenario envisaged by Kennedy and Craft – as noted on page 45. Additionally, it may transpire that two (or more, in the case of multiple pregnancies) genetically related children are born as a result of the arrangement.

Furthermore, as suggested by Rapport (2003) and Blyth (2004), the potential ramifications for egg share donors need to be considered more extensively, specifically, because egg sharing was the only choice, when all other options had been exhausted, other than forgoing any attempt at conceiving children. Subsequently, the wider implications of egg sharing need to be addressed, particularly in view of policy

developments that required donors to be potentially identifiable to any offspring conceived following a procedure taking place after 2005, and those that enabled egg share donors to learn the outcome of their recipient's treatment. I address some of these implications in greater detail in Chapters Ten and Eleven (see pages 227-229 and 250-251).

### **Recent developments: new variants of egg sharing**

Since being accepted, in principle, by the HFEA, egg sharing appears to have become more 'acceptable' in society as new variants of egg sharing emerged. These are 'egg sharing for research' and 'egg sharing for social reasons'. For the purpose of the thesis, I merely allude to their existence to demonstrate the impact that egg sharing has had on UK society. A brief account of the treatments can be found in Appendix Two (page 300).

### **Chapter review**

In this chapter I have documented the emergence of egg sharing in the UK. This demonstrates the growing acceptance of treatments using donor eggs, prior to the emergence of egg sharing. I locate egg sharing within the context of the UK regulatory framework and provide an account of the extensive debates sparked prior to, and following, the regulation of egg sharing. I illustrate that whilst advocates of egg sharing perceive the arrangement to be both practical and ethical, criticisms have been raised.

My analysis of the literature notes that these criticisms continue because of the potential future implications for egg share donors, for their offspring, and the offspring that may be born to the recipient as a result of the treatment. Concerns surrounding the provision of informed consent by egg share donors have also been voiced. These discussions focused upon the motivation to become an egg share donor, the decision-making process and the psychosocial implications of egg sharing. In the following chapter I locate the study within its methodological context.

## CHAPTER THREE

### Methodological approach

*The aim of methodology, then, is to describe and analyse... methods, throwing light on their limitations and resources, clarifying their presuppositions and consequences... to help us to understand, in the broadest possible terms, not the products of scientific inquiry but the process itself.*  
(Kaplan, 1998, p.23)

In this chapter I locate my study within the context of the philosophical positions that underpinned its development. I begin with an overview of how I first made sense of the research process before describing its ontological and epistemological foundations. I then discuss the choice of methodological approach and the rationale for its inclusion. This demonstrates how I applied the chosen methodological approach during data collection and analysis. Finally, I provide a brief introduction to the use of sensitivity, emotion work, and reflexivity within the study.

#### **Making sense of the research process**

Crotty (1998) advocates the use of four elements as the basis of the research process. These elements are: epistemology, theoretical perspective, methodology and methods, elements which he says “inform one another” in the research process (Crotty, 1998, p.4). Epistemology at its most basic level is concerned with “what it means to know” (Gray, 2004, p.16). It involves questioning how we can be sure that we actually know what we know, and which we believe we know (Guba & Lincoln, 1989; Crotty, 1998). As a theory of knowledge it is embedded in the theoretical perspective, that is, the philosophical stance that underpins the research, which in turn is embedded in methodology (Crotty, 1998). The theoretical perspective serves to inform the selection of the most appropriate methods to gather and analyse the data (Crotty, 1998). However, an element of the research process missing in Crotty’s framework is ontology. In acknowledging and justifying this omission he asserts that ontology, as part of the research process, emerges and sits alongside epistemology. Therefore, as ontology is concerned with the study of being, that is, an analysis of the “structure of reality” (Crotty, 1998, p.10), it too informs the theoretical perspective. In doing so it “embodies a certain way of understanding *what is* (ontology) as well as a certain way of understanding *what it means to know* (epistemology)” (Crotty, 1998, p.10, emphasis original). Thus, epistemological and ontological issues have a tendency to emerge

together, hence Crotty's omission (Crotty, 1998). As I began my research journey I also referred to the work of Beck who states that social research enables us:

To understand social reality as different people see it and to demonstrate how their views shape the action which they take within that reality. Since the social sciences cannot penetrate to what lies behind social reality, they must work directly with man's definition of reality and with the rules he devises for coping with it. While the social sciences do not reveal ultimate truth, they do help us to make sense of our world. What the social sciences offer is explanation, clarification and demystification of the social forms which man [sic] has created around him.

(Beck, 1979 cited in Cohen & Manion, 1994, p.26)

These processes: explanation, clarification and demystification, are themes that best fit the purposes of this research. That is, in order to explore and understand egg sharing I sought information from those who knew best about their own situations: the egg share donors. By doing this I hoped that the process of what it is like to be an egg share donor would be demystified. However, before I pursued these ideas, I examined my own theory of knowledge (epistemology) and the assumptions about the nature of the lived experience (ontology) upon which these were based (McLeod, 2001). Therefore, as I developed the study I began by asking myself some research specific questions, these were: (1) What was it that I wanted to know? (2) How best could I find this out? (3) Which were the best methods that I could use to help me to find out?

In the study I answered these questions by examining the underpinning ontological assumptions that guided its development. I begin with an overview of the epistemological and ontological assumptions that underpinned the philosophical approach of the study.

### **Ontological and epistemological foundations**

In locating the study within a philosophical framework I began by considering its ontological foundation. As ontology is concerned with an explanation regarding the very "nature of reality" (Guba & Lincoln, 1989, p.83) it was evident that I needed to consider the nature of the reality that I explored. As a starting point, this was the first question that I applied in the development of the study; this, in turn, was underpinned by a set of more detailed questions based on the overall aims of the study. These were: (1) What did I already know about egg sharing? (2) What was the basis of this knowledge? (3) How would I apply this existing knowledge in the research process? (4) What were the

realities of being an egg share donor? (5) How could I explain these realities within the context of the study?

I located my answers to these questions within the context of the exploration of the 'lived experiences' of egg share donors and what this represented to them. It was this concept, the analysis of 'lived experiences' that informed the epistemological element of the study. This, in turn, influenced the theoretical and methodological decisions undertaken. In the pursuit to develop knowledge and understanding of the lived experiences of egg share donors I took into account the view posited by Becker who states that:

...experience is a valid and fruitful source of knowledge. Any person's knowledge is based upon what that person experiences, whether it be firsthand experience or vicarious, secondhand experience. Experience is the source of all knowing and the basis of behaviour. Experience, what we are aware of at any point in time, is the foundation of our knowledge of ourselves, other people, and the world in general. Without human experience, there would be no human world.  
(Becker, 1992, pp.10-11)

Using the explanation espoused by Becker (1992) and the epistemological basis of the study, I was able to reject epistemologies that I believed were not relevant to the study. For example, objectivist epistemologies purport that meaning and meaningful realities exist independently of our consciousness of thought. Thus, objects exist independently of experience and consciousness; the truth about an object lies within the object itself and meaning can be explored scientifically and objectively. In contrast, subjectivist epistemologies, again in opposition to the exploration of experience, purport that meaning is ascribed to an object by the subject. Meaning occurs within the human mind and is not influenced by the object, but rather our way of thinking about that object.

There is, however, another epistemological stance that rejects these ways of thinking – this is constructionism. Inherent within this way of viewing the world is the notion that there is no objective truth waiting to be found; instead, it requires our engagement with the realities that exist in the world, and that it is this engagement with the world which enables truth, or meaning, to become evident. Therefore, meaning does not take place independently of the mind, but requires a mind in order for meaning to become apparent. Thus, meaning (knowledge) is constructed and not discovered (Crotty,

1998). This epistemological stance (constructionism) is the one that was more broadly applicable to the study as I generated knowledge about the lived experiences of egg share donors. This epistemological stance acknowledges that meaning may be constructed in different ways, by different people, despite the fact that they may actually be explaining the same phenomena. In this process, meaning is developed through the interplay between object and subject, and these dynamic interactions enable meaning to become clear (Crotty, 1998). Moreover, a constructionist epistemology also mirrors the phenomenological concept of intentionality (see page 55).

In my discussion of the epistemological position underpinning the study, that of 'lived experience', I acknowledge the different ways in which these experiences may be expounded. As such, the study rejected the aforementioned ontological positions and adopted a relativist ontological position. Relativist ontology rejects the view that explanations can be made about the world; instead it accepts that the world, and thus our understandings of the world, are diverse and unstructured. As such, the onus is upon the extrapolation of meaning that is socially and structurally located (King & Horrocks, 2010). A relativist ontological position acknowledges that multiple realities, perspectives or understandings of the lived experience can be used as the basis from which to generate knowledge (Van Manen, 1990). Thus, it acknowledges that:

If there are always multiple interpretations of reality that exist in people's minds, then there is no process by which the ultimate truth or falsity of the constructions can be determined.  
(Polit & Beck, 2008, p.15)

Consequently, the emphasis upon multiple interpretations of reality informed the development of my philosophical framework.

### **Adopting a phenomenological approach**

My exploration of the epistemological (lived experience) and ontological (relativist) assumptions underpinning the study were also closely associated with the phenomenological approach to research; an approach that Kvale states:

Is interested in elucidating both that which appears and the way in which it appears. It studies the subjects' perspectives of their world; attempts to describe in detail the content and structure of the subjects' consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings.  
(Kvale, 1996, p.53)

In my own attempts to explicate essential meanings regarding the lived experiences of the participants in the study, I adopted a phenomenological investigation. In doing so I acknowledged that "the voices and interpretations of those under study are crucial to understanding the phenomenon of interest" (Polit & Beck, 2008, p.15). Therefore, since I wanted to best understand the phenomenon of being an egg share donor, using the voices and interpretations of those who had experienced egg sharing as a donor, I adopted a particular strand of phenomenology, that of interpretive (hermeneutic) phenomenology.

### **Foundations of the phenomenological approach**

The philosophical movement of phenomenology began with Husserl (1859–1938) who began to extend his ideas under the tutelage of Brentano (Macann, 1993; Langdrige, 2007). Husserl's interest was in the '*life-world*', and the notion that individuals are part of the world and not separate from it. Husserl stated that:

The life-world, for us who wakenly live in it, is always already there, existing in advance for us, the 'ground' of all praxis whether theoretical or extratheoretical. The world is pre-given to us.  
(Husserl, 1970, p.142)

Thus, for Husserlian phenomenologists, this experience of the life-world, and the intersubjective relationship between the subject and the object, shapes and determines the interpretation of meaning.

During the development of his philosophical ideas Husserl published *Logical Investigations* (1900; 1970) which expound his ideas regarding human consciousness and the way in which the world reveals itself through this consciousness. Husserl advocated the need to go 'back to the things themselves' in order to understand how the world is a lived experience rather than an object of study (Langdrige, 2007). This led Husserl to develop 'transcendental' or 'Husserlian' phenomenology (Rapport, 2005).



For Husserl intentionality is a key feature of human consciousness, in that when we are conscious, we are always conscious of something (Crotty, 1998; Langdrige, 2007; Smith, 2008). Intentionality is the relationship between human beings and the world (Crotty, 1998; Langdrige, 2007). It is “a consciousness of the world, or, more specifically, the relationship between a person’s consciousness and the world” (Langdrige, 2007, p.13). It is based on the correlation “between what is experienced (the *noema*, or noematic correlate) and the way it is experienced (the *noesis*, or noetic correlate)” (Langdrige, 2007, p.15), terms that Husserl began to use following his ‘transcendental’ turn.

Husserl argued that experience is always essentially an experience of something; central to this concept was the notion of essences. For Husserl essences represented the ability to describe ‘structures of experience’ rather than describing individual experiences (Todres, 2005; Langdrige, 2007). The methods proposed by Husserl to identify essences were: *epoché*, *the phenomenological reduction* and *imaginative free variation* (Langdrige, 2007).

Husserl used the Greek word *epoché* to describe “the process by which we attempt to abstain from our presuppositions, those preconceived ideas we might have about the things we are investigating” (Langdrige, 2007, p.17). Therefore, in order to identify essences, researchers need to hold in abeyance their own preconceived ideas about the topic of investigation, in order for it to be viewed with a fresh perspective (Crotty, 1996; Paley, 1997, Speziale & Carpenter, 2007; Rapport, 2005). This process of *epoché* is also referred to as ‘bracketing’ or the ‘phenomenological reduction’ (Becker, 1992; Drew, 1999; Speziale & Carpenter, 2007; Rapport, 2005; Langdrige, 2007), though the concept of ‘bracketing’ is one that has been debated by existential phenomenologists.

Some authors suggest that it is virtually impossible to fully bracket off one’s own preconceived ideas (Heidegger, 1927; 1962; Merleau-Ponty, 1945; 1962) because every experience in life is always an experience in relation to something else. These experiences must, then, be contextualised in relation to their history and cultural locations in order to gain understanding. It therefore requires, not description, but rather an interpretation of the experience being examined (Heidegger, 1927; 1962). However, for Husserlian phenomenologists ‘bracketing’ is an integral feature of the philosophical approach, a process that incorporates three distinct elements: “description, horizontalization and verification” (Langdrige, 2007, p.18).

In the act of '*description*' researchers treat all data with equal value and avoid developing hierarchies of meaning. This is the process of '*horizontalization*' whereby the whole of the data are examined and described in order to identify the essence of that which is being investigated. By treating data horizontally (equally) no single element is regarded as more important than the other. It is only on completion of this process that hypotheses can be tentatively created, thus enabling hierarchies of meaning to be established. Meanings are then verified by returning to the phenomenon in order to clarify the analysis within the context of the phenomenon that has been explored. The final stage used to identify essences is '*imaginative free variation*', the process of exploring the phenomenon in different ways. The aim of this process is to allow varied elements of the experience and the essences associated with it to come into view (Langdridge, 2007).

### **Heideggerian (existential) phenomenology**

As a student of Husserl, Heidegger sought to make sense of 'being-in-the-world' (Heidegger, 1962), a world that is already there when man or woman came into existence (Macann, 1993; Rapport, 2005; Langdridge, 2007). Heidegger became an ardent critic of Husserl's idealism. It was his attempt to distance himself from the philosophical principles underpinning the transcendental phenomenology of Husserl that led Heidegger to the existential turn in phenomenology, the focus of which is on existence (Macann, 1993; Chadderton, 2005; Langdridge, 2007). The roots of existentialism can be traced back to the works of Kierkegaard (1813-1855) and Nietzsche (1844-1900), although it is the philosophies of Heidegger that have had a continued impact on philosophy and phenomenology.

In *Being and Time* (1927, 1962) Heidegger examined 'what is' with regards to 'what exists'. In this work his critique of Husserl is most evident. In presenting his existentialism theory Heidegger aligned phenomenology with language and the interpretation of language in a way that had not previously been undertaken. Central to Heidegger's philosophy was that people are inseparable from the world in which they live; therefore it is not possible to 'bracket' off the world to arrive at an understanding of the phenomena. Heidegger believed that existence could not be described but had to be interpreted (Langdridge, 2007).

Heidegger used the term *Daesin* which, when translated from German, means 'being there', a term that also represents the person, subject or man (Becker, 1992; Langdridge, 2007). Heidegger's belief was that in order to understand *Daesin* (man),

one should attempt to understand him from within the context of which an understanding is sought (Becker, 1992; Macann, 1993; Rapport, 2005). That is, in order to understand and contextualise the lived experience of participants, one needs to attempt to do this from the perspective of those participating. Thus, in doing so, Heidegger made the distinction between the *ontic* (that which can be revealed by empirical investigation) and the *ontological* (the philosophical study of Being) (Langdrige, 2007). Key features associated with the exploration of Daesin are: temporality, facticity, mood, being-towards-death, care, authenticity, and being with.

For Heidegger *temporality* represented the experience of time in relation to existence. Heidegger said that for Daesin, the understanding of what it means to exist is based not only in the present, but also in the past, and in future projections. His term *facticity* refers to the notion that our entrance into a world that predates us means that many decisions about our existence are already pre-determined, e.g. ethnic group (Becker, 1992) and these pose limitations on the way of being. Daesin has the ability to create himself; however, this is constrained by facticity. Thus, Daesin's existence is determined by the choices made, choices that are influenced by Daesin's historical situatedness, and by physical, psychological, and social factors (Moran, 2000; Langdrige, 2007).

*Mood* is the term Heidegger used to refer to the way in which the world is experienced pre-reflectively. That is, our experiences of the world, as lived, are determined first and foremost "pre-reflectively through a mood and only later understood through reflection" (Langdrige, 2007, p.31). In his accounts Heidegger discusses anxiety (*Angst*) and fear (*Furcht*), making a sharp distinction between the two. Fear, he suggests, is always a fear of something, whereas anxiety is a mood that is shapeless and represents an anxiety of nothing other than "Being-in-the-world itself" (Moran, 2000, p.241). This mood of anxiety represents an awareness of the "nothingness of existence" (Langdrige, 2007, p.29). This represents Daesin's awareness that life is inescapably finite in nature and an acknowledgement that there will be an end to existence. His explanations for the ways that we exist are based upon the notions of the *inauthentic* and *authentic* modes of being (Moran, 2000; Langdrige, 2007).

Heidegger believed that for the majority of time our existence is inauthentic, in that there is disengagement from our existence, where we hide from the reality of our existence, as one that will ultimately come to an end. Conversely, authenticity represents those moments when we acknowledge that we exist, are no longer taking

the world for granted, and are accepting of the concept that existence is one that will come to an end (Macann, 1993; Moran, 2000; Langdrige, 2007). Although these notions of existence focus upon man as an individual, Heidegger later began to view the very nature of existence in a relational manner. He stressed the social nature of being and the concept that all being-in-the-world is actually being-in-the-world-with-others. Therefore all experiences are experiences that take place in relation to another. This view acknowledges that people are interpersonal beings, and that their existence is shaped by these interpersonal relationships (Becker, 1992; Langdrige, 2007).

Heidegger extended his philosophy of understanding into a hermeneutical (interpretive) way of understanding. This is linked to the context within which the experience is taking place, whilst making sense of both the cultural and situational contexts of those under investigation (Macann, 1993). As such, language is central to the development of understanding (Heidegger, 1927; 1962). Heidegger also played an influential role in the philosophical thinking of Hans-Georg Gadamer (see below), following his move to hermeneutic phenomenology (Crotty, 1998; Moran, 2000; Rapport, 2005; Langdrige, 2007).

### **Hermeneutic phenomenology**

Hermeneutics is defined by Langdrige (2007, p.41) as the “study of interpretation”. Rapport (2005, p.125) in her discussion of the approach describes it as the “the science of interpretation”. This interpretation involves developing an understanding of and making sense of people’s experiences within the world (Van Manen, 1990; Rapport, 2005; Langdrige, 2007).

The movement grew from the work of Husserl and Heidegger and was developed further by Gadamer (1900-2002). Gadamer was also influenced by the work of Dilthey who believed that understanding was achieved using dialogue and the interpretation of that dialogue “always occurs with reference to a personal, shared, and historical position” (Van der Zalm & Bergum, 2000, p.214). Gadamer extended the work of his mentor, Heidegger, from interpretive phenomenology into the “philosophy of Gadamerian hermeneutics” (Rapport, 2005, p.128). For Gadamer, who is considered to be one of the twentieth century’s most critical thinkers, there was an inextricable link between understanding, language and interpretation (Crotty, 1998; Rapport, 2005; Langdrige, 2007).

Gadamer's greatest work was *Truth and Method* (1975; 1996). In this publication he challenges the use and quantity of method that is required to achieve understanding. Though not opposed to scientific method, Gadamer argued that achieving the whole truth about a phenomenon is not restricted to the application of scientific methods. Gadamer suggested that an understanding of other aspects of human existence could be achieved, primarily through art, history and language (Langdrige, 2007).

Gadamer emphasised conversation as the central element from which understanding can be achieved. Conversation helps the revelation of that which may have previously been concealed, and meaning is revealed through the mutual sharing that is involved in conversation (Langdrige, 2007). For Gadamer, understanding was also achieved using Heidegger's concept of facticity, in that understanding is always culturally and historically situated (Crotty, 1998; Langdrige, 2007).

Gadamer believed language revealed 'being', and that 'being' can be understood through the 'fusing of horizons' – the historical and the cultural. Gadamer used the term *historicity* (pre-reflective understanding) to represent the idea that we need to be aware of our own beliefs as these are influential in developing understanding (Gadamer, 1976; Rapport, 2005). It is this awareness of self, and our personal histories that encompass the Gadamerian use of the term 'fusing of horizons'. Van der Zalm and Bergum (2000, p.215) state that "understanding begins with self-understanding – the values, the beliefs, the sense of self. In understanding self, one can begin to understand the other". Thus, the 'fusing of horizons' enables the generation of knowledge which:

Is intricately connected with the creative, expressive and perceptive facets of the person, and the manner in which the person creates, discovers and perceives meaning in the actions and words of a shared relation with another. The results of a phenomenological inquiry  
(Van der Zalm & Bergum, 2000, p.216)

Through this 'fusing of horizons' there is an acknowledgement that historicity and the "effective consciousness" (Gadamer, 2000, p.28) merge together to enable the lived experiences of beings to be actualised. That is, sense can be made of, in this case, the participants' accounts of their lived experiences, through an analysis of the language and the way they are told. As the process involved in the fusing of horizons is a circular

one, Gadamer used the term attributed to Schleiermacher (1768-1834), the *hermeneutic circle*, to represent the generation of understanding (Rapport, 2005).

A guiding principle attributed to the hermeneutic circle is that analysis “proceeds from a naïve understanding to an explicit understanding that emerges from explanation of data interpretation” (Carpenter, 2007, p.89). Understanding is achieved through an examination of the whole, in relation to the part. Thus, “to understand any given part, you look to the whole; to understand the whole, you look to the part” (Smith et al., 2009, p.28). It is a process with no beginning or end, top or bottom, thus understanding becomes revealed through the circular movement with the text in “a continuum” (Rapport, 2005, p.130). This movement between the whole and parts of the whole of the text was a central feature of the analytical processes employed in the study; a process that had similarities with the method I chose for data analysis; the voice-centered relational method.

### **Interpretive versus descriptive phenomenology**

In my decision to use an interpretive phenomenology as opposed to descriptive phenomenology I was guided by the fact that I had used a literature review during its development, whereas descriptive phenomenologists are not guided, in the first instance, by a review of the literature or by a set of subject specific questions. The onus of descriptive phenomenological studies is to provide a description of the lived experience of participants that is not influenced by prior understanding (Speziale & Carpenter, 2007). Conversely, interpretive studies advocate the use of a literature review and subject specific questions. The literature review can highlight omissions, which can provide indicators as to gaps in existing knowledge; acknowledging these gaps can lead to the emergence of new studies (Lopez & Willis, 2004).

Further distinctions between the two philosophical approaches are discussed by Rapport (2005, p.130). According to her, interpretivist phenomenologists assert that:

- Meaning is unique and cannot be described;
- Interpretation is vital if we are to move beyond the data.

In contrast, descriptive (Husserlian) phenomenologists assert that:

- Unified meaning cannot be teased out and described precisely as it presents itself (Giorgi, 1992, p.123);

- Description is vital to account for variety in phenomena.

Consequently, descriptivists such as Giorgi (1992) have criticised the interpretivist tradition on the premise that developing multiple interpretations of meaning is not an objective scientific approach; therefore multiple interpretations of phenomena will produce uncertainty in the findings. For descriptivists the quest is to find a commonality of experiences so that the generalisation of a given phenomenon is possible (Giorgi, 1992; Lopez & Willis, 2004). Interpretivists, however, argue that as each person's experience is unique, such experiences cannot be generalised, or be used to reveal commonalities in the data (Paley, 1997). In making these distinctions between the two philosophical approaches, however, there is an acknowledgment that some phenomenologists advocate the complementarity of the two approaches (Todres & Wheeler, 2001), a complementarity which other phenomenologists (e.g. Van der Zalm & Bergum, 2000) believe exists within hermeneutic explications of meaning.

In reaching this conclusion Van der Zalm & Bergum (2000) state that hermeneutic phenomenology possesses both descriptive and interpretive elements and go on to cite the works of both Husserl (1962) and Heidegger (1965) in support. Though hermeneutics goes beyond a process of mere description in elucidating the lived experience, it looks for meanings that are embedded in common life practices, rather than providing a description of core concepts and essences (Lopez & Willis, 2004). Hermeneutics, therefore, represents an approach that provides a way of approaching the study of a phenomenon rather than a set of guidelines for undertaking research. Thus, it is a guide to the practical application of methods rather than a methodological approach governed by a set of rules.

### **A hermeneutic methodology**

It has been suggested that the generation of knowledge that is *verstehen* (understanding) cannot be appropriated through empirical-analytical sciences (Van Manen, 1997 cited in Van der Zalm & Bergum, 2000). Rather it is achieved through the sharing of common meanings that are bound by mutual history, language and culture, as evidenced in the approach advocated by Gadamer (1975; 1996). Used as a method of analysis, researchers who adopt the interpretive phenomenological approach seek clarification and validation of their findings from external sources (e.g. their supervision team). This is in stark contrast to the approach adopted by descriptive phenomenologists whereby validation is undertaken entirely by the researcher (Rapport, 2005). In the study, the benefit of employing the interpretive approach meant

that I could validate my own interpretations of the data with external sources. In my use of the hermeneutical method, I took into account the methodological steps Van Manen (1990) advocates when conducting hermeneutic research (see Table 3.1).

**Table 3.1** Methodological structure of hermeneutic research

- |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ol style="list-style-type: none"><li>1) Turning to a phenomenon which seriously interests us and commits us to the world;</li><li>2) Investigating experience as we live it rather than as we conceptualise it;</li><li>3) Reflecting on the essential themes which characterise the phenomenon;</li><li>4) Describing the phenomenon through the act of writing and rewriting;</li><li>5) Maintaining a strong and oriented [pedagogical] relation to the phenomenon;</li><li>6) Balancing the research context by considering parts and whole.</li></ol> <p style="text-align: right;">(Adapted from Van Manen, 1990, pp: 30 – 31)</p> |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

In his discussions regarding the impetus of phenomenological research Van Manen (1990, p.36) states that “lived experience is the starting point and end point of phenomenological research”. This emphasis upon ‘lived experience’ embodies the idea that research that adopts a phenomenological orientation is not undertaken in a disembodied fashion. Rather, it is a process that is:

Always a project of someone; a real person, who in the context of particular individual, social, and historical life circumstances, sets out to make sense of a certain aspect of human existence.  
(Van Manen, 1990, p.31)

Thus, when turning to a phenomenon, our commitment to the people involved in it should enable their world as it is lived to become apparent through our interest in the project. To do this it is essential that lived experience is central to the research aims and that these lived experiences are explored in all their aspects and modalities (Van Manen, 1990).

Subsequently, reflection upon the essential themes inherent within a project is necessary. Thus, it is a process that Van Manen suggests brings into “nearness that which tends to be obscure, that which tends to evade the intelligibility of our natural attitude of everyday life” (Van Manen, 1990, p.32). Consequently we should be reflectively asking about the constitution of the lived experience as it is recounted, in order to make sense of the experience that has been elucidated. In this way, writing and rewriting enables meaning to be derived about the experience. Language and conversation are used as the media through which understanding becomes apparent



(Van Manen, 1990). This is aided by maintaining a strong and orientated [pedagogical] relation to the phenomena in question.

In the study, I chose to substitute the term 'pedagogical' with the term 'psychosocial'. This was influenced by Langdrige's (2007) proposal to bracket off the term 'pedagogical', as this is predominantly used in education, and to adopt terms more relevant to specific investigation. Thus, I adopted a strong and oriented psychosocial relation to this investigation. In my substitution of the word 'pedagogical' I took into account the nature of the lived experiences I examined. In the context of the aims of the study, the emphasis I placed upon the examination of the decision-making process and the place of informed consent within the context of becoming an egg share donor. These aspects represented experiences that were both psychologically and socially orientated. Thus, conceptually, the study has explored the psychosocial impact of egg sharing on donors' lives. Van Manen (1990) advocates that this step is necessary to avoid becoming side-tracked, losing focus, becoming disinterested, wandering aimlessly, or settling for concepts and ideas that are preconceived. He states that:

To become orientated to an object means that we are animated by the object in a full and human sense. To be strong in our orientation means that we will not settle for superficialities and falsities.  
(Van Manen, 1990, p.33)

The final element of the methodological themes discussed above is the consideration of the whole and the part, through an examination of the study's design, and the text upon which the study is based. One is advised to stand back and examine the entirety of a project in order to ascertain where parts are the most relevant for inclusion. Maintaining this distance enables an assessment of the grounding of the study and an analysis of the forms of knowledge that have emerged both conceptually and theoretically (Van Manen, 1990). However, in his analysis of these methodological themes, Van Manen makes it explicit that they do not form a set of specific procedures that should be followed systematically in the research process. Instead, he urges the researcher not to feel compelled to execute each step in order, or to feel the need to complete each step before progressing, but rather to move intermittently, or simultaneously, through the various elements he proposes. He suggests that the provision of these elements can help a researcher to understand the research, but essentially:

The critical moments of inquiry are ultimately elusive to systematic explication. Such moments may depend more on the interpretive sensitivity, inventive thoughtfulness, scholarly tact, and writing talent of the human science researcher. (Van Manen, 1990, p.34)

As such the onus of the research process is upon the researcher and their interpretations of their work.

Whilst keeping in mind the overall framework of the elements proposed I paid particular attention to the concept of 'lived experiences', a central feature of the study. In doing so, I took into account my role as a researcher and the role of my own 'lived experiences' in relation to the stories recounted by participants. This process involved periods of self-reflection, reflections that occurred throughout the study (see pages 17 and 253-256).

#### **Data collection using hermeneutic phenomenology**

Within hermeneutic phenomenology language is the means by which knowledge and understanding are generated. Using hermeneutic interviews in the study the emphasis was upon developing trust in the relationship between the interviewer and the interviewee. Trust facilitates the process whereby participants translate what they know into what they tell, a process that encourages a 'conversational relationship' to develop (Van Manen, 1990). It also requires that the researcher gives of themselves whilst gaining an insight into the perspectives of participants, a process that acknowledges our own 'being-in-the-world', thus enabling multiple perspectives to be derived from the interview process.

The study employed two methods of data collection. These were semi-structured e-mail interviews, and an online self-completion survey. The use of semi-structured interviews in the study allowed participants the opportunity to recount their stories as they had been lived. It also provided me with an opportunity to locate myself more closely with the data collection process through the two-way flow of conversational communication as I explored the experiences of egg share donors. This two-way flow of communication was missing in the survey data; however, respondents were given the opportunity to provide qualitative comments about their experiences (see pages 160 and 161-163).

The rationale and justification for the inclusion of two different methods and phases of data collection are discussed in Chapters Four and Five. These include a discussion regarding the reasons why I made revisions to my original philosophical framework and data collection methods.

### **Data analysis using hermeneutic phenomenology**

During the analytical stage of the study I returned to the work of Gadamer (1975, 1996) and his ideas about language as the basis of understanding (Chadderton, 2005). This was aided by the knowledge that the analytical process is a “dynamic relationship between the part and the whole, at a series of levels” (Smith et al., 2009, p.28). This enables us to “penetrate the layers of meaning” (Van Manen, 1990, p.119) from within the text in order to develop understanding through interpretation. The researcher is central to the process as emergent understanding of the themes is reliant upon the application of the ‘hermeneutic conversation’. This is the conversation that takes place between the researcher and the text during the act of interpretation. This method enables meaning and therefore understanding to be revealed from the underlying words in the text, a method that can be enhanced through collaborative analysis, either formally or informally (Rapport, 2003; 2005).

Analysis also reverted back to the concept of the ‘fusing of horizons’, encompassing both the reader and the text, in that the intentions and motivations of the author of the text become unimportant as the hermeneutic interpretation of the text seeks to objectify meaning from within the text (Langdrige & Butt, 2004). Hence, the process of reading and interpreting the text acknowledges the effect of the researcher’s horizons or prejudices on the process – which are shaped by reflection (Gadamer, 1976). Thus, researchers’ experiences cannot be eliminated from the analytical process as they shape the analysis and the findings reported. This view is discussed by Clough & Nutbrown, who state that:

Our *identity* – as man, woman, academic, mother, father – is (to a greater or lesser extent) a driving force in our research foci. *What* we do and *how* we do it is informed by who we are, how we think, our morals, our politics, our sexuality, our faith, our lifestyle, our childhood, our ‘race’, our values. In other words, we are (as researchers) our own blueprints for our research methodology.  
(Clough & Nutbrown, 2007, p.82, emphasis original)

The researcher must therefore acknowledge their presence during analysis to evaluate the impact that their history and culture has had on the process. Finally, the steps incorporated within the aforementioned approach are reliant upon the interaction with data on multiple occasions and at multiple levels. This feature of the analytical process is in keeping with the methods of analysis advocated in the voice-centered relational method (VCRM) of analysis (Gilligan, 1982; Brown and Gilligan, 1992; Mauthner & Doucet, 1998; 2003; Gilligan et al., 2003), a method of analysis that I introduce below.

### **Introducing the voice-centered relational method (VCRM) in the e-interviews**

I chose to use an adapted version of the VCRM for data analysis. The method was developed in response to a growing concern and dissatisfaction amongst some researchers about the single coding of data, a technique that did not allow multiple coding of the same text to be undertaken (Gilligan et al., 2003). Hence it has been used in a number of predominantly feminist studies (Gilligan, 1982; Brown and Gilligan, 1992; Mauthner & Doucet, 1998; 2003; Gilligan et al., 2003), as a method of interview narrative analysis.

As a method it acknowledges that human beings are embedded in complex webs of intimate and larger social relations (Gilligan, 1982), in stark contrast to the perception of 'individuals' as independent, self-sufficient, separate entities in society, a theme linked predominantly to liberal political thought and Western philosophical traditions (Mauthner & Doucet, 1998). In opposition, the adoption of a 'relational' ontology allows the generation of a different way of understanding human nature and human interaction - not in isolation from, but in relation to – wider social, cultural and structural constructs (Mauthner & Doucet, 1998). This ontological position views people as "interdependent rather than independent" (Tronto, 1995, p.142).

The VCRM approach advocates four listenings (readings) of the text to be undertaken during analysis. Each listening serves a distinct purpose as the researcher elucidates meaning from within the text. However, although a reading of the transcripts is taking place, this method asks that the researcher listens to the text as opposed to simply reading the text - a process that is:

Designed to bring the researcher into relationship with a person's distinct and multilayered voice by tuning in or listening to distinct aspects of a person's expression of his or her experience within a particular relational context.  
(Gilligan et al., 2003, p.159)

The authors state that each of these listenings should “guide the listener into tuning into the story being told on multiple levels and to experience, note, and draw from his or her resonances to the narrative” (Gilligan et al., 2003, p.159). I briefly introduce the role of each of the four listenings below to demonstrate how multiple readings have the potential to generate deep, rich meanings to be extrapolated from the data.

The first *listening to* the text is usually accompanied by a listening to the recorded interview. However, in the absence of the traditional tape-recorded interview this element of the analytical process was omitted. This did not affect my analysis of the data as I developed a method of overcoming this absence of a verbal account (see pages 98-100). This enabled me to minimise what might potentially have been the negative effect that the absence of a recording may have had on the analysis.

Whilst undertaking this first listening the researcher locates him or herself within the interview process and notes their reactions to what is being heard. In the study I used this first listening to aid the development of case studies that chart the stories of participants. The second *listening* involves actively listening for the use of ‘I’ (‘we’, or ‘you’), a listening for the ‘self’ within the context of the story being told (Brown & Gilligan, 1992). In the study, in conjunction with this second listening, I undertook the formation of ‘I’ poems (see pages 177-183), poems that are designed to allow the rhythms and distinctive cadences of the voice to be heard (Gilligan et al., 2003).

The third *listening* incorporates listening for the relationships (Mauthner & Doucet, 1998) whereby participants are located within the context of their wider interpersonal relationships (Brown & Gilligan, 1992; Gilligan et al., 2003). The fourth *listening* involves locating participants’ accounts in relation to wider social, political and societal structures (Brown & Gilligan; 1992; Mauthner & Doucet, 1998; Gilligan et al., 2003). The final stage involves the thematic breaking down of the data, a process that enables the various themes and sub-themes that arise from the data to be organised and structured prior to the writing up of the findings.

### **On sensitivity, reflexivity and emotion work**

At the outset of the study I realised that I was exploring a sensitive topic. Therefore, the well-being of participants was of paramount importance throughout the study. Consequently, the study was conducted in a way that elicited information in a delicate, sensitive manner (Herzberger, 1993). This was aided by my ability to adopt a reflexive approach within the research.

Being reflexive places a requirement upon the researcher to locate themselves within the context of their research and to acknowledge that:

No research is completely free of bias. It is recognised that the closer our subject matter is to our own life the more we can expect our own worldview to enter into and shape our work. (Shah, 2006, p. 211)

Nevertheless, in order to be reflexive, there is a need to critically examine and evaluate that which “occurs between the self and the social world” (Christodoulou, 2006, p.129). Furthermore, “we need to be aware of our personal responses and be able to make choices about how to use them” (Etherington, 2004, p.19). By doing so we become aware of the ways in which our interpretations are shaped in relation to our position and our understanding of the world (Christodoulou, 2006). These interpretations need to be explicated in relation to the research process and the analysis. These bring to the fore the role that the researcher’s own biography may have had on the research.

Reflexivity is an inherent feature of the VCRM of data analysis (Brown & Gilligan, 1992). The process of multiple readings of the e-interview data meant that at each stage of the process I was reflecting. This process enabled me to examine how my own experiences influenced and shaped the way in which I interpreted that which was said (Mauthner & Doucet, 2003). The reader-response element of the method requires the researcher to read for him or herself in relation to participant’s responses (Brown & Gilligan, 1992; Mauthner & Doucet, 1998; Gilligan et al., 2003; Martin, 2008). I identified how my responses to participants were shaped at both an emotional and intellectual level (Brown, 1994). Thus, I acknowledge the role that my emotions had in the study.

In the account provided by Hochschild (1979, p.561) she states that “emotion work refers more broadly to the act of evoking or shaping, as well as suppressing feeling in oneself”. Therefore, the ability to manage emotions when undertaking sensitive research was an important aspect of the study, although, the role of emotions and emotion work in qualitative research has been lacking in much of the literature (Dickson-Swift et al., 2008). When the role of emotion work is mentioned, it is usually in conjunction with ethical issues and the well-being of participants (Malacrida, 2007), an issue that dominated the development of my own ethical protocols (see Chapters Four and Six). However, little reference is made to the emotional well-being of researchers. Stoler states that:

Emotional reactions and personal needs do not just vanish because one has declared oneself a researcher. Ignoring them is unrealistic and deprives us of the opportunity to examine them rationally and take steps to reduce their bias in our work and their impact on our lives and emotional wellbeing. (Stoler, 2002, p.270)

Thus, by acknowledging the impact that emotions may bring to the research act, one is able to counteract, (to some extent), their impact on the research.

Emotion work and the situatedness of the researcher are aspects of qualitative research far removed from positivist methodologies (Stanley & Wise, 1983; Mantzoukas, 2007; Dickson-Swift et al., 2008). In positivist epistemologies the onus is on measuring and verification, thus evidence of emotion in the research endeavour may indicate a source of bias (Dickson-Swift et al., 2008). Conversely, the interpretive tradition, the basis of the study, accepts the subjective nature of the research act, and the role of the researcher in the research. This shift can be attributed, in part, to feminist methodologies that argue for the role of the researcher's emotions within the research process to be made explicit (Stanley & Wise, 1983). This was an important aspect of the study, as I located myself within the context of the stories being told; I also explored my own personal (emotional) responses, my personal biography and my emotional well-being throughout the research process (see Chapters Four, Five and Nine).

### **Chapter review**

In this chapter I have described how I grounded the study within the context of its main aims; the exploration of the 'lived experiences' of egg share donors. The use of hermeneutic (interpretive) phenomenology as a philosophical approach to the study has been introduced. In doing so, I discussed the role of my ontological and epistemological positions and the influence that they had on the development of this research. I provided an overview of the works of Husserl, Heidegger and Gadamer and the way that they contributed to the development of hermeneutic phenomenology. I then introduced the framework proposed by Van Manen and discussed how elements of his framework have been relevant to the study. In doing so I discussed how I used hermeneutic phenomenology in data collection and analysis and how this linked with the voice-centered relational method of analysis. Finally, I briefly examined the undertaking of sensitive research, the adoption of a reflexive approach to research, and the place of emotions within qualitative research.

In Chapter Four I demonstrate how I translated this methodology into method. I provide a discussion of the methods that were developed as I prepared to undertake data collection and analysis in the study, as it was originally planned. I then explain the unforeseen circumstances that occurred during the study's development that subsequently led to a thorough revision of the data collection methods (see pages 81-86). I also explain the need to revisit my philosophical framework and to make amendments to it in order to ensure a consistent approach to the research.



## CHAPTER FOUR

### Methods – the original study

*A well carried through qualitative interview may be a rare and enriching experience for the interviewee. It is probably a very common experience from everyday life that another person in an hour or more is only interested in, sensitive towards, and seeks to understand as well as possible one's experiences of a subject matter.*

(Kvale, 1983, pp: 178-179)

In this chapter I begin by explaining why I considered the examination of the 'lived experiences' of egg share donors to be a sensitive topic of investigation (an issue I alluded to briefly in the previous chapter). In providing this explanation I then demonstrate how this impacted on the development of the methods that I initially intended to use. Briefly I refer to the process of obtaining ethical approval for the study prior to making contact with potential collaborators.

This is followed by an in depth account of the research design where I make visible the various decisions that I made during the design of the study. In doing so I refer back to the key philosophical principles of hermeneutic phenomenology, and how these informed and influenced the overall design of the research. I describe the rationale behind my decision to conduct semi-structured interviews and how I prepared the interview schedule. I then introduce my entry into the field as I sought collaborators who would allow me to recruit participants for the study. I describe the process and impact of trying to seek collaborators and the role that gatekeepers can have on the research endeavour. Finally, I include a discussion as to why, despite the rigorous design of the study, this intended approach did not work, and subsequently had to be abandoned.

#### **Researching a sensitive topic**

At the outset of the study, when I first submitted my PhD proposal, I realised that I would be embarking on what I believed to be a sensitive area in which to conduct research. This awareness made me review my own suitability as a Doctoral student researching infertility, as I had no personal experience of the topic area. This made me re-evaluate my position as a researcher, a woman and a mother; issues I merely allude to at the moment but will revisit later in the thesis (see pages 17-18 and 73). During

these considerations I looked at the work of Lee & Renzetti and what they defined as a sensitive topic. In their discussion they suggest that:

A sensitive topic is one that potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and/or the researched the collection, holding, and/or dissemination of research data.

(Lee & Renzetti, 1993, p.5)

In this instance, the notion of substantial threat is made with regard to the potential harm that can befall the researcher and the researched. This was an issue that featured extensively in the development of the study, once I had been granted my PhD studentship.

As discussed in the previous chapter the well-being of the participants played a paramount role in the study's design due to its potentially sensitive nature. Thus, as I developed the ethical protocols that underpinned the study I ensured that I minimised any risks to those involved. Additionally, sensitivity was required not only in the development of the study, but also in the collection, analysis and reporting of its emergent findings (see Chapters Eight, Nine and Ten).

### **Approaching the study sensitively**

In their discussion of conducting sensitive research Sieber & Stanley state that:

*Socially sensitive* research refers to the studies in which there are potential social consequences or implications for the participants in the research or for the class of individuals represented by the research.

(Sieber & Stanley, 1988, p.49, emphasis original)

In providing this definition they surmise that when the nature of a research area is particularly 'socially sensitive' it poses complex ethical issues that need to be taken into account at every stage during the development of a study. In a later paper Sieber suggests that:

The ethics of social research is about creating a mutually respectful, win-win relationship in which participants are pleased to respond candidly, valid results are obtained, and the community considers the conclusions constructive... it requires investigation into the perspectives and cultures of the participants... early in the process of research design, so that their needs and interests can be understood and appropriately served.  
(Sieber, 1998, p.128)

Sieber notes that, unless this occurs, the likelihood is that the researcher will leave the field (the research setting) “in pandemonium” and that the “ensuing turmoil may harm all of the individuals and institutions involved” (Sieber, 1998, p.128). Thus, to ensure that the well-being of all those involved in the research endeavour are treated sensitively, a study must be managed appropriately at all stages of its development. These views played a central role in my study as they served as a guide to its development.

Initially, issues related to data collection and the ethical protocols underpinning the study were the primary focus, as I concentrated on developing a study that would protect the well-being of participants. These foci broadened when I began also to consider more closely my own role in the research, what I was intending to do and its possible emotive impacts.

I believed that it was potentially emotive for me because, from personal experience, when I have heard something about the health of someone else it has tended to evoke a range of feelings, dependent upon the person and the nature of the problem. More specifically, if the health problems are being experienced by another woman, and they are ones that only a woman may experience then the intensity of empathic response has been greater. As a woman, I would argue that it is easier than for a man to begin to comprehend what it might be like for that particular woman, at that particular moment in time, upon hearing their diagnosis. I would argue that the experience of infertility is no different in this respect, especially if it is female factor infertility, something that is more closely aligned to the human psyche of a woman as our reproductive capacities are an integral feature of our existence, particularly since society places an emphasis upon reproduction. Subsequently, Doyal (1995, p.95) suggests that “in most cultures women experience powerful pressures to ‘prove’ their ‘femaleness’ by becoming a mother”. Consequently, when the natural life course (conception and reproduction) are disrupted *per se* I would suggest that this has the capacity to become an emotive subject.

In the study, I knew I would have to be particularly conscientious in my explorations of infertility, infertility diagnosis, and the impact of a diagnosis on the trajectory of deciding to become an egg share donor. I believed that, as a woman who had not had to deal with this type of life event, I would have to adopt a careful and cautious approach for my own sake as well as that of the participants as I undertook the interviews. Thus, by acknowledging the extent to which the study reflected the aforementioned definitions of what constitutes sensitive research, I was able to ensure that whilst I considered, first and foremost, the well-being of participants, I also took into account my own well-being. Thus, I ensured that relevant external support was in place should this be required during the duration of the study (see page 122).

### **The original study**

When I embarked on the study I had intended to conduct a prospective qualitatively-orientated study. The plan was to recruit approximately 20 women, who had participated in an egg sharing programme, and who would be willing to be interviewed face-to-face. I had decided that semi-structured interviews were the most appropriate method of data collection in keeping with the philosophical approach of hermeneutic phenomenology, using the interviews as a method of eliciting the 'lived experiences' of participants. Recruitment was to take place via at least one UK assisted conception unit that offered egg sharing.

At the beginning of the study two private assisted conception units (i.e. operating outside the NHS) had indicated their interest in assisting with the recruitment of participants the study. This, however, proved to be an unproductive endeavour, an issue discussed later in this chapter (see pages 81-84). Unaware that this method of recruitment might not work, I proceeded to develop what was intended to be the study proper.

The study was designed to be prospective in that participants would be recruited into the research once they had shared their eggs with up to two unknown recipient(s) and all would be awaiting the results of pregnancy tests. It was crucial to the prospective element of the study that donors would not yet have had the opportunity to find out the outcome of either their own or their recipient(s)' treatment, since otherwise, this could have biased their view of egg sharing (if, for example, they had been unsuccessful whilst their recipient had been successful).

I envisaged that the principal method of enquiry would involve adopting a relational ontological position (see for example, Gilligan, 1982; Brown & Gilligan, 1992; Mauthner & Doucet, 1998; 2003; Gilligan et al., 2003; Martin, 2008) for the reasons previously set out in Chapter Three.

This meant that the emphasis of the interviews would be on providing women with the opportunity to convey their experiences of egg sharing, and what this had meant for them and their families, both currently and in relation to anticipated futures. It was also designed to investigate whether they had shared their decision to become an egg share donor with any other family members or friends, and the effects, if any, that their decision had had on other family members or friends.

### **Gaining ethical approval**

Ethical approval for the study was sought from the University of Huddersfield's School of Human and Health Sciences Research Ethics Panel. In the application I stipulated that the study would comply with the codes of practice for ethical research set out by the British Sociological Association (BSA, 2002), the Economic and Social Research Council (ESRC, 2005), and the British Psychological Association (BPS, 2006). In addition, one of the assisted conception units indicated that approval from its internal ethics committee would be required. A full discussion of the ethics process is provided in Chapter Six.

### **Developing the original study**

The first phase of the study involved developing an interview schedule and attempting to recruit participants who would be willing to be interviewed face-to-face. An interview is a methodological approach that involves a dialogue taking place between people as part of the research process. It is a dialogue with a distinct purpose, the generation of data for analysis which is gathered in an attempt to answer the research question(s) (Robson, 2002). An integral part of the interview process, in some cases, is usually the development of an interview schedule, the development of which I discuss in the following section.

### **Semi-structured interviews**

For the purpose of the study I intended to conduct a single semi-structured interview with each participant that would last for approximately one hour, which, I estimated, should be sufficient to elicit the rich, in-depth data required for analysis. However, I also planned that the length of interview was to be guided by the participants themselves

and how much information they wished to share. In making this decision I acknowledged that interview duration might also be influenced by participants' psychological well-being at the time of being interviewed. Here the realisation was that awaiting the outcome of a pregnancy test, following a cycle of egg sharing, was likely to be stressful and that these emotions had the potential to impact on the interview process. Therefore, the timing of the interviews was designed to be sufficiently flexible to prioritise the health and emotional well-being of participants.

My decision to use semi-structured interviewing was based on the premise that it is an approach that allows flexibility (Burman, 1994). This element of flexibility ensures that the interview process is not too rigidly defined, thus providing the opportunity to accommodate individual differences in the depth of information they wished to provide. It also enables questions to be adapted based on participants' response(s) (Robson, 1993; Burman, 1994). Thus, it is a process of guiding the interview rather than trying to enforce a standardised, 'one size fits all', approach to the interviews. The use of interviews was also consistent with the philosophical approach that underpinned the study – that of hermeneutic phenomenology.

For hermeneutic phenomenologists, humans are self-determining and, as such, the approach emphasises the need to develop an understanding of the experiences of participants through "ordinary language" (Rapport, 2005, p.136). Thus, as self-determining individuals, the onus is on a move towards the appropriation of meaning and understanding that enables new meanings of 'lived experiences' to be elicited (Rapport, 2005). The emphasis is upon uncovering the reality of experience, as it is experienced by those taking part in the research. This can be achieved through the orchestration of a well developed interview that enables the capture of the very nature of the reality that is being sought. I now explain how I undertook the design of the interview schedule that I intended to use in the original study.

### **Designing the interview schedule**

In choosing to conduct semi-structured interviews I realised that as I intended to interview women at a single point in time - midway through their treatment - that this may affect the interview process. As commented upon previously, I had an awareness that, undertaking egg sharing may be stressful for participants. Thus, I endeavoured to ensure that I was prepared for the showing of emotion. Consequently, I knew that I needed to ensure that the questions I asked were structured sensitively, in a way that would not cause any unnecessary (emotional or psychological) harm to the

participants. As indicated, I had already decided that a fully structured interview schedule was an inappropriate method of data collection as it would have been insufficiently flexible to allow participants' own stories to emerge from the process. Due to the potentially emotive nature of the study, a semi-structured approach would also offer women the opportunity to express themselves more freely, providing them with a greater opportunity to tell their stories.

The potential benefit associated with the use of open-ended questions is that they provide sufficient scope to elicit further information through the use of prompts. Cohen and Manion discuss the advantages of open-ended questions and suggest they are advantageous because:

They are flexible; they allow the interviewer to probe so that she may go into more depth if she chooses, or to clear up any misunderstandings; they enable the interviewer to test the limits of the respondent's knowledge; they encourage co-operation and help establish rapport; and they allow the interviewer to make a truer assessment of what the respondent really believes. Open-ended situations can result in unexpected or unanticipated answers which may suggest hitherto unthought-of relationships or hypotheses.

(Cohen and Manion, 1994, p.277)

Moreover, as I sought to capture a narrative account of experience, I believed that the use of open-ended questions would best meet the overall the aims of the study. Therefore, whilst designing the interview schedule, I kept this notion at the forefront of my mind whilst formulating my questions. I also took into account the twelve aspects associated with the use of an interview to collect qualitative data as proposed by Kvale. He states that these aspects are:

1) centered on the interviewee's life-world; 2) seeks to understand the meaning of phenomena in his life-world; it is 3) qualitative, 4) descriptive, and 5) specific; it is 6) presuppositionless; it is 7) focused on certain themes; it is open for 8) ambiguities, and 9) changes; it depends upon the 10) sensitivity of the interviewer; it takes place in 11) an interpersonal interaction, and it may be 12) a positive experience.

(Kvale, 1983, p.174)

This view of the qualitative interview was in keeping with the hermeneutic phenomenological principles that underpinned the study, in particular the focus upon

eliciting the 'lived experiences' of the participants. In his discussion of each stage of the process, Kvale refers to the way the researcher has to work with the data being generated. A researcher should be able to read between the lines and look for meaning in what has been said. They should be able to judge how a participant is dealing with the process using signals that may be communicated non-verbally (Kvale, 1983). This was an important part of the process that became more relevant in the revised study (see pages 98-100).

The data collected are descriptive in that participants are describing their direct experiences, descriptions that should be detailed enough to yield answers to the research questions in a rich and informative way. The researcher should enter the process with no pre-conceived ideas as to the answers to the questions they are posing; instead, they should be open to discovering new and previously unexpected outcomes. However, researchers need to be aware of their own ideas about the possible outcomes of their research and the impact this may have on the data collection process. Subsequently, it is necessary to ensure that the focus of the study is not affected by the researcher's own ideas as this may affect the data collected, although, participants are guided towards generating answers that meet the research questions and the themes being explored. This enables their own accounts of their experiences to become evident without the researcher exerting any influence on the participants to respond in certain ways (Kvale, 1983).

The potential ambiguities that can arise when using interviews, such as unclear answers, can be managed through a process of clarification. This is where the advantage of a semi-structured approach becomes evident. The flexibility of the approach is particularly advantageous to clarification because prompts (supplementary) questions can be used to aid understanding. I therefore ensured that I developed a set of prompts (see Appendix Three, page 302) that were to be used in the interview process as necessary when listening to the accounts given by participants. I deemed this necessary as the ability to understand the responses to the questions was fundamental to making sense of participants' experiences. This was a stage in the development of the interview schedule that I felt was most conducive to meeting my overall aims. This was assisted further by a consideration of the notions of change, sensitivity, interpersonal interaction and the positive experience (Kvale, 1983).

Kvale suggests that change within the process stems from the notion that as participants open up and discuss their experiences they may develop a new awareness



of these experiences. This may become apparent as experience becomes revealed within the context of the interview (Kvale, 1983); particularly since the interview process is reliant upon participants revisiting their past experiences in order to generate answers to the researcher's questions. Thus, by revisiting their past experiences, this may invoke a deeper understanding of them, which they may have previously blocked from their minds. This, I would suggest, serves to reinforce the notion that researchers need to be not only reflexive in their approach to data collection, but need to ensure the safety of self and the participants during the interview process. Therefore, it was crucial that I was aware that this type of change might happen, and that this change might evoke revelation of emotionally charged and deep-rooted feelings, incidents that may have put both myself and the participants at risk or in a vulnerable condition.

For me, this change took place during the early stages of the study, when I began to focus upon the giving of informed consent, and the framing of the decision-making process. As participants shared their own experiences, it was evident, in some cases that their perceptions of decision-making changed following treatment. That is, doubts regarding decision-making became evident; a theme that demonstrated that one's perceptions about decision-making may alter over time. Subsequently, at this stage I accepted that change might occur, for both me and the participants, and that this change could signify the need for additional support. It was due to this issue that support mechanisms had been considered in my ethics application. It was possible, however, within the context of the interview schedule, to minimise any potential risks associated with this type of change. I therefore thought carefully about the framing of my questions, how I would ask them, and what answers to them might reveal. I was acutely conscious that my questions might evoke thoughts or feelings that had previously not been experienced or explored. By doing so, I was able to incorporate a sensitive approach to the overall design of the interview schedule.

Sensitivity is an aspect of the interview process that is linked to the researcher and their knowledge of their subject (Kvale, 1983). Kvale suggests that the researcher needs to bring to the investigation their knowledge of the area being investigated. This view indicates that it is necessary to have some insight (fore knowledge) of the nature of the topic under investigation, but that it should not cloud the overall aims of the study and the data collection process. These views were particularly relevant to the development of the interview schedule as I used prior knowledge of the area of investigation to inform its development. However, the use of open-ended questions ensured that I did not incorporate questions that may have led the participants to

answer in a certain way. This was relevant when I considered aspects related to the interview as an interactional experience i.e. a two-way process of information sharing that is led, in part, and influenced by the researcher (Kvale, 1983).

The final aspect Kvale cites is the notion of the interview as a 'positive experience'. This prompted me to adopt an approach whereby I took into account the fact that "the interview-situation may for both parties be characterised by positive feelings of common intellectual curiosity and reciprocal respect" (Kvale, 1983, p.178). This view reverberated in my mind as I prepared the interview schedule and as I returned to and revisited the main aims of the study. I focused upon the sensitive nature of the investigation, the emotive nature of the questions that I needed to ask, and how these questions might affect the participants. I realised that I wanted to ensure that engagement in the interview process would be a positive experience for those who had agreed to take part. Therefore, though the aim of the schedule was to gather sufficient in-depth, rich data for analysis, I was also mindful that I wanted to promote a somewhat positive experience for participants. This meant that I spent a considerable amount of time refining the questions until I felt that they were right. Thus, I attempted to ensure that I had framed my questions sensitively, as I endeavoured to take the well-being of participants into account. I also felt that the development of rapport and trust within the process would be conducive to the development of a positive experience. This was a feature of the development of the study that became evident in the revised study.

Whilst undertaking the final preparation of the schedule I was guided by a consciousness of the potential impact of the research on my own emotional well-being (as discussed previously); however, I had not anticipated the full extent of the range of emotions that I might experience whilst conducting the interviews. I was rather naïve at this stage of the process, so, although I believed that I had taken into account all possible outcomes, the reality was somewhat different. This is an issue that I merely allude to for the purposes of this chapter; however I return to it and explain its effects in greater detail in Chapter Six (page 122).

Finally, although I had spent a lot of time developing the interview schedule, it was never used, although it was amended (see pages 95-96 and 104-105). This happened because of the problems experienced when trying to gain access to participants. These issues are discussed in detail in the following section of this chapter.

### **Gaining access to participants**

As mentioned previously in this chapter, when I embarked on the study I had intended to recruit a purposive sample from at least one assisted conception unit in the UK. Though this strategy was, in theory, in place I knew that recruiting participants would not necessarily be straightforward, potentially because of the emotive, sensitive nature of the study, and the intended timeline within which I wanted to undertake the interviews (once egg sharing had taken place, but before pregnancy test results confirmed or disconfirmed a pregnancy). So although I had these thoughts at the back of my mind I had not considered them to be actualities, since two assisted conception clinics, each with significant egg sharing programmes, had previously indicated their willingness to support the study by facilitating participant recruitment. At this stage my Director of Studies made initial contact with the two clinics regarding their willingness to support the study. This was due to his extensive knowledge of the field being studied, but also he knew, in a professional capacity, the main contacts at both of the clinics.

Following initial expressions of interest there was an almost categorical assurance that at least one of these clinics would allow the recruitment of participants for the study from their patient base. This meant, or so I thought, that the study was definitely viable in terms of gaining access to women who may be interested in taking part. As I had already been granted the relevant university ethical approval I used the supporting documentation that I had prepared and collated it, ready for a meeting that had been organised with the staff who were acting as the principal 'gatekeepers', for their unit. A distinction is made here between the managerial team of the clinic, and the people with whom the meeting took place, the clinic counsellor, and the egg share co-ordinator.

The meeting that was arranged with the aforementioned staff at a unit in the South of England following prior written communication with the clinic's medical director went exceptionally well and once one or two issues had been clarified regarding the focus of the study, it was almost certain that the clinic would be the base from which I could attempt to recruit participants. I left a comprehensive information pack with the clinic staff which contained: a copy of the proposed research project, a patient information leaflet, an introductory letter for participants, and a letter for the clinic director. These were left with the clinic staff for further review and discussion with the clinic director prior to my being given, what I naïvely assumed would be, official confirmation to go ahead with participant recruitment. This, however, was not to be.

On New Year's Eve, 2007, it was made clear that the clinic in question was no longer willing to allow me to recruit any of their patients for the purpose of the study. This information was conveyed to me via a thoughtful, insightful, and apologetic e-mail from the counsellor at the clinic. It was made clear that this decision had been made by the clinic's medical director, in respect, not of my particular project alone, but in relation to the type of research projects that the clinic director was now prepared to support. There was very little that I could do to change this decision, or to even challenge it, therefore I simply accepted it.

As mentioned earlier in this chapter (see page 74), a second clinic had also previously expressed an interest in becoming collaborators. So, following discussion with my supervision team, a decision was made to find out if they were still willing to collaborate. This second clinic, which was based in the North East of England, was approached by my Director of Studies in the first instance, as he had met the clinic director on a number of informal occasions. I received a response that informed me that they were interested in finding out more about the study before they could make a decision as to whether to facilitate the recruitment of participants from their clinic. This resulted in a meeting being set up with the main contact at the clinic, the clinic director. The meeting was scheduled for January 2008 and it was agreed that my Director of Studies would attend this meeting with me.

At the meeting, which included the clinic director and two other members of staff, we discussed the aims and scope of the study. The meeting went well and though no formal answer was given at the meeting, there was a sense that they had seen the potential in the study. They did, however, note their concerns regarding how I might use the findings from the study. This alerted me straight away to the fact that they were not totally comfortable with the idea of the study drawing on their client base, although, I came away from the meeting with the feeling that I would hopefully receive a favourable response sometime in the very near future. I was assured that they would be in touch during the next couple of months, to let me know the outcome of their decision. However, despite subsequent e-mail communication from my Director of Studies, whom I had decided was the best person for the job, thus freeing up my time to continue with working on the study, no one from the clinic responded until midway through 2008.

By this time, due to the time limited nature of the study, it became necessary to revisit my aims, and my methods for conducting the research, specifically, due to the length of

time spent waiting for a response from the second clinic. Consequently, I had begun to doubt whether they were still willing to be involved. This led me to develop an alternative method of recruitment that could be factored into the study should this eventuality occur. It transpired that the second clinic had decided that they would not be able to help with participant recruitment for the study either, a point I return to later in this chapter (see pages 84-86). The justification provided for their inability to assist was an internal personnel matter which had caused some administrative problems. This meant that, once again, the study was in jeopardy and some difficult decisions had to be made regarding recruitment and access to potential participants. I have to acknowledge that, at this time, I felt as though I had nowhere to turn and my study was about to evaporate into thin air. So, feeling very downhearted, and disillusioned, I continued to seek alternative ways to conduct the study.

Fortunately, in the interim, my Director of Studies had mentioned my study to someone who worked at another clinic based in the South of England. This clinic also ran a significant egg sharing programme and they expressed an interest in the study and its aims. I was cautioned not to get too hopeful as this too might prove unproductive but this positive response offered some hope that the study could be resurrected. Depressingly, however, this glimmer of hope soon dwindled when there were no positive responses to the e-mails sent by my Director of Studies. This was due, we gathered later, principally to staffing issues within the clinic and not an unwillingness to be involved in the study. So, despite this further promising and positive interest in the study, it, too, failed to generate active support for the study.

Nevertheless, I had to acknowledge that the amount of time I could dedicate to these endeavours was limited. I was aware that I was under pressure with regard to completion. I knew that I had an obligation to my funding providers, to complete the research within given timescales. I was also acutely aware that my funding would cease at the end of three years. This knowledge meant that I had to make these changes as seamlessly as possible in order to ensure a consistent approach to my study. These setbacks meant that the main aims of the study had to be revisited in an attempt to establish how the problems of recruitment could be resolved and rectified in order to progress the study. These issues are discussed later in this chapter and therefore warrant no further exploration at this time. What they do serve to reinforce and highlight, however, are the difficulties that one may encounter when conducting social research that is dependent on gatekeepers. They also suggest that it may be beneficial to consider alternative methods of data collection at the outset of an

investigation should there be issues with potential collaborators such as those I faced in the study. I discuss some of these issues below as I demonstrate the impact that gatekeepers can have on the research process.

### **The impact of gatekeepers**

At the time of attempting to get the study off the ground the impact of gatekeepers had never really concerned me. This again demonstrates my own naïvety. As a novice researcher I had not fully anticipated how difficult it might actually be to gain access to participants, nor had I fully taken into account how, as Bryman (2008) describes, political the process can be. It is not merely about forming collaborative working relationships; it is also about mediation. Bryman also suggests that gatekeepers may attempt to influence the investigation and its outcomes by monitoring the types of questions that are being asked of participants. This view is endorsed by Seiber (1993), who suggests that gatekeepers have the capacity to influence what the research reports.

Seiber's point is one that was evident in one of the attempts to establish a collaborative working relationship with one of the clinics. At the face-to-face meeting (January 2008) it became evident that even though there was interest in the study – indeed, there was a consensus of opinion that the questions I was attempting to answer required addressing – this was not going to be a straightforward process. Indeed, it became evident, early into the meeting, that if I were to use their clinic as a base for recruitment, then they would want to have some form of control over the data once it had been collected. This made me wonder whether they would also wish to exert their influence over the type of questions I intended to ask of participants.

This theme has resonance with a study conducted by Illingworth (2001), who discusses the problems she faced gaining access to participants. In her study she had hoped to interview women who were involuntarily childless. In her negotiations with gatekeepers regarding the aims and methods of her research, the questions Illingworth was attempting to answer were met with derision. Ironically, the assisted conception unit where she wanted to conduct her study knew her, so, in theory, she thought that her ability to recruit from the unit was almost a foregone conclusion. She notes that, in keeping with her feminist methodological approach to her study, she was aware of the significance of power relations, and the impact that these may have on a researcher and their research. She states:

It became clear the consultant involved exercised a significant and intractable degree of control over the research site, making it clear that this degree of control would necessarily extend to cover research design, interaction, process and findings. I was requested to submit a lengthy research proposal including a detailed account of expected research findings - a problematic issue given the nature of my research and methodology which informed it. The consultant would then 'vet' my research design. (Illingworth, 2001, paragraph 6.2)

Thus, my own experiences with gatekeepers reflected those faced by Illingworth. For me, this proved to be an illuminating experience and an issue that I had not anticipated prior to the meeting with the second clinic. On reflection, I realised that there may have been a particular reason for this clinic's expression of interest in controlling the data. Indeed, the fact that they expressed an interest in the data made me consider whether they were primarily interested in ensuring that the 'right type' of information about egg sharing would be shared with the wider community. I felt they believed I should present egg sharing in a solely positive way, and that any attempts that I might make to provide a less than positive assessment of egg sharing, if this is what my findings indicated, would not be permissible. These misgivings, though not expressed directly, were what I concluded to be the concerns of the staff at the clinic.

In addition, as the study was investigating ethical issues associated with the provision of egg sharing, a treatment available predominantly in private fertility clinics which therefore has to be paid for, this could also have been a factor that influenced the gatekeeper's decisions not to become involved in the study. Furthermore, the voicing of concerns about data made me wonder if the clinic's staff were anticipating that the study may not portray egg sharing in a totally positive way, and were therefore attempting to pre-empt my findings for me.

Here I acknowledge that I might appear to be somewhat cynical; however, it was around this time that I began to develop my critical feminist position (see pages 192-193 and 249). I considered that allowing the clinic staff any level of involvement in my data would not be constructive, or conducive to, or in keeping with, the main aims of the study.

Additionally, this analysis is consistent with my discussions of the theories pertaining to the gift in Chapters Nine and Ten (see pages 190-191, 205-209 and 235-236). In the analysis presented, I provide evidence that the gift relationship involves a two-way

reciprocal arrangement. This arrangement does not involve a third party unless applied to blood, tissue and organ donation. However, egg sharing or the gifting of eggs involves a third-party and the provision of subsidised treatment. Thus, I would suggest that this might alter the concept of the freely given gift. This experience and my analysis served to demonstrate the influence that gatekeepers can have on research projects, and how they can, in principle, jeopardise and bias the quality of the findings ultimately reported.

Bias affects many of the social interactions that take place on a day to day basis. However, as a social researcher, one has to be able to look at the data as they present and draw conclusions from them, whilst accepting that researcher bias occurs naturally. The ability, therefore, to be transparent and rigorous in the data collection and analysis processes is an essential feature of good qualitative research. However, external bias such as that which may be exhibited by 'gatekeepers' has the potential to negatively affect a research project, principally because they may wish to safeguard against the reporting of any outcomes which may adversely affect their best interests. This was, and remains, a pivotal moment in my journey through the study, a moment that has provided a crucial learning experience. Furthermore, these experiences have resonated with the view suggested by Bryman regarding the gaining of access to potential participants. Bryman states that:

Access is usually mediated by gatekeepers, who are concerned about the researcher's motives: what the organization can gain from the investigation, what it will lose by participating in the research in terms of staff time and other costs, and potential risks to its image. Often, gatekeepers will seek to influence how the investigation takes place, what kind of questions can be asked... the interpretation of findings, and the form of any report to the organization itself.  
(Bryman, 2008, p.131)

This quote reflects most appropriately the issues I faced when trying to gain access to participants at the second clinic. It also mirrored the way in which an organisation can reject a research project simply because of its design, which is seen as potentially working against the organisations' own interests.

### **Chapter review**

In this chapter I have documented how I prepared for the study that I had originally planned to undertake and the problems I encountered. I started by locating the study



conceptually, as one that was perceived to focus on a sensitive area. In doing so, I justified my decision and explained why this conceptual decision was relevant to the study. I then demonstrated how I approached my chosen topic in a sensitive way and why I deemed this necessary. Having outlined how I had sought ethical approval for the study, I reported on my decisions to use semi-structured interviews and how I undertook the process of designing the interview schedule, whilst maintaining my focus on the potentially sensitive and emotive nature of the study. I described how I intended to recruit participants for the study and how my intentions were thwarted. Finally, I described the role of gatekeepers and the impact that they have had on the original version of the study.

In the next chapter I build on this methods chapter by demonstrating how all was not lost. I explain how the rigorous, thoughtful, insightful and painstaking work that I undertook during the preparation of the original study was transferable, in part, to the revised study. I discuss the revisions made to the original study in the following chapter.

## CHAPTER FIVE

### Methods – the revised study

*If we can understand the potential for using hermeneutic phenomenology to explore people's 'lived experiences' through in-depth learning, sound critique and methodological evaluation, we can gather rich data to influence service delivery, treatment of patients and policy agendas.  
(Rapport, 2005, p.137)*

In this chapter I describe the decisions undertaken to revise the study. It starts with an in-depth discussion regarding my decision to use Computer Mediated Communications (CMCs) for data collection. It explains how I came across this approach by chance and how I adapted it so that it was suitable for the study. I describe how I managed data collection using the new data collection methods employed in the study: the asynchronous e-mail interview and the online self-completion survey.

In doing so, I demonstrate throughout, the many challenges I faced during this stage of my study. These discussions both highlight and reinforce the issues that researchers may face when conducting research in a sensitive area. It also reinforces the view that research is an iterative process, in that it requires the researcher to constantly revisit the main aims of a study, in light of changing situations, and to make sound methodological decisions based upon those circumstances.

#### **Background to the revised study**

As discussed previously my attempts to gain access to potential participants via three clinics failed. Hence, I needed to develop a new recruitment strategy. This led to the decision that the prospective focus of the study would be changed to a retrospective one because it would not be possible to recruit women immediately following a cycle of egg sharing without active clinic participation; I would need to seek women whose egg sharing experience had been some time in the past. This retrospective turn would have to take into account the possibility that people's perceptions change over time, perhaps affected by their memory, recall and subsequent experiences (Somerville, 2001). Taking this into account I decided to recruit women who had been egg share donors at any point during the previous five years. This timescale was chosen to minimise the impact of retrospective accounts on the data collection process. Nevertheless, I acknowledged that these accounts would now be influenced by knowledge of the outcomes of the treatment.

The other decision made was to try and recruit up to twenty participants via the Internet. I now describe my decision to utilise the Internet in the study prior to explaining how I chose the new methods of data collection that could be employed via the Internet.

### **Researchers and the Internet**

The Internet provides researchers with a way of accessing and retrieving information from a variety of media, including online journals, books and research archives. Historically, quantitative researchers in particular, have used computers profitably, but the emergence of new ways of using computers as information and communications technologies (ICTs) has meant that computers now offer more opportunities for qualitative researchers as well (Bampton & Cowton, 2002). The distinction I make here is that no longer is the use of the Internet restricted to gathering secondary data for analysis; there are now more opportunities to use it in innovative ways to conduct empirical qualitative research and to acquire primary data. These include access to personal Web pages, videoconferencing, access to discussion lists, conducting online focus groups, undertaking participant observation and synchronous and asynchronous e-mail interviewing (Kollock & Smith, 1999; Mann & Stewart, 2000; Illingworth, 2001; Bampton & Cowton, 2002; Gibbs et al., 2002; McCoyd & Kerson, 2006).

In the UK, official statistics show that access to the *World Wide Web* (www) via the Internet at home continues to grow. In 2008, 16.46 million UK households had access to the Internet; of these, 56% had broadband connectivity, an increase on the previous year, with 69% of adults<sup>11</sup> accessing the Internet every day (Office for National Statistics (ONS), 2008). The most popular activity cited was the use of e-mail (sending and receiving) (ONS, 2008a). By 2009 18.3 million (70%) of homes in the UK had access to the Internet. Of the households with access to the Internet, 90% were using broadband, of these, 37.4 million (73%) adults accessed the Internet “every day or almost everyday” (ONS, 2009, p.2). These statistics demonstrate that Internet usage, and the use of e-mail, in the UK, is widespread, indicating that e-mailing has become a commonplace form of communication in UK society, and thus a relevant form of data collection in this study. Overleaf I discuss what led me to select asynchronous e-mail interviewing as my new method of data collection.

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<sup>11</sup> Adults are defined as individuals aged 16 and over (ONS, 2008).

### **The asynchronous e-mail interview**

Considerations regarding the redesign of the study focused upon my need to gather qualitative data. Coincidentally, whilst re-evaluating the viability and design of the study I received a journal article, by e-mail, from my Director of Studies. This serendipitous e-mail exchange alerted me to a new way of conducting sensitive research using the Internet. The article written by McCoyd & Kerson (2006) was read with interest as it detailed a research project that had been conducted using the Internet. The authors had undertaken a sensitive research project with a cohort of women who had terminated a “desired pregnancy following the diagnosis of a fetal anomaly (termination for anomaly [TFA])” (McCoyd & Kerson, 2006, p.390). The authors had also encountered problems in recruiting participants, though these were not associated with gatekeepers. In their comprehensive account of their research endeavour they indicated that originally they had hoped to recruit women for face-to-face or telephone interviews via physicians’ offices. However, their experience of a poor response rate led them to posting information about their research on a Listserv<sup>12</sup> that was connected to a website for women who had undergone pregnancy termination because of fetal anomaly. This posting led to women responding to their requests, and who opted to be interviewed by e-mail. In their analysis of this method of interviewing, the authors found that respondents tended to be more candid about their experiences; the method allowed time for self-reflection and the interviews themselves tended to be more complete than when using conventional methods (McCoyd & Kerson, 2006).

Bampton & Cowton (2002) report on another study in which their intended plan was to conduct face-to-face or telephone interviews with participants. The authors note that whilst they conducted some face-to-face interviews, they abandoned their reliance upon this method of data collection in favour of the integration of e-mail interviewing due to the geographical location of participants and the practicalities associated with the arranging of telephone interviews (particularly the difficulty in arranging a mutually convenient time). They explain that their decision to adopt this approach was guided by a participant, who suggested questions were sent by e-mail. The authors state that:

The first interview was regarded as a success by both interviewer and interviewee — so much so that the interviewee commented in one e-mail: "The interview method seems to work well, maybe you could get a mini-paper out of it".  
(Bampton & Cowton, 2002, paragraph 4)

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<sup>12</sup> An electronic mailing list.

Thus, on my return to the article by McCoyd & Kerson, and following a more thorough reading, I realised that I had come across a new method of gathering qualitative data that if developed rigorously, was transferable to my study. My decision to develop e-mail interviewing as the primary method of data collection meant that in terms of the overall design, some changes were necessary. These changes proved to be not too problematic, but they did warrant submission of a revised ethics application, a matter discussed later in this chapter.

Having decided to use e-mail interviews in the study I undertook a full consideration of the various Internet methods that can be used for qualitative data collection. I opted to use an asynchronous method of e-mail interviewing instead of the synchronous method. The key differences between these two modes of information exchange are that synchronous information exchanges are undertaken in 'real time'; that is, there is an instantaneous exchange of information as all parties are online at the same time, such as that which is found in instant messaging (IM) (Mann & Stewart, 2000; Illingworth, 2001; McAuliffe, 2003; McCoyd & Kerson; 2006; Evans et al., 2008). In contrast, asynchronous methods of information exchange represent information exchange via e-mail or web postings, but which takes place over time. Replies may occur within minutes, days, weeks or even months. However, a benefit of using asynchronous information exchange is that it is not time zone restricted or dependent upon the recipient's schedule, thus allowing discussions to be sustained through a series of message exchanges (Kollock & Smith, 1999; Mann & Stewart, 2000; Evans et al., 2008). The decision to use asynchronous e-mail interviews was also influenced by the fact that the method appeared to offer more flexibility than any of the aforementioned methods.

Methodologically, e-mail interviewing is a relatively new method of collecting qualitative data with proven utility (see for example, Donath, 1999; Illingworth, 2001; Bampton & Cowton, 2002; McAuliffe, 2003; McCoyd & Kerson, 2006). Moreover, there have been suggestions that the method has the potential to yield rich, in-depth data and that it may in fact be a more appropriate method when collecting potentially sensitive and emotive data. This is primarily because the anonymity associated with some online communication methods may offer participants a greater feeling of security about their identity (Mann & Stewart, 2000; McCoyd & Kerson, 2006).

Asynchronous e-mail interviewing involves conducting the interview over an extended period of time. Whilst not time-limited *per se*, the period of time over which the

interview takes place is usually defined at the start of the data collection period. This was the case in the study; in that I put specific time protocols and guidance in place to control the interview process (see Appendix Four, page 303). However, these timescales can be subject to change, and are dependent upon the requirements/needs of the participants (Mann & Stewart, 2000; Illingworth, 2001; McAuliffe, 2003; McCoyd & Kerson, 2006). Asynchronous methods require commitment from both the researcher and the researched to be involved in the process for as long as it takes. This could be anywhere from a few hours, to a week, to a month or, in some cases, even longer, as was the case with most participants in the study.

Adopting this interview approach meant that the interview schedule had to be redesigned in order to accommodate the change in data collection methods. It also meant I had to consider how to manage the e-mail interview process which, from here on, will be referred to as the e-interview. To do this I first had to consider the broader ethical issues relevant to e-interviewing.

### **Recruiting participants**

As data collection was now going to be Internet based I decided to utilise the Internet to recruit participants to the study. In the event, access to participants was aided by the availability of Internet-based infertility support groups and online charitable organisations. Two support groups; Infertility Network UK (INUK) and Fertility Friends - and one charitable organisation - National Gamete Donation Trust (NGDT) - were identified as being of potential use in the study.

In the first instance it was decided that INUK and Fertility Friends might be the most appropriate to use. Contact was made with the managers of each of the websites, identified in the first instance by my Director of Studies because of his existing personal relationship with them. They were informed of the nature of the study and asked whether they would consider posting my study information on their websites (see Appendix Five, page 287). They were informed that if they agreed I would contact them once I had received ethical approval.

Such agreement was obtained and, following the successful ethics application, information about the project was posted on the relevant sub-section of the website forums in July 2008 and remained "live" for 12 months, the duration of the data collection period. However, this way of gaining access to potential participants meant that I was now reliant upon self-selecting participants.

### **Managing the e-interviews**

Prior to using e-interviews to collect qualitative data I first had to consider how I would manage the process. Furthermore, in choosing to conduct e-interviews, I acknowledged that this method was not entirely in keeping with the philosophical approaches of hermeneutic phenomenology. Traditionally, hermeneutic researchers would generally seek to undertake face-to-face interviews in the pursuit of data collection (Rapport, 2005). Now I had to ensure that a conversation was developed throughout the process of the e-interviews, so that I stayed as close to the study's philosophical underpinnings as possible. Hence, I was able to maintain my presence in the process of data collection, whereby I concentrated on gathering as much of the "experience as immediately lived" (Rapport, 2005, p.137).

However, unlike conventional, face-to-face interviewing, e-interviews pose different procedural and practical considerations. Thus, in order to ensure that I was conducting the e-interviews rigorously and transparently, I considered how to manage the process. This began with preparing and piloting the e-interview schedule.

### **Piloting**

Piloting of the e-interviews took place with the assistance of two members of my supervision team. This decision was based upon the potentially sensitive nature of the study and not wanting to try out an untested process on actual egg share donors. Furthermore, because of the previous recruitment difficulties, I did not want to risk reducing my overall sample due to piloting.

To pilot the e-interviews my supervisors first had to access the information about my study from one of the websites on which it was posted. During the pilot one member of the team identified a problem with the posting on one website. This appeared to be a technical error associated with the way in which the contact link had been set up. Consequently, I made contact with the person responsible for the administration of the website and the problem was rectified. Following the identification of this minor dilemma, another potential difficulty was also identified; this was linked to the completion of the consent form.

The consent form was sent as an attachment which participants were asked to complete and return by e-mail. It became evident that the instructions I had given for completing the form were not sufficiently informative. This highlighted the need for minor revisions to be made to the consent form prior to the study going "live". The

revisions required were: the need to ensure that I clarified that participants had understood the information with which I had provided them. I also needed to ensure that I asked them whether they had any questions for me prior to beginning the e-interview. Once these aspects had been rectified I was ready to proceed with recruitment in the 'virtual' realm. However, before I could undertake formal data collection I had to first consider issues pertinent to conducting e-interviews. This commenced with a consideration of Internet etiquette (netiquette).

### **Netiquette**

Netiquette is the term used to refer to the act of complying with established online communication conventions, and adhering to standards relating to social relations using online environments (Mann & Stewart, 2000). One such convention is that, in general, when conversing by e-mail, text should be able to be viewed in a single screen, as this then eliminates the need to scroll up and down the page which can be confusing or irksome (Mann & Stewart, 2000; Crystal, 2001). Based therefore on this convention, a decision was made to send interview questions in a series of separate e-mails. This served what I believed were two distinct advantages; that it would make the process more interactive, and it would allow me to clarify responses and incorporate supplementary questions where relevant (Bampton & Cowton, 2002).

The formality of language was also a consideration, in that, there are standard conventions to employ when using e-mail. This included the use of appropriately structured e-mails with the right level of formal language – especially in introductory e-mails, a practice in keeping with conventional letter writing. The formality of language may, of course, change as the research progresses and rapport develops with participants (Mann & Stewart, 2000). This was a feature of the e-interview process that became evident in the study (see page 100).

### **Introducing the study**

The information posted on websites asked women to make contact with me via e-mail if they were interested in finding out more about the study. In the absence of face-to-face interaction a detailed information sheet was developed as a preamble, detailing the main aims of the study (see Appendix Six, page 306) and the guidelines to which participants were asked to adhere should they consent to take part in an e-interview; this was sent as an e-mail attachment.



### **Semi-structured e-interviewing**

As the original interview schedule had five separate areas that I wished to explore I used each of these areas in the development of the e-interview schedule. These broad overarching themes of exploration were separated into a series of questions that focused upon a specific aspect of the study. Each of the series of themes had no more than four or five broad, open-ended questions that required answering.

Participants were informed that supplementary questions might be used throughout the e-interview process. Thus, I was able to follow the lead given by participants in order to facilitate their expressions of their 'lived' experiences of egg sharing, a method congruent with the philosophical underpinnings of phenomenological interviews (Carpenter, 2007). This method of managing the e-interview was in keeping with the practicalities of the process discussed by Hunt and McHale (2007). They suggest that it is in the best interests of the researcher to be clear to participants at the outset how many questions they may be asked in the e-interview. This gives them an insight into what the process will entail.

Additionally, in managing the administration of the semi-structured e-interviews I focused upon the well-being of participants throughout the process. I decided that once each series of questions had been answered and responses received via return e-mail, I would forward the next set of questions to participants, until all five sets of questions (with prompts where necessary) had been answered. However, before doing so, I asked participants to indicate, by e-mail, when they were ready to move on to the next stage of the e-interview. This meant that I validated participants' well-being through the process of constantly re-checking and affirming with them that they were happy with the process before continuing. In this way I was able to make an assessment of well-being based on their willingness to receive the next series of questions. Any intimation that they were unwilling to proceed would have been an indication that possibly all was not well; this would have led me to pursue questioning about their well-being. Fortunately, this did not occur. However, because I had incorporated this measure into the e-interviews, this ensured that I was paying close attention to the well-being of the participants at each stage of the process. This was also facilitated by the use of appropriate prompts.

Prompts and supplementary questions were used to assess whether there was anything else participants would like to share with me about their experiences. This process enabled the generation of additional information and allowed me to undertake

an assessment of participants' well-being in the absence of non-verbal communication. In this way I was able to elicit more information about the lived experiences of participants, as I had not set a limit as to how many additional questions I asked. This meant that questions were asked until it was felt that data saturation had been achieved and that no new themes would emerge from further questioning.

Morse (1989), however, has stated that the notion of data saturation is a myth, proposing that if the same study were to be conducted with a different set of participants at a different time then new themes would undoubtedly emerge. Therefore, data saturation can only be achieved *per se* with a particular group of participants, at a particular point in time. Hence, for phenomenologist researchers like me, the onus was upon achieving an understanding of a phenomenon using the multiple perspectives provided by participants that aid the generation of theory (Streubert, 1991). During this process participants were also advised that they could stop and ask me questions at any stage (something which happened during two of the e-interviews), thus aiding the two-way flow of information, the conversational development of the e-interview in the 'virtual realm'. Through this means it was hoped that the participants would feel that they had some control over the process. It also offered them the opportunity to reflect before answering the questions being asked of them. They were also able to review their previous answers or indeed amend them which, again, might have given them a sense of having more control over their input in the e-interview.

### **Reflexivity, emotion work and the e-interview**

Hunt and McHale (2007) suggest that the ability to reflect during the e-interview enables information to be processed at a deeper level. Thus, it allows for a more comprehensive response to the questions being asked of participants. However, I acknowledge that the inclusion of time and space to reflect might affect a participant's ability to stay as close to their experience as it had been experienced, particularly since this method requires writing and, as Van Manen (1990) suggests, writing is inherently a process that requires reflection. Thus, reflection may make it difficult to remain close to the lived experience. However, because of the retrospective focus of the study, reflection was an inherent feature of the e-interviews. Hence, whilst I acknowledged that reflection can affect the immediacy of the experience recounted, this can aid the re-telling of an experience, since the process of reflection incorporates a re-visitation of the event as it was lived.

Prior to conducting the e-interviews I envisaged that the process might be difficult, though I had not realised quite how difficult it would be. As I viewed responses to my questions on screen I became immersed in the stories that were being told about the quest to become a parent. At times I found them difficult to comprehend due to the depth of emotion displayed in the text. This meant that I devised a strategy for the e-interviews that enabled me to better deal with participants' responses.

This involved checking my inbox for responses, and once a response was received, I checked the identity of the sender, logged off, and then composed myself ready for reading their reply. Having read the response, I then logged off again in order to compose myself, whilst formulating a response that would be appropriate to the, at times, obvious emotional needs of the participant. In the instances when this approach was adopted this all took place within a relatively short time frame. Subsequently, managing the e-interview process in this way enabled me to manage my personal reactions to the emerging narratives. This meant that even though I had developed some standardised responses and prompts, so as to cover all aspects of the research, I also ensured that I was responding directly to each participant on a personal level, guided by their words, be this the need to check on their emotional well-being, to clarify whether there was anything they wished to add, or to simply empathise with them by making direct reference to points in their narratives where it was evident that the experience they were writing about was difficult for them to deal with. Thus, by using this strategy, I was also able to minimise the effects that the process of the e-interviews had on me emotionally.

The additional space to think and reflect proved advantageous as I was able to seek support to deal with the intensity of the emotions I experienced during the e-interviews. In the first instance this came from my supervision team through debriefing, although it came to a stage whereby more specialised support was needed. Counselling support had been organised prior to undertaking data collection, in case it was warranted, and I was able to draw upon this support to help me to deal with the issues I faced whilst undertaking data collection.

### **E-interview timescales**

As e-interviews were utilised to collect data it was necessary to devise specific timescales in order to manage the length of time each interview took. Subsequently, specific, but flexible, parameters were developed that were incorporated into the e-

interview guidelines sent to participants as an e-mail attachment prior to the commencement of the e-interview.

In the guidelines I specified that e-interviews would work within a three-day window. This meant that once I had forwarded a set of questions to participants they then had, in theory, three days to respond. I then had a further three days from the receipt of the answers to respond to the participants. Therefore, since I had broken the questioning process into five different themes of questions it would take, in principle, up to five weeks to complete each e-interview. This timeframe was, however, entirely reliant on the participants and how quickly their responses were received. At first this may appear potentially problematic with regards to the amount of time required to conduct the e-interviews. It did, however, have its benefits (see pages 100-101).

### **Data collection**

Data collection began in the 'virtual' realm in July 2008. As mentioned previously, the study was now fully reliant upon recruiting a self-selecting sample of women for inclusion in the study, in turn entirely dependent upon women seeing the information about the study on an infertility support group website. This process was frustrating as it was totally outside my control. Indeed, recruitment turned out to be an incredibly slow process.

In the first two months that the study was "live", two participants were recruited, and four by December 2008. Data were, at times, collected simultaneously as some e-interviews ran concurrently. The length of time taken to conduct the e-interviews varied and was dependent upon the needs of the participants. Once data collection was complete (one year "live" posting on the Internet) website managers were contacted by e-mail to thank them for their assistance with the study. I advised them that data collection had ceased and requested they remove the study information from their websites.

### **Dealing with the lack of non-verbal communication**

Using CMCs to conduct qualitative research means that some of the basic tenets of qualitative research, specifically those of non-verbal communication and the face-to-face interplay between the researcher and the researched, are missing. This lack of auditory or visual presence in the e-interview needs to be compensated for at the outset of a study (Ferrara et al., 1991 cited in Mann & Stewart, 2000). This was an issue given full consideration prior to the undertaking of the e-interviews as it was

deemed problematic due to the sensitive nature of the research area. Subsequently, specific protocols were developed in the attempt to alleviate these omissions. In the study participants were asked to use a variety of methods to emphasise points or to express strong emotions. Participants were informed that if they wanted to emphasise a point or express how they were feeling at a specific point in time that they had the option to use CAPITAL letters, **bold** words, *italics* and different coloured **fonts** for emphasis (adapted from McCoyd & Kerson, 2006) or emoticons.

Emoticons or “emotion icons” are (typo)graphic depictions of facial behaviours used to convey social emotion (Derks *et al.*, 2007, p.842; Derks, 2007), such as “:) for smiling or ;) for winking” (Evans *et al.*, 2008, p.317). Accordingly, the use of emoticons (e.g. ☺, :- ( ) can serve as nonverbal surrogates, in that they can be suggestive of facial expression or they can add paralinguistic components to the message, components that might be missed without the inclusion of this method of relaying emotionality. Emoticons may also enhance the exchange of social information by providing additional social cues beyond those that are found in the text of a message (Thompson & Foulger, 1996). Derks (2007) suggests that the main motives for using emoticons are to express emotion, to regulate the interaction, to strengthen the message and to put the content into perspective. As such, emoticons can impact on the way the receiver understands the message. All the aforementioned methods are paralinguistic conventions that can be used to replace the emotions observed during face-to-face interactions (Mann & Stewart, 2000; Evans *et al.*, 2008). Further usage of paralinguistic can include the use of acronyms (e.g. LOL ‘laugh out loud’) and exclamation marks (Evans *et al.*, 2008). Participants’ use of these methods to reinforce the written expressions of feelings was entirely discretionary. However, it was viewed as a useful way of compensating in the e-interview for the lack of non-verbal communication.

In the event, participants’ use of paralinguistic to emphasise points meant that I was able to identify sentient words, phrases or sentences that indicated the sharing of an emotive experience. In my observations of the content of answers I was able therefore; to identify any underlying issues evident in what was being said (see Chapter Seven). Therefore, in the absence of face-to-face verbal cues, my incorporation of this method offered participants the opportunity to convey their experiences with emphasis of various kinds.

However, prudent use of emoticons and paralanguage has been advocated by some authors, as there are contextual and cultural implications (Mann & Stewart, 2000). For example, the Westernised convention of using sideways-on emoticons may be misconstrued in, for example, Japanese cultures where the convention is to use horizontal formation. Furthermore, it has been posited that emoticon use is akin to unimaginative or lazy communication that may alienate persons who are members of more sophisticated communities in the virtual realm (Mann & Stewart, 2000). However, whilst I recognised these alternative viewpoints, I found the use of paralanguage conventions enabled me to reach a deeper level of understanding about the thoughts and experiences that were conveyed by study participants.

### **Developing rapport**

Interviewing the first two participants was emotionally challenging, as I had no idea of how women would respond to the questions being asked. Indeed, at times, I was taken aback by how frank and open their responses appeared to be. At times, what they wrote indicated highly emotional experiences and it made me realise how fortunate I was to conceive naturally. What I did find surprising was being thanked by the participants for attempting to understand their experiences.

Drawing on the views posited in studies by Kalfoglou and Gittlesohn (2000) and McCoyd & Kerson (2006) regarding the status of the researcher, I felt that there was tremendous benefit to be had from allowing oneself to be seen within the context of a research study such as this, as a human being with real thoughts and feelings who has the ability to empathise with participants rather than being viewed purely as a detached researcher. This was evident as rapport developed with each of the four participants during the e-interviews. It also reinforced the notion that it is possible to be able to connect with someone in cyberspace, in the sense that, over time, the nuances of conversation change. Shortened versions of names were used; the process became less formal and rigid e.g. 'hi' being used instead of 'dear'. These changes in the communication process became evident as the e-interviews progressed. This was important because it demonstrated that participants were happy to be involved, and that they appreciated the time they spent communicating with me, the researcher. Additionally, it reflected the change in the dynamics of the interview process, in that it became apparent that participants were not intimidated by the process.

This may, in part, have been because they were already members of online support groups and were used to discussing their situations with others. Therefore, it is

possible that this made their conversations with me easier, thus enabling participants to 'open up' to my questions. It is also quite possible that speaking to me, a total stranger in cyberspace, was a cathartic experience, another way of off-loading the enormity of the journey they had been on. This view was expressed by one of the participants specifically, but each participant expressed how helpful they found the entire process.

### **Transcription**

The benefit of utilising e-interviews was that it obviated the need to undertake lengthy transcription. Hence, I was able to extend the length of time allocated for data collection. This is because the raw data captured from the e-interviews were used to develop the verbatim transcript.

I managed this process by allocating a word document for each participant. I then copied and pasted the interactions that took place via the e-interview into the document. This produced the final transcripts that I used for analysis. Undertaking transcription in this way alleviated any potential loss of data through conventional transcription due to poor quality or inaudible recordings (Mann & Stewart, 2000; Kvale, 2007). Thus, it could be argued that this method increased the reliability of the data generated as it was not affected in any way by the researcher's own interpretations. Furthermore, as the interviews were conducted over a period of time rather than at a single point in time, this aided the development of trust and rapport which enabled aspects of non-verbal communication to become discernible through the written texts.

### **Advantages and disadvantages of the e-interview**

Although I was able to use this method successfully in the study, there were a number of advantages and disadvantages that I identified before and during the e-interview process. An overview of the advantages and disadvantages is provided in Table 5.1.

**Table 5.1** Advantages and disadvantages of the e-interview<sup>13</sup>

<b>Advantages</b>	<b>Disadvantages</b>
<p><b>Recruitment using the Internet</b></p> <ul style="list-style-type: none"> <li>• Cheaper than conventional fieldwork.</li> <li>• Can reach geographically dispersed populations.</li> <li>• Can overcome 'gatekeeper' issues.</li> <li>• Alleviates the need to travel.</li> <li>• International recruitment possible.</li> <li>• Opportunity to access a well-defined, specific population e.g. those people who use a specific website.</li> <li>•</li> </ul> <p><b>The e-interview process</b></p> <ul style="list-style-type: none"> <li>• Alleviates the need for transcription.</li> <li>• Increased external validity - audit trail is maintained.</li> <li>• Increased flexibility for participants – they are not pressurised to answer questions 'on the spot'.</li> <li>• Gives participants greater control over the process.</li> <li>• Researcher has the time to reflect on participant responses before asking any further or supplementary questions.</li> <li>• Can be undertaken from anywhere in the world providing there is access to an Internet connection.</li> <li>• Participants may feel a greater sense of anonymity as there is no face-to-face contact.</li> <li>• Lack of face-to-face interaction reduces influence or perception of one another e.g. appearance, culture.</li> <li>• Rapport can be developed with participants due to the length of the process.</li> <li>• Increased familiarity may yield a greater volume of data.</li> <li>• Analysis takes place at every stage of the interview.</li> <li>• Less intrusive.</li> <li>• May be a cathartic process for participants.</li> </ul>	<p>Sample restricted to those with Internet access.</p> <ul style="list-style-type: none"> <li>• Participants may exclude themselves from a study if they are not confident of using the Internet and e-mail.</li> <li>• Identity fraud is possible.</li> <li>• As new information is added to websites, older information can become more difficult to locate.</li> <li>• Reliance on self-selecting participants.</li> </ul> <ul style="list-style-type: none"> <li>• Can be time-consuming and labour intensive.</li> <li>• Length of time involved may dissuade participants from taking part.</li> <li>• Can be problematic undertaking more than one interview at a time.</li> <li>• Participants may drop out.</li> <li>• Reliance on the availability of good Internet connections.</li> <li>• Increased reliance on the written word to seek 'hidden meaning' within the text.</li> <li>• Lack of non-verbal communication.</li> </ul>

As can be seen from the features incorporated in this table there are a number of disadvantages that can be associated with the use of e-interviews. I would argue, however, that the advantages of the e-interview sufficiently outweigh the disadvantages of the method, thus making it an effective and innovative way to conduct qualitative research.

<sup>13</sup> Adapted from Hamilton and Bowers (2006, p. 826).



### **Rationale for further revisions to the design: the online survey**

Notwithstanding the positives of using e-interviews, due to the poor recruitment rate, it was necessary to develop additional recruitment methods in an attempt to increase the size of the sample in the study. The rationale was that even though the e-interviews had generated valuable data from four participants, such a small sample was deemed insufficient to meet the aims of the study. This led me to consider alternative methods of recruitment whilst I awaited e-mail responses from potential participants.

As indicated previously, I had wanted to include the experiences of 20 egg share donors in the study. This led me to develop a new data collection strategy, an online self-completion survey. Information about the survey was posted on the websites that were collaborating with the study. However, before I could administer the survey, I had to revisit my philosophical framework in order to accommodate the methodological changes associated with this part of the study.

### **Revisiting my philosophical framework**

Whilst maintaining my relativist ontological position I acknowledged that my methodological framework had to address this new method of data collection. Hence, there was a need to incorporate a positivist ontological position into my overall philosophical framework. Here the focus was upon gathering largely quantitative data that could be analysed in conjunction with the qualitative data captured from the e-interviews. In doing so I acknowledged that the most significant difference between the two methodological approaches is the way that they treat data and data collection (Brannen, 1992). So, rather than changing my entire philosophical framework, I maintained my original epistemological and ontological foundations whilst incorporating elements of quantitative methodology.

### **A mixed methods approach**

Qualitative researchers use themselves as a vehicle for the production of knowledge and understanding. That is they “look through a wide lens, searching for patterns of inter-relationships between a previously unspecified set of concepts which, as the research progresses, change their definition” (Brannen, 1992, p.4). Conversely, quantitative researchers distance themselves from the research act. They formulate hypotheses that are then tested upon the data. Subsequently, the quantitative researcher will isolate, define and measure variables, and variable categories, in order to test them against hypotheses. Qualitative researchers tend to adopt a flexible, reflexive approach whereas quantitative researchers are less flexible in their approach

(Brannen, 1992). Whilst acknowledging that there are inherent differences between the two methodological approaches I was able to integrate them into the study. This changed the approach from purely qualitative to a mixed methods study.

In the paradigm debates across the quantitative and the qualitative divide there has been an acceptance that the two methods can be integrated successfully in a single study. As a result, the incorporation of the underlying philosophical, epistemological and theoretical explanations of both traditions allows the ideologies to be combined in a way that enables them to complement one another. Subsequently, if planned properly and combined well, one approach can enhance the other (Bryman, 1992). In the study the two paradigms were combined through the conducting of semi-structured e-interviews that were then built upon by undertaking a self-completion online survey, for which the original research instrument (the interview schedule) was redesigned.

### **Designing the self-completion survey**

The semi-structured e-interview schedule was not an adequate instrument for use as a standalone online survey. This was due to the limited number of questions that were used as the basis of the free-flowing e-interviews. Hence, the schedule had to be redesigned in order to ensure that it would collect the correct type of both quantitative and qualitative data. Survey development was undertaken in two separate phases involving both a hard copy and an online version. I developed the hard copy of the survey using the questions from the semi-structured schedule, which enabled me to consider what data the questions had generated, and to incorporate changes in the schedule based on the identified gaps in the depth of questions used in the e-interviews. I formulated questions that were designed to capture demographic information about participants, as well as finding out about their experiences of egg sharing. Specifically, in my exploration of these themes I returned to the e-interview schedule to ensure that no areas were overlooked. I then used each of the areas of exploration as the basis of the development of the survey. To do this the survey was separated into themes designed to capture specific aspects of respondents' experiences. I chose to separate the survey into the following areas: demographic information, treatment pursued prior to proceeding with egg sharing, the decision to become an egg share donor, their experiences of egg sharing, their understanding of the informed consent process and the changes relating to donor anonymity (see Appendix Seven, page 308-315).

Once developed, the hardcopy was scrutinised by my supervision team in order to check the clarity of the questions. Their involvement in this process led to minor revisions, deletions and additions prior to the preparation of the online version. Once I was sufficiently confident that the survey would capture the kinds of data I wanted, I set up the online version using the Bristol Online Survey (BOS) resource.

### **Bristol online surveys (BOS)**

BOS is a survey development service set up by the University of Bristol Institute for Learning & Research Technology (ILFT) (University of Bristol, no date). BOS enables users to develop and administer online surveys to specific populations. It has features similar to those offered by other survey development websites (see for example, 'Survey Monkey' [www.surveymonkey.com](http://www.surveymonkey.com)). For the purpose of the study, the decision to use BOS was threefold; familiarity, the fact that it had been developed specifically for academic use, and also because it was available for use in the university.

I was first introduced to BOS by a member of my supervision team whilst undertaking my Masters degree. Following her input, guidance and the provision of an overview of the way the site operates I used the service to gather data for my Masters dissertation. Thus, having prior knowledge of BOS, I chose to utilise this service as the research instrument for the second phase of data collection for the study.

There are many advantages associated with the use of BOS as a data collection instrument. It is a site that is easily navigated and provides all the necessary tools required to build a survey. Its features are supported by help pages and tutorials that enable the user to gain a greater insight into its features. Moreover, having used BOS previously I was familiar with it. This meant that building the online version of the survey was undertaken with relative ease. Furthermore, having successfully piloted and run a survey using BOS, I had a clearer understanding of the way questions should be developed in order to generate and capture the relevant data. This familiarity was taken into account in relation to data protection, confidentiality, anonymity and gaining consent from online participants.

The aforementioned issues were key features of the study and they needed to be reflected in the development of the online survey. I developed the survey in a way that would not capture any respondent identifying information, which would have required an additional user's agreement direct from the site administrators at the University of Bristol. I made this explicit in the online introduction to the study that I provided for

respondents. This information also outlined the online consent process and the fact that if respondents consented to being involved in the study, their entry to the survey would indicate that they had given their consent. Respondents were reminded that even though, through this means, they progressed to enter and take part in the survey they were free to withdraw from the study at any time.

### **Formatting questions**

When uploading questions onto BOS, they can be formatted in a variety of ways, dependent upon the kind and level of data to be generated. As I wished to capture some statistical data from which specific inferences about the demographics of the population could be drawn, questions had to be developed accordingly. However, as I also wanted to capture some qualitative data, I had to ensure that question formatting allowed for this type of data to be captured.

Thus, qualitative data were sought through the incorporation of free text boxes following some questions, a methodological approach endorsed by Boynton & Greenhalgh (2004, p.1314), who state that “ticking a particular box, or even saying yes, no, or maybe can make respondents want to explain their answer, and such free text annotations may add richly to the quantitative data”. I took this into account during the formatting of questions.

Where I sought to extract multiple answers, questions were set up as multiple choice questions. Questions requiring a single answer were restricted to single answer formatting. Additionally, I had the option to set questions at either a mandatory or optional level; questions could be made mandatory based upon the response to a previous, related question. This would alleviate (in theory) the need for respondents to read questions that were not applicable to them. However, just because this feature existed, it did not detract from the fact that respondents may have chosen to read and answer subsequent questions regardless of whether they were applicable to their circumstances. I chose therefore not to use this option. This decision was informed by the fact that if questions were made mandatory my respondent rate might be negatively affected. If respondents were required to answer questions with which they did not feel comfortable they might opt to withdraw from the survey altogether.

As I developed the survey I returned to the aforementioned sub-headings and used these to assist in the preparation of questions. I chose to maintain the five main areas utilised in the e-interview schedule as headings for each section of the survey.

Questions were then developed to fit with the specific theme being explored. The survey comprised 31 questions, including a final question for respondents to provide any further information about their experiences.

The survey was “live” from December 2008 until July 2009 and during this period it attracted 26 responses. Initially, the response rate was slow and this led me to develop a means of further publicising the study. This appeared to be beneficial and led to a more satisfactory response rate. However, when I undertook analysis of the returned surveys, some were very incomplete and subsequently had to be discarded. This factor demonstrates that even though I had attempted to minimise the return of incomplete surveys there are no guarantees of achieving complete returns using this type of survey method.

### **Data analysis**

BOS was used to undertake the analysis of the 13 complete surveys that were included in the study (see Chapter Eight). The rationale underpinning my decision to use BOS for analysis was that there was no need to transfer data to a different analytical package as analytical tools are incorporated in BOS.

### **Poster development**

As alluded to earlier in this chapter the initial response rate to the online survey was somewhat slow. This led me to develop a poster that I designed specifically as a means of communicating with egg share donors. It sought those with experience over the last five years.

The poster (see Appendix Eight, page 316) asked women who were interested in sharing their experiences of egg sharing with me to get in touch using the study’s dedicated e-mail address or by telephone. I also provided the website address for my survey as an alternative way of taking part in the study without having to make personal contact with me. I envisaged that posters would be displayed on the notice boards of clinics currently offering egg sharing.

### **Contacting clinics**

In my attempts to further publicise the study I made direct contact with all 42 assisted conception units offering egg sharing, sending them an information pack containing the poster, a letter that explained my study and with a pre-paid return postcard on which I asked them to indicate whether or not they had been able to display my poster. In

advance of sending out the information packs I was able to make telephone contact with half of the clinics to identify to whom to address my correspondence (phase one), although due to the time-limited nature of the study I was unable to contact all clinics directly. This meant that information packs were sent out to remaining clinics without my having spoken to them in the first instance (phase two).

Eight clinics returned postcards indicating that they had not been able to display the poster, five were returned that indicated that the poster would be displayed, and one centre, which transpired to be a group of clinics, allowed me to post information directly onto their website bulletin board. Of the cards received there were some discernible differences evident in those who were willing to display the poster. There were more positive responses from the phase one clinics; those I had contacted first – five out of the eight cards returned indicated that they would display the poster. While there were only five cards returned by phase two clinics; those I had not contacted in advance. Of these, only two indicated that they were willing to display the poster. No other responses were received. However, what this demonstrates is that telephone contact prior to the sending out of information appeared to be the most efficacious method. It also suggests that the information pack may have simply been discarded by other clinics as unsuitable for display. However, I can merely speculate upon this, which again demonstrates the difficulties I encountered accessing a sufficiently large and appropriate sample for the study.

### **Chapter review**

In this chapter I have discussed how I revised the original study. I began with a discussion surrounding the rising use of the Internet and how this has provided a new way of conducting empirical qualitative research. I then explained my new method of recruitment.

I demonstrated that this relatively new method of data collection, when developed rigorously, can capture rich, in-depth qualitative data. Asynchronous e-interviewing not only obviates the need for lengthy transcription, it is a method that also allows rapport to develop with participants. Although the e-interviews worked well with those who agreed to participate, I have explained that the low number of e-interview participants necessitated the development of yet another method of data collection in order to increase the sample. In doing so I explained the rationale behind the development of the online survey and the poster. I then demonstrated how these attempts to increase my sample size proved successful. In the next chapter I describe, in detail, the specific

ethical considerations incorporated in the thesis. This describes my original ethical considerations and the revisions made because of the methodological changes.

## CHAPTER SIX

### Developing ethical research: special considerations

*Women are more used than men to accepting intrusions through questioning into the more private parts of their lives... I have often been aware of an identification, as women interviewees have begun to talk about key areas of their lives in ways which denote a high level of trust in me, and indicate that they expect me to understand what they mean simply because I am another woman.*

(Finch, 1984, p.47)

In this chapter I briefly describe how I planned the original study as described in Chapter Four in an ethically responsible manner. I explain how I gained ethical approval for the original study prior to undertaking the revisions discussed in Chapter Five. I demonstrate how the ethical protocols that underpinned the planning for the original study were of use to the development of the ethical protocols used during the e-interviews. I illustrate the similarities in my ethical decision-making and demonstrate how e-interviewing as a methodological approach raised different ethical issues to those covered in the original ethics application.

Drawing on the original ethics application, (see Appendix 9.1, page 318) the chapter describes how the original application was revised for new methods of data collection via the integration of ethical protocols that are best suited for use in the 'virtual realm'. The chapter commences with a discussion regarding the ethical planning of research. I then provide an account of ethical protocols specific to the undertaking of research using the Internet. It then describes the various ethical decisions made regarding the use of the e-interviews and how they were incorporated in the study. Finally, I describe the additional ethical considerations required following the incorporation of the online self-completion survey in the study.

#### **Planning ethically responsible research**

Ethics are "central to modern life" (Vardy & Grosch, 1999, p.3) and are concerned with "the morality of human conduct" (Edwards & Mauthner, 2002, p.14). They are integral to the research process and as such serve to govern the way that social scientists work. Therefore, ethical considerations are central features of the social research process as they arise and inform research at different stages throughout the process (Bryman, 2008). Moreover, as ethical issues are evident at every stage of the research



process they should be considered both at the outset of a study and also, wherever necessary, throughout the duration of the research (Edwards & Mauthner, 2002). The need to be mindful of this concept was evidenced by the change in data collection method. Fundamentally, when planning to conduct any type of social research, it is essential to ensure that the planning and design of the study reflect the needs and interests of all those involved (Seiber, 1998). Seiber states further that:

The ethics of social research is about creating a mutually respectful, win-win relationship in which participants are pleased to respond candidly, valid results are obtained, and the community considers the conclusions constructive.  
(Seiber, 1998, p.128)

Consequently, decisions made regarding the methods employed in a study are inseparable from ethical decision making, a view endorsed by Markham, who states that:

Every method decision is an ethics decision, in that these decisions have consequences for not just research design but also the identity of the participants, the outcome of our studies, and the character of knowledge which eventually grows from our field of work.  
(Markham, 2005, p.796)

As discussed in Chapter Nine (pages 184-186), ethics are central to Westernised ideologies including the research process. This positive regard for ethics within the context of the research process draws heavily upon traditional medical ethics, which are adapted for social science researchers (Homan, 1991). These principles pay special attention to the well-being of participants in any type of research. Downie & Calman (1987) cited in Homan (1991, p.13) state that “in research on man [*sic*], the interest of science and society should *never* take precedence over considerations related to the well-being of the subject” (emphasis added). This view confirms the importance of the well-being of participants. It also reinforces the concept that when conducting research using human subjects, it is necessary that the researcher pays attention to the ethics of their investigation.

### **Gaining ethical approval: the original study**

As discussed in Chapter Four, ethical approval for the study was sought from the University of Huddersfield’s School of Human and Health Sciences Research Ethics Panel (see page 75). In the preparation of my ethics application I envisaged that the

entire process, including the preparation of the relevant documentation, completion of the pro-forma ethics application and the accompanying risk assessment document (see Appendix 9.1-9.9, pages 318-340) would take a period of six months. This was a realistic timeline as I began work on the preparation of relevant material in October 2007, I submitted my ethics application on 9th January 2008, and I was granted ethical approval in March 2008. I now briefly describe some of the aspects incorporated in my original ethics application.

### **Gaining access**

Permission to access patients had been given by the medical director of the first assisted conception unit approached to collaborate with the study, subject to prior ethical approval as outlined above. It was intended that research participants would be recruited via this clinic. The identification of those suitable for inclusion in the study would be undertaken by distributing an information leaflet at the clinic.

### **Confidentiality and anonymity**

Participants' rights to confidentiality were to be maintained throughout the study. All elements of the study were to be conducted to ensure compliance with data protection legislation and the University of Huddersfield's requirements relating to secure data storage.

Prior to data collection commencing, participants were to be reminded and reassured that all data collected as a result of their participation would be treated as confidential. They were also to be informed that no identifying data would be shared with a third party, included in the thesis itself or in any other material written or published from the study.

In view of personal health issues limiting my ability to operate a computer keyboard for an extensive period, it was going to be necessary to employ another person to undertake the transcription of the data. Participants were to be advised that the person transcribing would also be required to provide a written assurance of their agreement to adhere to the confidentiality and data protection regulations set out by the University (see Appendix 9.9, page 340).

Participants would be asked to sign a consent form prior to the interview. This makes explicit reference to arrangements for maintaining participants' confidentiality as outlined above (see also Appendix 9.8, pages 338-339).

## **Obtaining informed consent**

Seiber states that:

Informed consent means far more than a consent statement – it means communicating respectfully and openly with participants and community members throughout the project, respecting autonomy and life-style, and providing useful debriefing about the nature, findings, and value of the research and its likely dissemination.  
(Seiber, 1993, p.19)

Thus, I acknowledged that obtaining consent was not a one-off event but rather an iterative process, a process that requires the researcher to check at intervals, during the progress of a study, that consent is still valid (Murray & Sixsmith, 1998).

In the original study I devised a consent form that was to be given to participants. They would be asked to read and sign it if and when they agreed to participate in the study. As discussed, I was aware that obtaining consent is not a one off event and that it may become necessary later in the study to confirm consent was still valid. This check would also be undertaken to assess whether participants still consented to the use of their non-identifying data to be used in the writing of the thesis and any published work that arose from the study.

I now describe how these ethical considerations were incorporated into the revised study. I also illustrate how the ethical issues pertinent to the methodology of Internet research were considered, prior to their integration into the study.

### **Planning ethically responsible Internet research**

As discussed earlier in this chapter, the study complied with relevant ethical requirements guidelines throughout its development. This overview of the fundamental ethics of social research was no different when conducting an Internet based study such as this. However, in addition, specific attention was given to how, due to the sensitive nature of the study, and the nature of the e-interview process, the well-being of participants could be protected.

The first area on which I concentrated was the obtaining of informed consent, the completion of consent forms and how the process could be managed online. I then focused upon confidentiality and anonymity before moving on to consider identity verification and overcoming the absence of non-verbal communication between myself

and research participants. This led to a consideration of the nature and purpose of debriefing participants and how this could be managed online. The final ethical consideration undertaken was with regard to the well-being of both myself and the research participants. This meant that I paid specific attention to my communication with participants as discussed in Chapter Five. This led to me thinking carefully about my choice of words, the timescales involved in the e-mail exchanges, and how these might affect my perception of participant well-being. I also gave consideration to the affect that this might have on participant's self-reporting of well-being.

I now describe how I gained ethical approval for the revised study. I then give specific attention to the additional ethical issues that needed incorporating in the study. This attention is warranted due to the relatively new method of data collection used. I now describe how I had to revise my ethical decisions in light of the change in data collection methods described in Chapter Five.

### **Gaining ethical approval: the revised study**

Following the need to revise my data collection method it was necessary to submit a revised ethics application to the School Research Ethics Panel. In the first instance, I sought advice about the intended change to data collection methods with the Chair of the Panel. Subsequently, a thorough analysis of the potential ethical implications that this method might pose, including my own internet safety, was undertaken, prior to submitting a revised ethics application (see Appendix Ten, pages 341-345) which was later approved.

In addition to adherence to aforementioned codes of practice (see page 75) the study also adhered to Internet-specific codes of practice produced by the Association for Internet Researchers (Ess and AOiR, 2002) and the British Psychological Society (2007).

### **Obtaining informed consent**

In considering how informed consent could be gained from online participants I was guided by the work of Seiber described earlier in this chapter (see page 111). However, I would also suggest that the voluntary nature of the research process, combined with the right to withdraw from the research, served as a reinforcement of the consent process. If participants had chosen to withdraw from the study, or to not answer questions that were sent to them, this would have provided an indication as to whether

their consent was still valid, a principle to which I return later in this chapter (see pages 116-117). However, my first considerations focused upon how I could obtain informed consent from participants in the 'virtual realm'.

Traditionally, informed consent is obtained by requesting participants to sign a consent form, a practical method best suited to face-to-face interactions (Bryman, 2008). However, when using online methods of research, obtaining and confirming informed consent is not so straightforward, although Sharf (1999, p.247-249) states that once "an investigator solicits respondents to participate in an on-line survey or interview... those who do respond have made a conscious choice to do so". In this sense, consent can be assumed (Sharf, 1999). Although acknowledging the view enunciated by Sharf, I chose to adopt a more rigorous approach to obtaining informed consent.

Initially, I considered mailing out a consent form to be signed and returned by post. However, there were no assurances that the signature on the returned form would be that of the participant (Bennett, 1998 cited in Mann & Stewart, 2000). I then considered asking participants to print, sign and return a form by post. The form would have been sent electronically in the first instance, as I would not have had their addresses. It also seemed most appropriate to send it electronically as initial contact with participants had been made electronically. Again, as there were no assurances that the form returned would be from the consenting participant, I believed that this method would not be suitable (Mann & Stewart, 2000). I chose instead to send the consent form as an e-mail attachment, a method of obtaining informed consent similar to that used by Beck (2005) in her study of birth trauma.

Beck (2005) sent interested participants details about her study and the consent form as attachments for electronic completion, although she does not comment upon the efficacy of the method. However, in my summation of this approach I am able to demonstrate that it is a method of obtaining consent that works, with the right level of planning. Furthermore, the utilisation of this approach meant that certain strategies could be put in place to ensure that consent was being obtained from the relevant individual.

These considerations led to a thorough revision of the original consent form so that it was suitable for electronic completion. The form explained the nature and purposes of the study, described how participants' identities would be protected, and the methods

that would be used to store their data. The information also reminded them that they were free to withdraw from the study at any time, without the need for any explanation.

### **Completing the consent form**

To complete the electronically dispatched consent form (see Appendix Eleven, page 346) participants were asked to check the boxes to indicate that they had read, understood and agreed with the statements provided. At the end of the form they were asked to write a short sentence stating that:

They had read the consent form, that they had had the opportunity to ask questions and that they understood that they had the right to withdraw from the study at any time with no consequences for themselves.

(Adapted from McCoyd & Kerson, 2006, p.394)

Participants were informed that, if they encountered any problems opening or downloading the attachment, to let me know by return e-mail, so that I could organise an alternative way for them to provide informed consent. This happened on one occasion – subsequently, the consent form was copied into the body of an e-mail which was returned to the participant. She was able to complete the form and return this by e-mail.

### **Managing the consent process**

Once consent forms had been obtained from participants the attachment was saved and assigned a unique identifying number, before it was stored in a separate password protected, encrypted folder. A hard copy of the form was then printed and stored in a secure, locked location at the University of Huddersfield. Participants were also reminded throughout the e-interview that they were free to withdraw from the study, at any time, should they wish to do so, thus ensuring that participants maintained their right to be autonomous individuals (Cormack, 2000; Bryman, 2008).

Finally, participants were offered the opportunity to see how their stories had been incorporated into the thesis. In this way, in keeping with the iterative nature of the consent process employed in the study, participants' consent to the use of their data was undertaken before the final submission of the thesis. To do this, contact was made with all four participants, via e-mail during the writing up phase of the study. They were informed that thesis submission was imminent and they were then re-offered the opportunity to be sent the extracts of the thesis that contained their data. This offer was

taken up by all four participants and, once their identity had been verified (using the aforementioned security question); the relevant documentation was forwarded to them via e-mail.

Whilst awaiting their responses regarding the use of their data, I accepted that I was taking something of a risk. I knew that the nuances of participants' stories might be lost if they asked me to omit any part of their stories from the thesis. It might have also caused participants to become defensive about the way I had undertaken the analysis and interpretation of their stories (Bryman, 2008). However, as I had endeavoured to be an ethical researcher whilst conducting this sensitive study, I could not, in all conscience have submitted the thesis, or contemplated the production of other written outputs, without first referring back to participants about the use of their data. So, this was a risk that needed to be taken. Adopting this procedure also made the process a collaborative and democratic one in that it reduced the power imbalance that can be experienced between researcher and the researched (Tindall, 1994; Bryman, 2008). Furthermore, in the application of this approach to data verification, participants were able to see how confidentiality and anonymity had been maintained.

### **Maintaining confidentiality**

The following protocols were employed to maintain participants' rights to confidentiality throughout the study. All data collected from the e-interviews were cleaned of all potentially identifying information, including e-mail addresses and names of spouses/partners (where included), before being copied into the password protected Word document that was being used to collate the data. Thus, all elements of the study complied with both the conditions set out by the 1998 Data Protection Act and the University's requirements for the secure storing of data. Participants were informed during the consent process that these methods would be used to ensure that their data remained confidential.

### **Anonymity**

Protecting the identity of participants is of paramount importance when conducting social research using traditional methods of data collection. This is no different when recruiting online - through support groups or online forums. Participants' identities needed protecting and the use of pseudonyms was the way in which this was undertaken.

At this point, though, it is crucial to note that, as participants were recruited from an online forum, they may have already been interacting in the 'virtual' world using a pseudonym. It was therefore deemed necessary to ensure that they were allocated a dedicated pseudonym for the purpose of the study – thus further protecting their identities, particularly since some studies have suggested that people in online communities using pseudonyms actually care about the reputation of their pseudonym and may treat it with the same regard that they have for their real names (Donath, 1999; Bruckman, 2002). Additionally, the pseudonyms they use online may identify them if they were to be used in dissemination of any material arising from their participation in a study such as this, so a method was developed to manage the assignation of pseudonyms for the study.

A collaborative approach to the assignation of pseudonyms was used. Participants were offered, via e-mail, a list of pseudonyms from which to choose, the list having been devised using an Internet search to identify women of historical significance in Britain (see Appendix Twelve, page 347). The selection of a pseudonym from the devised list was optional. Participants were offered the opportunity to select their own pseudonym, if they preferred. This option gave them more control over their representation in the study. For me, this represented a more personalised approach and was also in keeping with the sensitive approach used in the study.

Each time a pseudonym was chosen by a participant that name was removed from the list. The updated edited list was sent again by e-mail to new participants. Pseudonym assignation was not, in fact, undertaken until the e-interviews were at their conclusion, once I had developed a rapport with the 'real' identities (or so to speak, see identity verification below) of the participants at the other end of the computer network. Participants were reminded, at the stage when they chose their pseudonym, that this would be used to protect their identities, in both the thesis and any subsequent publications.

### **Identity verification**

The reliance upon online communications meant that it might be difficult to verify a person's identity. This posed a minor dilemma, though as Horn (1998, cited in Mann & Stewart, 2000, p.197) states "you don't have any more guarantees that someone is who they say they are just because you can see them". Take, for example, the work carried out by Garfinkel (1967, cited in Denzin, 1989, p.38). Garfinkel had interviewed 'Agnes' over an extended period of time before it emerged many years later that he



had been told falsehoods. These falsehoods meant that the story he had been told changed, when 'Agnes' disclosed that she had deceived him about a sex change. Subsequently, Garfinkel wrote the story Agnes wished to be told rather than the truthful version of that story. In principle, this means that one has to assume that participants are not being deceitful in their interactions in the research process, although this may prove more problematic when conducting research online. However, there were a number of measures that I incorporated into the study to aid identity verification and to reduce possible identity deception.

Mann & Stewart (2000) suggest that the statements people make online are probably aimed to be truthful. Subsequently, the way responses to questions are formed can give an indication as to whether the person is who they say they are. This view is discussed in other studies (see for example, Donath, 1996; Shepherd, 2003; Hamilton & Bowers, 2006), thus supporting the notion that the way meaning is communicated in written form can alert the reader to the identity of the writer. This does not mean that a participant's 'real' identity is disclosed, but that the nuances of written communication can alert the researcher to potential deceptive intrusions in the data collection process.

As the study involved communicating with women I was confident that it would be possible to ascertain whether I was actually conversing with another woman. Crucially, the way language is used by men and women differs. It is argued that women's language use and their written word is less confrontational and more affiliative than that of their male counterparts (Gilligan, 1982). That is, women's language use is epitomised by the integration of a consideration of others in both spoken and written form, a feature that is excluded in men's language (Francis et al., 2001). Thus, I believed I would be able to identify the gender of the participants through the language and their words, as they were revealed on screen.

Due to the nature and focal point of the study, I believed that it might also be more difficult to continue to assume a persona that is not authentic, such as a man attempting to disguise himself as a woman, because of the type of questions I posed. This view is discussed by Donath (1999), who cites the work of Goffman (1967) and his concept of the presentation of self, in particular the 'expression given off' and the fact that it is harder to pretend to be someone else and maintain that pretence over time. Consequently, as Donath (1999, p.38) suggests, sustaining "a voice and reactions that are convincingly a woman's may prove to be quite difficult for a man".

As the study focused upon exploring decision-making and informed consent within the context of becoming an egg share donor, I believed that it would be difficult for anyone other than a woman to answer the questions posed, due to their gender-specific nature. Consequently, the nuances of the interplay between male and female use of written language was used as an indicator as to the identity of the participants. Furthermore, as the questions I asked in the study focused upon aspects of reproductive histories, infertility diagnosis, and the treatments pursued prior to egg sharing. This in itself, it could be argued, would make it difficult for anyone other than a woman with these experiences to successfully maintain a false persona for anything other than a short period of time. Additionally, it has been suggested that “knowledge of the substantive areas being addressed can be viewed as a test of authenticity” (Hamilton & Bowers, 2006, p.824), in that difficulties answering questions about a specific aspect of the research (for example in this study, the specifics of being an egg share donor) might be used as an indicator of potentially deceptive behaviours. Again, this might provide a level of assurance as to the identity of the online participant.

An additional measure employed in this phase of data collection was the inclusion of a security question. Participants were asked, intermittently, to answer the question to which they had provided the answer at the outset of the study. This enabled identity authentication to be undertaken throughout the e-interview process. This security measure was also used in the follow up e-mail exchanges with participants regarding the sharing of the data and findings with them.

### **Debriefing**

At the end of the interview process a debrief statement was sent as an e-mail attachment in keeping with the online nature of the study. Participants were asked to verify that they had read and understood the statement. They were also asked whether they had any further questions for me now that the e-interview was complete. In the statement I indicated that I would contact them by e-mail a week later to check on their well-being and to find out if there was anything else they would like to add to their answers. They were reminded that they could contact me at any time should they have any questions or any concerns regarding their participation in the study. Finally, participants were reminded that their anonymity would be maintained at all times.

### **Participant safety**

Additional counselling and support was to be made available to participants recruited through online forums should the need arise. As in the original study design, this support could be provided via the nationwide independent counselling service offered by the British Infertility Counselling Association (BICA). Funding had been allocated so that any such support required by any participant could be provided at no cost to her. In the event, the need did not arise.

### **Researcher safety**

The British Sociological Association places an emphasis upon safety issues in relation to social research. It pays particular attention to the safety of researchers and states that:

Social researchers face a range of potential risks to their safety. Safety issues need to be considered in the design and conduct of social research projects and procedures should be adopted to reduce the risk to researchers.  
(BSA, 2002, p. 2)

Furthermore, it has been mooted that:

Subjectivity and collaboration makes the researcher vulnerable. Emotionally immersed in the lived experiences of others, continually sensitive to the potentially injurious nature of language, and experiencing the rights [*sic*] of passage as an interviewer/observer-all require an inner strength that can be enhanced by self care. The researcher can use the ethics committee as a guide and support through the process. [He or she] can use debriefing to explore personal responses and weigh risks/benefits. Personal education in ethics and consultation with experts when it is believed that the... researcher is being hurt is advocated.  
(Robley, 1995, cited in Carpenter, 2007, p.68)

This need to consider researcher safety was an issue that underpinned the study from its inception. Here the burden was upon personal and psychological safety whilst undertaking the fieldwork. Issues that I considered relevant to my own safety included: suitability, psychological well-being and emotional health. As discussed previously (see Chapter Five) at the time of accepting my studentship I was aware that there were a number of factors that might have an impact on my undertaking the study. One of the main areas that required some consideration was related to my suitability to undertake the study.

,Prior to commencing the study my Director of Studies prompted a discussion regarding the impact that my involvement in the study might have on my psychological well-being. It was suggested that making use of the counselling facilities provided by the University should be considered if the need arose. Knowing that this support was available to me should it be needed was of value.

During this first phase of fieldwork, additional support was necessary. This was because I began to experience researcher fatigue due to the somewhat intense nature of the e-interview process. Indeed, Egan et al., (2008, p.1290) suggest that the use of e-interviewing can cause interviewer fatigue because the method has no “temporal parameters”, e-mail can arrive at any time which means the researcher is constantly in “research mode”. Moreover, they suggest that prolonged engagement in the field combined with the simultaneous nature of e-interviewing can make it difficult to withdraw from the field (Egan et al., 2008).

In my case, I found that conducting e-interviews simultaneously increased my need to maintain focus. My ability to respond sensitively was also somewhat compromised in that it took me longer to frame my responses to participants in a way that was conducive to the e-interview process because I was dealing with more than one participant at the same time. I also found that some of the responses given by participants affected me emotionally (see pages 253-256). This is a theme echoed in the work of McAuliffe (2003), who found that in her e-mail interviews with social workers she paid particular attention to her responses to emotive answers from participants. Indeed she states that at times she ‘agonised over’ her responses as she sought to ensure that her words conveyed the right message and context. For me, this proved to be a useful lesson as I, at times, struggled to comprehend the gravity of the experiences being shared with me on the computer screen. However, through engaging in reflection I was able to manage the process whilst accepting that I might need to be better supported.

Therefore, in order to better manage my emotional well-being I used the support set up for me. This enabled me successfully to manage my online interactions with participants. It also meant that I was successfully able to complete data collection whilst alleviating any long-term effects that my prolonged engagement in the study may have had upon me. This ensured my own personal well-being was maintained throughout.

### **Ethical considerations: the online survey**

As the second phase of data collection was also conducted online, using the self-completion survey, additional ethical principles were employed. Initially, advice was sought from the Chair of the School Research Ethics Panel, from which I ascertained that there would be no requirement to submit another application since my previous ethics applications had been sufficiently comprehensive. Nevertheless, due to the nature of the online survey, it was necessary to address a number of additional ethical principles.

As the survey was conducted online and, as such, was reliant upon a convenience sample, I provided potential respondents with a clear and concise overview of the nature of the survey, and the methods employed to maintain anonymity and confidentiality. For respondents who completed the entire survey a debrief statement of thanks was provided at the end.

### **Chapter review**

In this chapter I have described the ethical considerations that underpinned the development of the original study as described in Chapter Four. I built upon these discussions by explaining how my original planning was incorporated into the ethical protocols that underpinned the revised study. I have also demonstrated how I went about gaining approval for both the original and the revised studies. I provided a brief overview of the ethical protocols that were developed for the original study. I then paid specific attention to the development of the ethical protocols that underpinned the use of e-interviewing. This is demonstrated through my comprehensive discussion of the ethics associated with conducting e-interviews.

My analysis demonstrates that it is possible to overcome the ethical ambiguities associated with Internet research. This is evident in my discussions of the informed decisions that were made as a direct result of those considerations. Finally, I describe the considerations given to the ethical issues associated with the integration of the online self-completion survey. This demonstrates that throughout each phase of the research process, I gave careful consideration to the role of ethics in social research.

In the following chapter I describe how I undertook the detailed analysis of the data from the self-completion online survey and the e-interviews. This begins with an overview of the methods used in the analysis of the survey data. The chapter then

returns to the voice-centered relational method of analysis. In presenting my review of the method I elucidate the various elements of the analytical process and describe the purposes for which they are employed. I then illustrate how this methodological approach to data analysis was undertaken in this phase of the study.

In the final section of the chapter I discuss the establishment of data validity within the context of the study. I do this by providing justification for the approaches integrated in the study in my attempts to demonstrate its validity.

## CHAPTER SEVEN

### Analysing the data

*When we raise questions, gather data, describe a phenomenon, and construct textual interpretations, we do so as researchers who stand in the world...*  
(Van Manen, 1990, p.1)

In this chapter I present an in-depth discussion of the methods employed in the analysis of the data. The chapter begins with an overview of the methods employed to analyse the online self-completion survey and explains how and why I undertook analysis the way I did. I then provide a comprehensive account of the analysis of the e-interviews. This provides an expanded discussion of the features of the VCRM approach to data analysis used in the thesis. I then demonstrate how these methods of analysis were employed as I sought to extrapolate the 'lived experiences' of the women who had taken part in the study. This is illustrated by my explanation of how I was able to make sense of, and understand, the experiences of participants as they were told to me.

The next chapter section provides an in-depth discussion of how the validity of qualitative research can be established. I draw extensively on the work of Yardley (2000, 2008) and explain how I applied the principles she advocates into the study. Finally, the chapter concludes with a discussion surrounding the triangulation of data, in particular, the way the approach was used to enhance the validity of the findings in the thesis by combining the findings from the methods of data collection.

#### **Analysing the self-completion surveys**

In the analysis of the surveys I followed the suggestions of Aldridge & Levine (2001) to ensure the:

Creation of illuminating accounts, persuasive narratives and plausible explanations, grounded in the survey findings, concerning the social structures, groups, and processes under investigation.  
(Aldridge & Levine, 2001, p.135)

Thus, survey analysis enables the researcher to make inferences about the sample population based on respondent answers. However, before embarking on analysis, it

was necessary to make a number of decisions regarding the inclusion or exclusion of responses. As discussed briefly in Chapter Five (see page 107), twenty six individuals responded initially. However, following detailed scrutiny a number of these returns had to be excluded from analysis. This was primarily because the data captured by the incomplete returns were predominantly demographic information – only the first four or five questions had been completed. There was nothing to be gained by the inclusion of incomplete returns because information concerning experiences of being an egg share donor had not been provided. This left thirteen completed surveys for analysis. It did, however, cause me to reflect on the process of administering self-completion surveys on the Internet. A downside evident in the study is the inability to control for the submission of incomplete returns. A possible explanation for this is that some returns may have been abandoned since, at the time, BOS did not permit respondents to save, exit from and then return to the survey later to complete it, (this feature is now available with BOS). Were I to use BOS again, I would make use of this facility, in the hope that it minimises non-completion rates.

Turning to the preliminary analysis of the self-completion surveys, I first ascertained the level of data upon which analysis could be based. As I was working with nominal level quantitative data I needed to adopt an appropriate analytical approach. Nominal level data are those that have categorical values which can be counted to make comparisons between subgroups of the sample surveyed (Coolican, 2004). Thus, “the numeric codes assigned in nominal measurement are not intended to convey quantitative information” (Polit & Hungler, 1999, p.440). Instead, the data are used as a means of categorising the features or attributes of the sample population. Such data cannot be subjected to mathematical calculations other than counting the data in each category (Oppenheim, 1992) so that statements can be made regarding the similarities and differences in the sample population based on the nature of the survey respondents completed (Polit & Hungler, 1999). Such statements are, however, somewhat restricted - the data cannot be used for anything other than descriptive analysis.

As noted earlier in the thesis, I chose to use the inbuilt functionalities of BOS for the study to aid descriptive analysis that enabled me to interweave the findings from the survey with the e-interview data (see Chapter Ten). This meant that I had qualitative data complementing the quantitative data from the online survey. I was able to use one of the features of VCRM to undertake thematic analysis of the qualitative data captured by the online survey. I chose to omit the first two stages advocated by the VCRM



approach because of the deficiencies in the contextual elements captured by the surveys. This did not mean that the stories of the survey respondents did not merit focused attention. Instead, the decision not to produce case studies or 'I' poems for the survey respondents was linked to the type of data collected and the unavailability of sufficient data to merit this approach. Regardless of this omission it was still possible to compare, contrast and integrate themes that emerged from both the online survey and e-interviews.

### **Locating associations**

In my examination and analysis of the survey data I sought to establish any interesting associations evident in respondents' answers. To do this I used the cross-tabulation tool available in BOS to extract information regarding the associations between, for example, the onset of infertility, access to egg sharing and the decision to become an egg share donor. By undertaking this level of analysis I was able to generate a clearer understanding of the journey to egg sharing that was experienced by the survey respondents (see Chapter Eight). Again, this enabled a more comprehensive representation of the survey respondents to emerge, from which to extract the findings presented in the thesis. This enabled me to link my findings to the theoretical concepts discussed later in the thesis (see Chapters Nine and Ten). It also provided me with an opportunity to develop wider theoretical thinking around the decision to become an egg sharer. This conceptual thinking encompassed the wider relational implications and impact of these decisions.

### **Background to e-interview analysis**

Whilst undertaking the e-interviews I became familiar with the stories that had been vocalised by participants. This connection with the data from an early stage enabled each reading (of the e-interview data) to provide a re-familiarisation with the stories that had been recounted. This process enabled analysis to feel less "messy, confusing and uncertain" (Mauthner & Doucet, 1998, p.122). Nevertheless, my familiarity with the data before formal analysis began did not detract from the fact that the whole process was somewhat daunting yet exhilarating. They suggest that the early stages of data analysis cause uncertainty because we do not yet know what to think about the stories that will emerge from the data. They state that analysing the data is where we:

Learn from and about the data; to learn something new about a question by listening to other people. But while this sense of not knowing and openness is exciting, it is also deeply uncomfortable. (Mauthner & Doucet, 1998, p.122)

Feeling uncomfortable was a concept that resonated within me as I began formal analysis. This was partly related to the 'emotional' aspects of the study (see pages 67-69 and 96-97), combined with the knowledge that I wanted to do justice to the stories participants had shared with me. At times I felt overwhelmed by the task as I attempted to make sense of these stories. As I approached each phase of data analysis I was guided by my personal responses to the stories as they unfolded. I now move on to demonstrate how I worked through each stage of the analytical process.

### **The voice-centered relational method (VCRM)**

The VCRM of analysis employs sequential readings of, or listenings to, the text in order to gain a greater insight into the meanings that emerge from the data. It is a process of psychological analysis that enables the human psyche to become evident. Subsequently, it renders visible the previously silent, invisible inner life-world of a person through their accounts of their experiences. It focuses upon the distinct characteristics of individuals, and the embodied nature of their experiences, to be situated culturally, historically and relationally (Gilligan et al., 2003). As such, it is a method of analysis that fits with the philosophical approach of hermeneutical phenomenology underpinning the study as detailed in Chapter Three.

As a method of conducting analysis an emphasis is placed on the multiplicity of meanings that can emerge from the same data set thereby allowing a greater understanding of the lived human experience to emerge (Gilligan et al., 2003). Each separate reading has a particular role within the analysis process. I will now illustrate how each of these readings was utilised in the analysis.

In the version of the VCRM approach utilised in the thesis, 'listening' to the text is advocated in order to locate emergent findings; however I was 'reading' text. So, whilst I might use the terms 'reading' and 'listening' interchangeably throughout the ensuing discussion, I would urge the reader to retain the idea that the term 'reading' is used to signify a 'listening to', and 'for', the emergent findings as they were located within the text of the transcripts.

### **Reading one: responding to the donors' shared experiences**

The initial reading (listening) comprised two distinct stages: (1) reading for the overall plot, the story that is being told, and (2) locating and reading for the researcher's reactions to the stories being told. The researcher locates herself in relation to the person who has been interviewed, bringing her own background, experiences and history into this reading (Mauthner & Doucet, 1998; Gilligan et al., 2003; Martin, 2008). Thus, analysis is transformed from an act of simply reading the data to one which involves actively listening to the narratives the data are telling (Brown & Gilligan, 1992).

As I read the participants' stories of their personal experiences of egg sharing, I listened for the overall plot, the main events, subplots, and protagonists behind their narratives and the way in which these were voiced (Mauthner & Doucet, 1998). I listened for recurrent words and phrases, and for any contradictions that arose from the voices of the women. As I listened I attended to the nuances of language, and the way the participants conveyed their experiences in relation to their wider social interactions.

This process relied on a reflexive approach to the analysis. In locating myself and my reactions to the stories as they emerged I acknowledged that my interactions with the data might shape the way in which I attempted to interpret what I could 'hear'. In examining my own views and assumptions, I was able to contextualise what I was hearing in relation to my own personal biography and my reactions to what I heard. Brown describes this first listening as one that requires:

...the listener/interpreter to consider her relationship to the speaker or text and to document, as best she can, her interests, biases and limitations that arise from such critical dimensions of social location as race, class, gender and sexual orientation, as well as to track her own feelings in response to what she hears – particularly those feelings that do not resonate with the speaker's experience.  
(Brown, 1994, p.392)

I also used the 'worksheet' technique (see Appendix Thirteen, pages 348-349) described by Mauthner & Doucet (2003, p.419), which requires the researcher to document their reactions and interpretations to the words spoken by the participant. Using two columns (one for the participant, the other for the researcher) personal reactions to the data are recorded. The researcher is then able to view how their own assumptions may affect their interpretation of that which has been spoken as this may later affect the way in which that participant is written about (Mauthner & Doucet, 1998;

2003; Gilligan et al., 2003). Mauthner & Doucet describe the rationale and potential benefits behind reading and documenting personal responses in this way and state that:

This reading is based on the assumption that locating ourselves socially, emotionally and intellectually allows us to retain some grasp over the blurred boundary between the respondent's narrative and our interpretation. Failure to name these emotions and responses might lead them to become expressed in other ways...This reading is also premised on the epistemological assumption that our intellectual and emotional reactions to other people constitute sources of knowledge.  
(Mauthner & Doucet, 2003, p.419)

Documenting my initial personal responses in this way provided me with an audit trail to which I could return during analysis, enabling me to scrutinise further the meanings inherent in the stories that were told. At this stage of the analytical process I also developed the case studies presented in Chapter Nine. This enabled me to maintain a holistic approach to the ensuing analysis.

### **Reading two: locating 'I' within the context of donors' experiences**

The second reading requires the researcher to recognise the use of the personal pronouns ('I', 'me', 'you', and 'we') – expressions of the self – as they are voiced by the participant. Listening to the data in this way enables a clearer understanding of the way in which the participant voices her experiences in relation to others and her story. Used in a similar way to that described by Brown & Gilligan (1992), Mauthner & Doucet (1998) and Martin (2008) this reading comprised two stages.

The first step used to identify the use of the personal pronoun was to colour code the interview transcripts. Physically tracing the personal pronoun in this way, using a highlighter pen, enabled a better focus upon the way in which participants voiced their experiences, to be undertaken. It also highlighted how they spoke about themselves within the context of their choice to become an egg share donor. It amplified their use of the personal pronoun – it also documented the way in which participants switched from talking about the first person 'I' to using 'we' or 'you'. This change in the way in which participants vocalised their experiences enabled a greater understanding of their perceptions of themselves as they changed within the context of their experiences. Listening for the 'self' in this way, as described by Brown & Gilligan:

...brings us into relationship with that person, in part by ensuring that the sound of her voice enters our psyche and in part by discovering how she speaks of herself before we speak of her.  
(Brown & Gilligan, 1992, pp: 27-28)

Consequently, analysing the data in this way allowed me to respond both intellectually and emotionally to the experiences that were voiced as they unfolded. It allowed me to document my responses to them and enabled me to try to get to know participants on their own terms as their stories were recounted, then listened to and then analysed (Brown & Gilligan, 1992). It also enabled me to reach a greater understanding of egg share donors' lived experiences and the interrelatedness of these experiences with their life-worlds. At this stage I also developed the 'I' poems (see pages 177-183). These poems reinforced the process of listening for the use of the personal pronoun.

### **Reading three: revealing relationships within the context of egg sharing**

This reading paid specific attention to the way in which relationships were voiced. Its focus was upon interpersonal relationships and the interplay between these and participants' experiences of egg sharing. In this reading I was interested in finding out how participants spoke of and about "their interpersonal relationships, with their partners, their relatives... and the broader social networks" (Mauthner & Doucet, 1998, p.131).

Following the method described by Mauthner & Doucet (1998) I used different colours to highlight and trace words with specific reference to relationships. I was able to distinguish changes in the language used ('we' or 'they') and the way in which they described their experiences with regard to their social relationships. This reading allowed the interplay between what is spoken about and the way it is spoken about to become clear. This reading distinguished several different relationships encountered by the participants. Relationships that were vocalised were: marital relationships, relationships with clinic staff, relationships with family and friends, the donor-recipient anonymous relationship, relationship to the potential child/children and relationships with online community forum members. Each of these relationships was spoken about in different ways and the use of language altered, depending upon the type of relationships participants had or were perceived to have with the aforementioned groups.

#### **Reading four: egg sharing within social and cultural contexts**

The fourth reading involved locating participants' experiences "within broader social, political, cultural and structural contexts" (Mauthner & Doucet, 1998, p.132). In doing so this allowed me to consider the participants 'in relation' to the wider psychosocial factors regarding their motivations to egg share. This reading enabled me to contextualise participants' personal experiences of egg sharing (reading two) with the wider social structures and contexts associated with infertility and the provision of fertility treatments. As such, I was able to understand the role that wider social relationships and structures had for egg share donors, and the part they played in their decision to become donors. It allowed me to explore the concept that egg sharing does not take place in isolation from social structures but in relation to these existing structures. This relational ontological position enabled me to examine and develop an understanding of participants from within their social context.

These structures, all of which had relevance to the main aims of the study, included: the existing family, the welfare of any child who might be born from their donation, the implications for their own child/children who had been or might be born, and the changing nature of the family dynamic (possible genetic half-siblings), social reactions to egg sharing and the impact of economic and political structures.

#### **Producing case studies**

Before moving on to what Mauthner & Doucet (1998, p.134) describe as the "reductionist" stage of analysis, whereby data are "cut up into themes and aggregated", a case study was produced. In my adaption of the principles underpinning the VCRM I chose to undertake the production of the case study in conjunction with the first reading of the transcript. This meant that I documented and summarised participants' narratives as they were recounted. I also documented my personal responses to their narratives before moving on to conduct further listenings.

These case studies provide an intimate portrayal of the experiences of egg share donors in relation to wider social contexts (see pages 166-177). They also provide a fascinating overview of their personal biographies prior to and during their egg sharing experiences. This maintains the holistic view of the participants, which may sometimes be eliminated when data are subjected to the reductionist phase (Mauthner & Doucet, 1998).

### **Constructing the 'I' poems**

Drawing on the work of Elizabeth Debold (1990) cited by Gilligan et al., (2003) I incorporated the development of the 'I' poem into the second phase of the voice-centered approach to analysis. The construction of the 'I' poems is undertaken in the conscious attempt to get closer to the nuances of the data. It encourages the researcher to assess how participants speak of themselves. Thus, it creates a "tuning in" to the data whereby the distinctive rhythms and cadences of the voices can be heard (Brown & Gilligan, 1992).

The development of the 'I' poems is governed by two rules of construction. These are: 1) "underline or select every first-person 'I' within the passage you have chosen along with the verb and any seemingly important accompanying words", and 2) "maintain the sequence in which these phrases appear in the text". The poem is then constructed using the highlighted sections of the transcript (Gilligan et al., 2003, p.162).

Utilising this additional strategy provided me with the opportunity to focus more specifically on the personal narratives of participants (see pages 177-183). Thus, the incorporation of the 'I' poem enabled me to pick up on the "associative stream of consciousness carried by the first-person voice, cutting across or running through the narrative rather than being contained by the structure of full sentences" (Gilligan et al., 2003, p.163). Therefore, rather than the subtleties of the use of the personal pronoun being overlooked, this method imposes a closer scrutiny of its use within the context of the narrative being told. It brings the researcher closer to the words, "rhythms, and shifts" in the language usage of the participants. The poems reflect the shift in meaning that occurs in the stories told by participants, often they will "fall readily into stanzas", at times they will not. Sometimes the poems are able to capture unspoken meaning that is "central to the meaning of what is being said. Other times it will not" (Gilligan et al., 2003, p.163). The development of the 'I' poem can be undertaken for the entire transcript, or 'I' poems can be produced for selected extracts of the transcripts (Gilligan et al., 2003). I chose to employ the first method in the study (see Appendix Fourteen, pages 350-359). However, for the purpose of the thesis only extracts of the poems are used to illustrate this process.

### **Thematic coding of the data**

The final stage of analysis used for the e-interview transcripts was thematic. Burman states that it is a method that:

...Is a coherent way of organizing or reading some interview material in relation to specific research questions. These readings are organized under thematic headings in ways that attempt to do justice both to the elements of the research question and to the preoccupations of the interviewees. (Burman, 1994, p.57)

Coding was undertaken manually even though I had been trained to use the software programme Nvivo. The rationale behind my decision to undertake manual coding of the data was purely pragmatic because I had undergone surgery to reduce a trapped nerve in my right elbow. This meant that my ability to use word processing and computer packages was disrupted at the precise moment when I needed to undertake the final stage of my analysis. As I found it easier to physically cut, as opposed to typing, I opted to print multiple copies of my transcripts which were subsequently cut up. These sections of the transcripts were categorised according to the meaning evident from the words portrayed on paper. This process was both inductive and deductive in that I induced what it was that was being said, in order to deduce what the meanings represented. In doing so, I produced a series of themes that were used for analysis purposes (see page 195).

This stage of analysis began with the development of the overarching themes evident within the data. Analysis of each of these broader themes then led to the emergence of sub-themes from which further subsets of themes emerged. Working with the data in this way I noted the inter-relatedness of the themes and the distinct characteristics that they portrayed.

At times, excerpts from the transcripts had multiple meanings and each of these meanings had relevance to the analysis. Consequently, multiple meanings were assigned to multiple categories wherever relevant – in keeping with the framework advocated by the VRCM approach to analysis. As analysis continued it became evident that many of the themes elucidated from the data merged with one another as the 'lived experiences' of the egg share donors became apparent.

As I worked through the process of "breaking down" the data in this way I was conscious that I might lose sight of the holistic approach advocated by VCRM. However, because of the nature of the method employed for the analysis I had become immersed in the data through the process of multiple readings, and was therefore able to maintain a holistic approach to analysis whilst attempting to reveal the lived



experiences of participants. In my attempts to delineate participants' narrative accounts I maintained a relational presence as a researcher whilst making sense of the accounts of egg share donors at multiple levels. Subsequently, as I read and re-read the transcripts, I focused upon every sentence and cluster of sentences as I attempted to locate the meaning of the experience(s) being recounted. This meant that I was able to maintain a close proximity to the data as I went about the process. Maintaining this presence meant that I focused upon what the written texts signified in relation to participants' stories as a whole. Remembering the distinct features associated with the way participants had told their stories and my responses to those stories as they had been told facilitated the development of my understanding.

### **Data validity**

Vigorous debate is ongoing about how the reliability and validity of qualitative research can be demonstrated (Yardley, 2000). Some of this debate stems from the inability to replicate qualitative studies in the same way as quantitative studies, since the social world, and the location of the participants, will change with time, thus changing the nature of the data gathered. There is also an awareness and acceptance that qualitative researchers have intimate connections with data collection and analysis which make it virtually impossible for a different researcher to generate the same findings (Denscombe, 2007). However, it is possible to demonstrate both the quality and validity of qualitative studies, a view endorsed by Whitehead (2003). In the study, a specific strategy was utilised in order to demonstrate the validity of the data collected.

### **Establishing data validity**

I chose to use the framework to establish data validity proposed by Yardley (2000; 2008) because of its particular relevance to researchers exploring health issues. Yardley's (2000; 2008) criteria are: "sensitivity to context", "commitment and rigour", "transparency and coherence", and "impact and importance". I also chose to include peer debriefing, member checks and data triangulation to demonstrate further both the transparency and validity of the study's findings.

### **Sensitivity to context**

In relation to this criterion, I endeavoured to maintain close proximity to the experiences of egg share donors as they were told to me, but these were embedded within the theoretical foundations underpinning the study. Thus, a critique of existing literature surrounding egg sharing from the donor's perspective was used to put the study into context (see pages 29-49). The philosophical framework of the study, hermeneutical

phenomenology, was chosen because of its emphasis on the extrapolation of the lived experiences of participants. Accordingly, it represented a philosophical approach that enabled me to examine the experiences of egg share donors as they were told, and to make sense of these experiences through the detailed analytical process described in the thesis. In doing so, I was able to locate and make sense of the experiences of the participants, whilst maintaining sensitivity to context in the way that the stories were told. I also examined donors' experiences in relation to the wider theoretical foundations of egg sharing. I took into account the political, psychological, social, socio-economic and structural factors that may impact on those choosing egg sharing, but also with regard to those experiencing infertility.

In maintaining this sensitivity to context I paid particular attention to the ethical issues pertinent to the study, during each stage of the development of the e-interviews (see pages 88-108). I also acknowledged my location as a researcher and the impact this may have had on the findings presented here. Thus, whilst taking into account the perspectives of participants, I recognised that my presence may have affected both the collection and the analysis of the data. Subsequently, I have attempted to make explicit the impact that my personal history and biography has had on the study.

### **Commitment and rigour**

I have maintained my commitment to the study throughout the three years it has taken me to complete this research. Moreover, whilst undertaking the study I immersed myself in data collection and analysis in order to “transcend superficial, ‘commonsense’ understandings” (Yardley, 2000, p.222). Thus, my prolonged engagement in the field whilst conducting the e-interviews led to a deeper insight into the personal lives of participants. It enabled the development of trust and helped to establish rapport with them, which also led to an empathic understanding of their experiences as they were recounted.

Over the course of the interviews this trust was evident as participants were happy to speak more generally about their lives and not just their attempts to overcome their fertility problems. I was told when children were ill or when work patterns had altered so that they were not available to answer questions. This development of trust, in relation to my commitment to the study, was evident when one participant sent me, by e-mail attachment, photographs of herself following a hospital admission for PCOS<sup>14</sup>. She

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<sup>14</sup> See Glossary.

also sent me her scan photos of the twins she was expecting as a result of her egg sharing cycle. Additionally, following their birth, she also sent a series of photos of her babies, as e-mail attachments.

Prolonged engagement also led me to learn the language of the women I interviewed. These were the common abbreviations that these women used to describe their involuntary childlessness, diagnostic procedures and the process of egg sharing, language that appeared natural for them to use. Such 'short cuts' might have been associated with the way they used language to communicate in online forums with other women experiencing infertility. However, this is a somewhat speculative notion and an area that was not explored further. Nevertheless, prolonged engagement throughout the e-interviews enabled me to generate rich, and in-depth, accounts of the experiences of egg sharing from the donors' perspective (see pages 165-230). In demonstrating my rigorous approach to data collection and the analysis, I also employed "methodological" data triangulation (Robson, 2002, p.174).

### **Coherence and transparency**

Yardley (2000) states that the coherence of a study can be demonstrated if there is a fit between the questions being researched and the methods utilised to conduct the research. In advancing this opinion Yardley (2008, p.249) states that coherent studies have a "solid grounding in the methods used and their theoretical background". In pursuing the ideas put forward by Yardley, I have included in the thesis comprehensive accounts of the processes involved throughout the study. The comprehensive documentation evidenced in the thesis should enable the reader to understand the rationale behind my decisions to revise the study in the way I did. Thus, I provide detail at every stage, of the steps, methods, procedures, and theoretical and philosophical approaches that were used.

Additionally, I present excerpts from participants' stories in order to demonstrate their relations to the findings presented in the study (see pages 142-230). This demonstration of the evidence base from which I drew my findings should enable readers to view more clearly the analytical formation of the findings as they are presented. I also used reflexivity to demonstrate an "explicit consideration of specific ways in which it was likely that the study was influenced" (Yardley, 2008, p. 250) by me, the researcher, making transparent the link between me and data collection and analysis.

### **Impact and importance**

Yardley (2000; 2008) claims that the most decisive criterion when assessing the validity of qualitative research is related to impact and importance, suggesting that it would be pointless to conduct a study that does not have the potential to make a difference. Impact and importance are linked to the criterion of sensitivity to context. Good qualitative studies build on what is already known about an issue (based on theory and research) and advance those ideas further, by answering questions that are significant to the issue.

In the study, I drew on existing literature about egg sharing as the foundation of my research. This enabled me to contextualise the findings generated by the study and to develop a greater understanding of egg sharing than existed previously. This is demonstrated in Chapters Ten and Eleven. However, whether the study has wider importance or impact may take some time to emerge and will be determined by others (Yardley, 2000).

### **Peer debriefing**

Peer debriefing is the process whereby a researcher has the opportunity to share their ideas with a (disinterested) peer. This enables the exploration of aspects of the inquiry, which may have previously remained implicit (in the researcher's mind), to be made explicit as part of the research process (Lincoln & Guba, 1985). Robson (2002) suggests that this concept has the potential to reduce researcher bias as debriefing can be undertaken after time spent conducting the research. This type of debriefing and support is usually undertaken by another researcher of similar status rather than more senior researchers. In the study I found that this interaction with other researchers enabled me to vocalise some of the challenges I faced as I developed the study, and as I proceeded through to writing up, I was able to draw upon their experiences in relation to those I faced, thus enabling a more comprehensive understanding of the research process. I was also able to use my peers as a 'sounding board' as I tentatively developed my analytical ideas. This enabled a cross-pollination of ideas to be generated about areas that I had not initially considered in the analysis process e.g. from social psychology around the decision-making process, and social anthropology, with regard to gift-giving and the debates about what constitutes altruism (see pages 188-191 and 203-205). Subsequently, peer debriefing enabled me to introduce and employ a more comprehensive range of theoretical concepts in the thesis.

Notably, in their discussions regarding peer debriefing, Lincoln and Guba (1985) caution against using members of the doctoral supervision team for debriefing. They suggest that it should be avoided because of the power differential and the impact that this may have on the junior, less experienced, researcher. However, this was not reflected in my experiences with my supervision team. So, whilst I acknowledge the opinion provided by Lincoln and Guba (1985) I would agree that this might be a useful approach for some researchers. I also acknowledge that in my own experiences, there were elements of a power differential evident; however, I felt that this existed because of their research expertise. Thus, I personally believe that the input of my supervision team has been influential in my development as a researcher. In fact, I feel that because of the quality of supervision provided, I did not have to concern myself with power differentials. Moreover, the debriefing process used in both the more formal supervision meetings, and the less formal meetings over coffee, meant that I could discuss some of the more salient features of the process when required.

Thus, the ability to meet with supervisors, sometimes at short notice, after a period of time in the field, allowed me to address the issues that my involvement in this area of research raised. Furthermore, being able to voice my concerns to more experienced researchers meant that I was able to learn from their knowledge. This reflective process was aided further by the new monitoring and progression procedures implemented at my institution. It is now necessary to undertake a progression viva at the end of each year of the doctoral process. This procedure has been pivotal in my development during the three years. Having to justify my progress to senior academics, external to my supervision team, meant that I had to make clear both what I had already done and what I intended to do. My theoretical thinking was questioned and this led me to develop my ideas further. I was able to gain further knowledge because of this input. Therefore, whilst it was not peer debriefing *per se* I believed that it was a process akin to debriefing in that it enabled me to finely tune my theoretical thinking in my development as a researcher. I would therefore argue that whilst this was not peer debriefing as I have previously defined it, it is another method whereby the establishment of data validity can be undertaken. This is because it enabled me to make explicit and transparent the processes underpinning the study.

### **Member checks**

At the beginning of the data collection process e-interview participants were informed that they would be able to see what I had done with their stories. Participants were reminded that they were free to ask for their data to be omitted from the thesis if they

felt that it did not accurately portray their experiences. They were also reminded that I would contact them in the future should I publish any articles that included their data.

Particular attention was given to explaining to participants what to expect when they read the extracts they were sent. This was a decision prompted by the fact that participants had an existing copy of their e-interview transcript (if they had chosen to retain it) that would look very different following my in-depth analysis. Therefore, by providing them with an overview of what I had done by way of analysis and what to expect, I believed participant validation was possible. Furthermore, providing a detailed explanation regarding the portrayal of their experiences enabled me to explain that I had written in a way more specifically suited to a social science audience (Bryman, 2008). I was aware, however, that my interpretations might be challenged and I planned that any request for data omission would be dealt with on its own merits. Fortunately, this did not occur as all participants were pleased with the way I had interpreted their stories, although it transpired that I had actually misinterpreted one aspect of a participant's journey to egg sharing. As I was made aware of this, because I chose to pursue member checks, I was able to ensure that the story portrayed was the story as it had occurred.

### **Data triangulation**

In utilising data triangulation in the study I sought to present a comprehensive account of the experiences of egg share donors. Triangulation is the process developed by Denzin (1970) combining research strategies as a means of enhancing the validity of conclusions made in a study. Denzin's view is endorsed by Bryman, who (1998) suggests that triangulation can enhance the conclusions drawn by researchers if the data provide mutual confirmation of the research outcomes. That is, merging quantitative and qualitative data has the potential to increase the validity of a study if findings are congruent. Coolican (2004), however, suggests that the aims of triangulation are to present diverse and multiple perspectives (as generated by the data) to provide a fuller account of experiences. Despite the somewhat ambiguous nature of the rationales behind the purpose of triangulation, the use of data triangulation proved advantageous in the study (Robson, 2002). It meant that I was able to gain more insight into the processes involved in deciding to become an egg share donor by examining both sets of data in order to locate similarities or differences in the experiences of those who took part in the study. In bringing together data from the e-interviews (qualitative), and the online self-completion survey (predominantly quantitative), I was able to compare the findings that emerged from both. Thus, I could

validate the experiences of the narratives of the participants as they were told to me against the data from the surveys and vice versa. Hence, the use of data triangulation proved beneficial to the study as it led to the incidental confirmation of the findings elicited from the e-interviews and the data generated by the survey. Significantly, the use of data triangulation enabled me to use methods that were complementary, which resulted in the corroboration of the findings generated through both methods of data collection.

### **Chapter review**

In this chapter I have described how I undertook analysis of both the online self-completion survey and the e-interviews. This demonstrates and highlights the logical progression of data analysis, from the holistic phase through to the reductionist phase. The following three chapters present the findings from the two phases of data collection, starting with the online survey findings in Chapter Eight.

## CHAPTER EIGHT

### Findings from the online survey

*Surveys call for an exercise of the sociological imagination. In surveys, as in fieldwork, we have to 'take the role of the other' (George Herbert Mead's phrase); that is, we make an imaginative leap into the roles of our respondents, trying to get inside their experiences, their private troubles, their private joys and aspirations, and their ways of thought and expression.*  
(Aldridge & Levine, 2001, p.3)

In this chapter the findings from analysis of the thirteen complete online survey returns submitted between 22<sup>nd</sup> December 2008 and 31<sup>st</sup> July 2009 are presented. As explained earlier, the survey questionnaire was split into five separate sections and so the findings from the survey are described section by section, for ease of understanding. Quantitative data collected from each section have been summarised using the built-in functionalities of the BOS package and the findings presented are complemented by qualitative data that were also collected.

These findings are no way representative of the population of egg share donors in the UK. The number of respondents to the survey account for less than 1% of the potential population of egg share donors based on the available figures (HFEA, 1992-2008). The survey does, however, provide an insight into the experiences of some egg share donors. These experiences, as I illustrate, can contribute to an understanding of why some women choose to become egg share donors.

#### **Section 1: demographic data**

The first section of the survey asked respondents to provide basic information relating to age, ethnicity, relationship status, and geographical location, their highest level of educational qualifications and the onset and length of their fertility problems.

#### **Age and its relationship to access to treatment**

The age range of respondents was 25-37 years, so they met the age criteria, i.e. aged between 23 and 39, whereby they could receive up to three cycles of NHS-funded treatment, although their eligibility would be dependent upon their meeting additional criteria (NICE, 2004).






Two respondents were over the age of 35 years, the upper age limit set by the HFEA for egg donors and sharers. In exceptional cases, eggs can be accepted from both donors and sharers older than 35 (HFEA, no date e). In order to ensure that I took these two women's respective ages into particular account I revisited the data, but it was impossible to establish whether they had first undertaken egg sharing prior to the age of 35 years or later than this usual cut-off point. For the purposes of the thesis, the age at which women become egg share donors was not an integral feature of the research. However, these two women's responses illustrate an aspect of egg sharing that is under-researched: the age when women consider becoming egg share donors. Even in this small sample there were wide variations in the ages of the respondents. I would conclude that given the current situation in the UK with regards to the paucity of donor eggs, this area may warrant further research.

### Ethnicity

As Table 8.1 shows, the majority of study participants identified themselves as White (84.6%); one respondent indicated that she was Black and one respondent reported that she was from a non-specified mixed heritage background.

**Table 8.1** Ethnicity of Respondents




How would you describe your ethnic background?			
White:		84.6%	11
Black:		7.7%	1
Mixed:		7.7%	1
Asian:		0.0%	0
Chinese:		0.0%	0

However, what the data reveal is in keeping with other research regarding the ethnicity of women and egg donation. Purewal & van den Akker's (2006) study reported findings from a small scale research project that investigated British women's attitudes towards egg donation. The research placed particular emphasis upon altruism and ethnicity. Their findings indicated that ethnicity impacted on attitudes regarding becoming egg donors. Of the 101 participants in the study, 55% were Asian, and 45% were Caucasian, and the researchers found much less willingness to donate amongst Asian participants, as compared with their Caucasian counterparts.

### Relationship status

When respondents were asked about their relationship status, twelve (see Table 8.2) indicated that they were married or cohabiting. This was not unexpected, although I had not anticipated that there would be a respondent who would indicate that she was single.

**Table 8.2** Relationship status










Are you?			
Married:		76.9%	10
Single:		7.7%	1
Divorced:		0.0%	0
Cohabiting:		15.4%	2
In a same sex relationship:		0.0%	0

The reason for my response to this respondent's information was linked to access to ARTs by single women. Although, not excluded by law from accessing fertility treatments, some clinics have used the welfare of the child requirement in the 1990 HFE Act to prevent single women accessing treatment (House of Commons Science and Technology Committee, 2005). Additionally, some NHS funders have also excluded single women from accessing treatment, as was the case with this respondent.

### Geographical location

As indicated by Table 8.3, the majority of respondents to the online survey were from the North of England (61.5%). This finding may indicate that there are differences in the provision of infertility services geographically, locally and/or nationally due to, for example, differences in the commissioning of services at local level or differences in the way in which the NICE guidelines are interpreted by Primary Care Trusts (PCTs). However, it was evident from other data that will be presented as part of the thesis that where someone lives does determine their access to NHS-funded treatment (see pages 198-199) and so this may be influential in the decision-making process.








**Table 8.3** Geographical location

1. Where are you from?			
Hampshire:		15.4%	2
Surrey:		7.7%	1
Kent:		7.7%	1
North Yorkshire:		7.7%	1
County Antrim:		7.7%	1
Greater Manchester:		30.8%	4
Cheshire:		7.7%	1
Northamptonshire:		7.7%	1
West Yorkshire:		7.7%	1

### Education level

As regards educational qualifications (see Table 8.4), the majority of respondents had qualifications beyond the school leaving age of 16 (61.6%). Significantly, as only a minority (38.5%) had only school leaving age qualifications, the findings tend to support the claims made by Ahuja et al., regarding the profile of egg sharers. In their analysis they suggest that women who choose egg sharing “are not the put-upon poor, but a well educated middle class group of self determined women who are capable of addressing the issues” (Ahuja et al., 1992, p.2849). That said, the evidence provided here also indicates that some women who are less well-educated than their counterparts also choose to become egg share donors. While the numbers are small (n=5), it became evident that not all egg sharers are the so-called “well educated middle class group” that Ahuja et al., (1997) suggest. Instead, women from different educational and class backgrounds also become egg share donors. Thus, it might be construed that their reason for entry into an egg sharing arrangement is no different to their well educated counterparts. That is, egg sharing represents an opportunity to access more affordable treatment and an opportunity to circumvent their involuntary childlessness becomes the motivating factor. This is regardless of their educational attainment.






**Table 8.4** Educational level

2. What is your highest level of qualification?			
GCSE:		38.5%	5
A Level:		15.4%	2
NVQ:		15.4%	2
HND:		7.7%	1
Undertaking BSc:		7.7%	1
Postgraduate Diploma:		7.7%	1
Masters:		7.7%	1

### Onset of fertility problems

When asked about the onset of their fertility problems there were varied responses (see Table 8.5). The majority of respondents (76.9%) had known that they had had fertility problems for four years or more. Three respondents (23.1%) had known about their fertility problems for 2 – 3 years.

**Table 8.5** Onset of fertility problems




When did you first think that you might have fertility problems?			
One year ago:		0.0%	0
Two years ago:		15.4%	2
Three years ago:		7.7%	1
Four years ago:		15.4%	2
More than five years ago:		38.5%	5
Other ( <i>please specify</i> ):		23.1%	3

It appears that for the majority, if not all, respondents, egg sharing did not represent a ‘quick fix’ solution to their involuntary childlessness. Rather, it offered them the opportunity to attempt to circumvent their childlessness through a treatment option they had not previously considered. It also links to them having pursued alternative treatments at a considerable time previously.

### Beginning fertility treatment

Evident from the findings was that some respondents had been pursuing treatment for quite some time (see Table 8.6).

**Table 8.6** Beginning fertility treatment

When did you start fertility treatment?			
Two years ago:		15.4%	2
Three years ago:		0.0%	0
Four years ago:		38.5%	5
Five years ago:		0.0%	0
Other ( <i>please specify</i> ):		46.2%	6

Just under half of respondents (46.2%) specified that they commenced treatment at some other time, the majority of whom (5/6) had been pursuing treatment for between nine months and a year. Significantly, one respondent indicated that she had started accessing fertility treatments over 16 years previously. As the findings indicate, all the women proceeded with egg sharing after some period of time, time which in most cases was utilised pursuing alternative treatments. What these data show are that for some women, egg sharing was the treatment of choice following their exclusion from access to NHS treatment, a theme I discuss in the next section.



## **Section 2: about their treatments**

This section of the survey focused specifically upon respondents' experiences with regards to fertility treatments, their access to NHS treatment, and the range of treatments they had pursued prior to egg sharing.

### **Access to NHS treatment**

Only two respondents indicated that they were able to access NHS treatment, stating that they were able to have one funded cycle only. Thus, the majority of participants (84.6%) were ineligible for NHS treatment (see Table 8.7). This figure highlights that there are significant issues associated with the ability to access NHS treatment. One respondent stated that the question was not applicable to them.

**Table 8.7** Access to NHS treatment

Did you receive National Health Service (NHS) treatment?			
Yes:		15.4%	2
No:		84.6%	11

Respondents cited a number of reasons pertaining to ineligibility for NHS treatment. The primary factor cited was the existence of a child from a previous relationship (n=5).

Other reasons cited included the length of the NHS waiting list (n=1), exclusion from treatment because the respondent was outside the age range (n=1), a diagnosis of unexplained infertility which meant that the PCT was only prepared to fund the medication required but not a cycle of treatment (n=1), a previous (male/female) sterilisation (n=2) and the fact that single women do not qualify for NHS treatment (n=1). This last respondent (single woman) did not provide a comprehensive account of her motivation to share her eggs, other than to state that it seemed like a “good idea” as it was a way of helping someone else.






The factors that excluded respondents from access to treatment in their local area may have been influential in their decision to pursue egg sharing although this is a speculative notion. However, the evidence presented here suggests that there are significant issues related to the provision of NHS treatment for fertility problems. Additionally, from the data presented here it is evident that ineligibility for NHS treatment, rather than the failure of other forms of fertility treatments, is crucial in egg share donor decision-making.

#### **Treatments prior to egg sharing**

This multiple choice question yielded varied responses about the range of treatments accessed prior to egg sharing (see Table 8.8). Six respondents had not attempted any other treatment prior to becoming an egg share donor because of their ineligibility for NHS treatment. One respondent had had a diagnostic procedure, a laparoscopy. Only three respondents indicated that they had attempted a range of treatments. One had tried IVF and ICSI, one had attempted IVF and ICSI and was moving on to embryo donation, and one had tried ICSI and IUI. The final three respondents had had a course of IVF (one with ICSI) during the same treatment cycle in which they became egg share donors.

This fits with my earlier analysis about some egg share donor motivations being driven by exclusion from NHS treatment, rather than because of failed previous treatments.

**Table 8.8** Prior treatments

In Vitro Fertilisation (IVF):		3
Intra-Cytoplasmic Sperm Injection (ICSI):		4
Intrauterine Insemination (IUI):		1
Donor insemination:		1
Other ( <i>please specify</i> ):		9






### **Section 3: about becoming an egg share donor**

This section of the survey focused on eliciting respondents' experiences of becoming an egg share donor. It explored how they came to hear about egg sharing and their initial reactions to what they learned about the procedure. Questions then concentrated on the decision-making process and explored how they reached their decision to become an egg share donor, and who was involved in the decision-making process.

#### **Finding out about egg sharing**

Respondents were asked to indicate how they first came to be aware of egg sharing. As Table 8.9 indicates, 7 respondents (53.8%) responded to this multiple choice question by stating that they found about egg sharing through a private clinic and 6 (46.2%) found out about the scheme via other means. Of these, one respondent indicated that she heard about egg sharing from two sources; private clinic information and from friends. None had accessed information via an NHS clinic. This factor reinforces the concept that once it was apparent that NHS treatment was not possible, the next logical progression for online survey respondents was to seek alternative sources of treatment. Even if respondents had been able to receive NHS treatment but it had not worked, they had also sought treatment information elsewhere, beyond the NHS system.

**Table 8.9** Finding out about egg sharing

Private clinic:		7
Internet search:		2
Friends:		2
Internet support group:		2
Other ( <i>please specify</i> ):		1

In the study, only one respondent found out about egg sharing through a medium other than the choices provided in the survey. In her case she was informed about the existence of egg sharing by a doctor with whom she had had a consultation, although it is not clear whether this doctor worked in an NHS fertility clinic or whether the consultation was with a general practitioner (GP).

Overall, the findings suggest that, rather than becoming defeatist, women are spurred on to find out how they can access treatment elsewhere.

### **Initial reactions to egg sharing**

Twelve women provided information about their initial feelings regarding egg sharing (in response to a free text question), indicating both positive and negative feelings.

Of respondents reporting positive feelings, seven (53.8%) indicated that they viewed the financial aspects associated with the treatment positively. One respondent remarked that she was “excited that we could afford IVF” (Respondent 9).

Similarly, another remarked that her:

“Initial feelings were that doing egg sharing dramatically reduced the cost of IVF.”  
(Respondent 10)

while another respondent said that she:

“Was happy to find a way the help us finance ivf without spending all the money we had saved up for the baby.”  
(Respondent 11)

This finding is suggestive of one of the controversies of egg sharing, that of its potentially coercive nature. It is the financial inducement that motivates women to become egg share donors. However, whilst just over half of the respondents cited finance as an initial reaction to egg sharing, significantly, ten out of the twelve respondents who answered this question (83.3%) referred to the ability to be able to help someone else.

Commenting upon the ability to help respondents provided some insightful responses. For example, respondent 4 said:



“My initial feeling was very positive, I felt good that I could try and help another couple in the same situation as me as well as helping myself.”  
(Respondent 4)

Similarly, respondent 8 commented that:

“It seemed like an ideal way to have treatment and to help others at the same time.”  
(Respondent 8)

Another respondent provided a view indicative of altruistic motivation that also reinforces the reality of egg sharing for some women. Although it might not work for her, this would not prevent her from continuing to try to help others:






“I was happy to help another family have a baby, I will be donating again even if I stop trying for a baby my self.”  
(Respondent 3)

These findings demonstrate how those considering egg sharing react initially to the information they receive about the treatment.

### **Choosing egg sharing**

The question regarding the choice to pursue egg share allowed multiple choice replies (see Table 8.10) and only four respondents (30.7%) provided a single reason for their decision, three of whom said that they wanted to be able to help someone (whom they perceived to be) in a similar situation to themselves. This suggests some altruism on their part, and that egg share donor decisions may have been guided by altruism, a concept evident in the data as most respondents showed a wish to help. Although, as discussed earlier, altruism is a contested concept and is a theme I revisit in Chapter Ten (see pages 203-205).

**Table 8.10** Choosing egg sharing

It seemed like a good idea:		4
I (we) could not afford to fund our own treatment:		7
I (we) could no longer afford to fund own treatment:		1
I (we) wanted to be able to help someone in a similar position:		12
Other ( <i>please specify</i> ):		2

All other respondents cited two or more reasons as to why they chose to pursue egg sharing. The two dominant factors were: wanting to help someone in a similar position (12/13) and being unable to afford to fund their own treatment (8/13).









Just four respondents indicated their belief that egg sharing seemed like a good idea, but provided no specified reason for this opinion. This might suggest that egg sharing, for those who choose to pursue it, is not actually perceived as a good idea *per se*, but rather it represents a means to a potential end. This links to the discussions I provided in chapter two regarding decision-making. That is, the decision to egg share could be made on the principle that it might enable them to conceive regardless of the future implications. On balance, egg sharing may appear more attractive than remaining childless.

It was not possible to ascertain the relative importance to donors of the different reasons for becoming an egg share donor since respondents were not asked to rank their replies in order of priority. Nevertheless, from the findings presented here, it is evident that the decision to pursue egg sharing is, in some cases, influenced by a number of factors and that the desire to help someone else (mentioned by 92.3% of respondents) and the inability to pay for treatment (mentioned by 53.8% of respondents) emerged as the most frequently cited reasons.

### **Combined decision-making**

Again, respondents were asked to answer a multiple choice question (see Table 8.11). Only four respondents (30.7%) chose a single option and indicated that their decision to egg share had been theirs alone, made in isolation of others.

**Table 8.11** Combined decision-making





Husband:		7
Partner:		1
Own decision:		10
Family:		4
Friends:		3
Counselling:		1
Clinic information:		4
Other ( <i>please specify</i> ):		1

The remaining nine respondents (69.3%) made it clear that their decision to become an egg share donor had been made with the assistance of others, in relation to other and wider mediating factors. Thus, husbands or partners, other family members, friends and counselling or clinic inputs had figured in their decision making processes, as indicated in Table 8.11.

#### **Impact of information on the final decision to egg share**

Earlier in the survey I had asked respondents how they had initially found out about egg sharing (see Table 8.9). I also asked about the information they had received about egg sharing, how they had received it and whether it had influenced their decision-making.

**Table 8.12** Information about egg sharing




Leaflets:		10
Verbal information e.g. counselling:		13
Egg-share donor stories:		4
Other ( <i>please specify</i> ):		3

As Table 8.12 shows, all respondents indicated that they had received information from at least one source. The primary source was verbal information, although 10 (76.9%) had also received information in leaflet form. Unfortunately, it was impossible to distinguish whether the verbal information had been provided by a clinician in the field of ARTs (as the example I provided was a counsellor), or whether this information had come from elsewhere, as these data were not gathered. With hindsight, this additional

level of information may have been beneficial to the analysis and reporting of these findings.

Just under half of the respondents (46.1%, see Table 8.13) reported that the information they had received did not influence their decision to egg share. In contrast, seven respondents (53.8%) indicated that the information they had received was helpful to them in making their decision.

**Table 8.13** Decision-making

Did this help you to make your decision?			
Yes:		53.8%	7
No:		38.5%	5
Other (please specify):		7.7%	1

Significantly, although over half of respondents said information helped them decide to proceed with egg sharing, there were no marked differences in the amount of information received (see Table 8.12). That is, it was not evident whether the range and type (verbal or written) of information received influenced their decision, or whether it was a specific piece of information that was the driver.

#### **Section 4: experiences of egg sharing**




The final section in the questionnaire focused upon the number of cycles of egg sharing recipients had undertaken, whether their treatment had been successful and, if so, during which cycle, and whether they had learned the outcome of the recipient's treatment and the impact this had had on them.

##### **Cycles of egg sharing completed**

Respondents had undertaken 20 cycles of egg sharing between them (see Table 8.14). Three respondents indicated that they had shared their eggs with two recipients. However, I am unable to state whether this applied to any other respondents. This information was not asked for in the survey and it was not provided in any of the other returns.

Of the cycles reported, nine respondents had proceeded with a single cycle of egg sharing, two had been through two cycles of egg sharing, one respondent had had three cycles of egg sharing and one respondent had had four cycles of treatments.



**Table 8.14** Cycles of egg sharing

One:		9
Two:		2
Three:		1
Other (please specify):		1

### Treatment outcomes

When asked about the outcomes of their treatment it was evident that success had been achieved by just over half of the respondents (see Table 8.15), although, of those who indicated a successful treatment outcome, this was not always on the first attempt.

**Table 8.15** Treatment success

Has your own treatment been successful?			
Yes:		58.3%	7
No:		41.7%	5

Seven of these 20 egg share cycles had resulted in a pregnancy for the egg share donor, although two of these led to a miscarriage. Five of the successful cycles occurred during the first attempt at egg sharing (including both miscarriages); the other two respondents were successful in their second cycle of egg sharing, and one respondent was still awaiting the outcome of her first cycle of egg sharing. What these findings illustrate is that egg share donors can achieve a successful conception and live birth. Moreover, the success rates enjoyed by study participants are comparable to the available data on the success of egg sharing for donors.

In 2006, 719 cycles of egg sharing took place in the UK, 32%<sup>15</sup>, of these cycles resulted in a live birth for the donor. In contrast, only 23% of non-egg share IVF cycles provided in 2006 resulted in a live birth. From these figures it would appear that egg sharing appears to have a better success rate. However, success rates in ARTs vary. This variance may be affected by the age of the women seeking treatment; however there is insufficient evidence available to establish why egg sharing appears to have a better live birth rate when compared with all women (HFEA, 2010a).

<sup>15</sup> The information that the HFEA publishes is a snapshot of data provided by licensed centres at a particular time. This information may be subject to change as individual centres notify the HFEA of amendments. Before publication, the HFEA performs a preliminary validation process on the data, and asks centres to confirm its accuracy, for which they remain responsible" (HFEA, 2010a).

### Knowledge of recipients' treatment

Respondents were asked whether they had found out about the outcome of their recipient's treatment. As illustrated in Table 8.16, the majority of respondents had found out, had attempted to find out or planned to find out (69.3%), although not all had yet chosen to obtain this information.

**Table 8.16** Recipient(s) results

<i><b>Respondent</b></i>	<i><b>Donor treatment outcome</b></i>	<i><b>Sought recipient information</b></i>	<i><b>Recipient outcome</b></i>
<b>1</b>	Pregnancy confirmed – suffered miscarriage	Clinic unwilling to release information	Unknown
<b>2</b>	Awaiting result	Will at some stage in future	Unknown
<b>3</b>	Negative	Not ready yet	Unknown
<b>4</b>	Negative	Not found out	Unknown
<b>5</b>	Negative	Not found out	Unknown
<b>6</b>	Negative	Found out	Both unsuccessful
<b>7</b>	Positive	Not found out	Unknown
<b>8</b>	Positive	Found out	One recipient successful, unsure about 2 <sup>nd</sup> recipient, own treatment successful on 2 <sup>nd</sup> cycle
<b>9</b>	Positive	Found out	Both successful
<b>10</b>	Negative	Found out	Recipient successful
<b>11</b>	Positive	Found out	Both successful
<b>12</b>	Positive	Found out	Both successful
<b>13</b>	Pregnancy confirmed – suffered miscarriage	Found out	No confirmation of recipient result available

Of these, six respondents said they had found out the recipient's result, and another respondent explained later in the survey that the clinic where she had had her treatment had said that they had not received a positive pregnancy confirmation from the recipient. She said that the clinic's interpretation, regarding the absence of this information, was that there had been a negative outcome for the recipient. An eighth respondent who had made attempts to seek this information stated that the clinic would not release the information to her. It is unknown whether this respondent was informed that she could gain access to this information by contacting the HFEA. The respondent who was awaiting the outcome of her treatment said that she would seek this information in the future.

Overall, it is evident from the findings presented here that the majority of respondents in the study thought about the possibility of a child being conceived by the recipient

throughout the arrangement. This may suggest that they were aware of the potential future implications, and also of the possibility of a child contacting them in the future.



These findings also suggest that the likelihood of wanting to find out about the outcome for the recipient was more likely for those who are successful in their own treatment, at least initially. The impact of a negative treatment outcome did seem, perhaps not surprisingly, to reduce the likelihood of the donor wanting to know about the outcome for the recipient. However, whilst there were no discernible differences regarding the intention to seek information about the recipient's treatment outcome, it did raise another theme of importance to the study.

It could be argued that an egg share donor's decision not to seek information about the outcome for the recipient(s) poses potential future implications for both herself and any donor-conceived individual (and for any children she may have herself). For the donor, it may leave her unprepared for the possibility of contact by the donor-conceived individual once (s)he is able to learn the donor's identity. For the donor-conceived individual such an encounter may prove problematic. Necessarily, these conjectures must remain speculative in the absence of empirical evidence, but should be borne in mind as future issues as egg share donor-conceived individuals begin to reach the age at which they can learn their donor's identity.

### **Giving informed consent**






As Table 8.17 indicates, a single respondent had not really fully understood to what she was consenting, but had not admitted her lack of understanding at the time. Thus, her ability to give informed consent appears to have been compromised. However, the other 12 respondents indicated that they had fully understood to what they were consenting. In addition, in their other comments, four respondents (30.7%) said that information regarding the consent process had been provided in a way that was understandable.

**Table 8.17** Giving informed consent

<b>Did you fully understand what you were giving consent to?</b>			
Yes:		92.3%	12
Not really but didn't want to admit it:		7.7%	1

Respondents' views on whether having the consent process explained helped or hindered their decision-making were mixed. The information provided about the consent process was beneficial to the majority of respondents (61.5%), the information either helping a little or a lot (see Table 8.18).

**Table 8.18** Understanding informed consent

<b>Did having the consent process explained help/hinder your decision to become an egg-share donor?</b>			
Helped a little:		38.5%	5
Helped a lot:		23.1%	3
No help at all:		15.4%	2
Hindered my decision:		7.7%	1
Don't know:		15.4%	2

Two respondents (15.4%) were unsure as to whether the explanations of the consent requirements were helpful. A further two respondents (15.4%) said that the explanations provided were of no help to them. One respondent said that the information had actually hindered her decision-making.

When questioned about who had provided the information about the consent process there were marked differences in the number of people involved (see Table 8.19).

**Table 8.19** Information providers about the consent process

<i>Respondent</i>	<i>Clinic counsellor</i>	<i>Fertility specialist/ consultant</i>	<i>Egg share co-ordinator</i>	<i>Fertility nurse</i>	<i>Other</i>
1	•	•	•	•	
2	•			•	•
3		•	•	•	
4			•	•	
5	•	•	•	•	
6	•				
7		•			
8			•		
9	•		•		
10			•		
11	•	•	•		
12			•		
13	•				




Whilst all respondents had received information about the consent process it was evident that some respondents had had more opportunities and access to information about the process than others. However, it was not possible to determine whether the involvement of more than one professional as an information provider reflected ‘normal practice’ of the respective clinics where treatment was undertaken or whether the provision of information by more than one professional was a result of a request by the respondent.

Each of the seven respondents who found the information provided helpful received information from either two or three sources. In contrast, there were variances amongst those who said that information had not been helpful. Of the six who said that this was the case, two had received verbal information only, three had received information from two sources (either verbal and internet forum or verbal and leaflets) and one had accessed four sources of information. Therefore, it is difficult to determine accurately whether access to more information *per se* is beneficial in facilitating decision-making.

### Discussing donor anonymity

All respondents reported that, prior to proceeding with treatment; they had been made aware of the removal of donor anonymity (see Table 8.20). This finding was in keeping with the statutory guidelines regarding information provision.

**Table 8.20** Discussing donor anonymity

Was donor anonymity discussed with you?			
Yes:		100.0%	13
No:		0.0%	0

Donors had also been informed about the potential future implications for themselves regarding the so-called ‘knock on the door’ scenario. Four respondents (30.7%) indicated that this information had helped them a lot as they reached their decision to proceed with egg sharing. Three respondents (23%) said that the information had been of no help at all. Interestingly, two respondents had made their decision to proceed prior to receiving this information. One respondent said that she had been determined to proceed, whilst the other respondent had undertaken her own research regarding the potential implications of egg sharing.

### Information about donor anonymity

Respondents were asked about the information they were given about egg sharing. The format of the free text question enabled respondents to provide a response that was as detailed as they wished to provide. As illustrated in Table 8.20 the information provided by respondents varied, in both content and context.

**Table 8.21** Being told about donor anonymity

What were you told about donor anonymity?
a donor conceived child could find out who donated once they're 18
Any child conceived from donor eggs has the right to trace you
I was told that due to a recent change in the law any child born as a result of my eggs could request my information (name, address etc). There is no guarantee that this child/ren would contact you as they may not be informed that they had been born as a result of donor eggs. I was advised that it is only the child themselves who can request this information and that they would be over the age of 18.
No-one can find out, except the child when it was 18, if it so wished
That if the recipient was successful in having a child, this child would be able to contact me when he/she reached 18.
That it doesn't apply any more in the UK and that the child has the right to contact the 'genetic' parent at 18.
That non-identifying information could be given to the recipient/child and that it would not be until the child reached age 18 that name and address could be given if the child requested it.
that the other lady would only know eye colour hair colour etc and the child if any could seek me at 18
That when any resulting child was 18 they could obtain identifying details about me if they wished to
we could find out if the couple were successful and our general info was passed to them and our details were kept by the hfea
We were told it is totally anonymous, if a child is born due to my egg share I could be traced by that child/ren when it is 18 years of age.

The data illustrate that the impact of the removal of donor anonymity had been discussed in some detail, although it is difficult to ascertain the extent of the information provided based on this limited evidence. However, respondents were all provided with the correct information about their involvement as an egg share donor regarding the extent of access to information about themselves and the use of that information.

### Donor anonymity and decision-making

Responses to questions concerning the effect of the information about donor anonymity and respondents' decision to proceed with treatment were varied. As illustrated in Table 8.22, 33.3% of respondents said that the information received was helpful to them, while 33.3% said that it was of no help whatsoever. Notably, only one

respondent indicated that information provision hindered decision-making, while 25% said something other than the choices provided.

**Table 8.22** Impact of information provision

30. Did the discussion regarding donor anonymity help/hinder your decision?			
Helped a lot:		33.3%	4
No help at all:		33.3%	4
Hindered my decision:		8.3%	1
Other ( <i>please specify</i> ):		25.0%	3
It did make me think twice but after discussion I was fine			
No impact			
We had already decided by this time we wanted to donate, but it was the associated issues of anonymity that my husband and I thought about for a long time			

This question captured additional responses. Two respondents indicated that the information made them think more about the potential future implications of egg sharing. The respondent who stated that information hindered her decision-making provided a reason for this. She notes that it made her realise that she would be “giving away a child”. She also stated that she would have preferred it if any child born because of her egg sharing remained unaware of her role in their conception, comments that indicate a level of unease with becoming an egg share donor. Significantly, this is the respondent who said that egg sharing seems okay in theory, however, the reality is different and not always positive (see “additional experiences shared” below). This view serves as an example of the impact of egg sharing for some women, a theme to which I return later in the thesis.

### **Additional experiences shared**

The survey concluded with an option for respondents to share more of their experiences, if they wished. Nine respondents chose to provide additional comments that provided a further insight into their experiences. These qualitative data illustrate the mixed views evident from the survey. For example, one respondent chose to comment that perceptions of egg sharing may change once treatment has concluded, saying:

“It is a easy decision to make at the time, however in retrospect had any woman got pregnant it would have haunted me... In theory egg donation is a good idea, the reality however is very different, especially considering potentially another family could have the baby you want...”  
(Respondent 6)

This very explicit statement serves to highlight the issues that some egg share donors might face: the reality of not achieving a pregnancy but having to live with the realisation that another family has a child, and that they also may have had had a child if they had not shared their eggs. This can be seen as the ‘double-edged’ sword of egg sharing. It is evident that this respondent was glad, in some sense, that neither party achieved a pregnancy. Additionally, another respondent stated that she:

“Found the experience of egg sharing not a nice one but this hasn’t stopped me from egg sharing purely as we could not fund a cycle any other way. My 1st cycle ended in miscarriage and I felt like some sort of baby making machine.”  
(Respondent 13)

It is evident that this respondent had a difficult time during her treatment, which had left her with very negative opinions regarding the people who had treated her. It could be suggested that this expressed negativity was because of the negative outcome of her treatment, although she notes that she is aware that not everyone has a bad experience and indicates that she will be having a further cycle of treatment.

Of the other comments received, the narratives were largely positive and there was evidence that the recipient of their eggs was also considered. For example, one respondent said that:

“I hope the recipient of my eggs had a successful outcome. We were unfortunate the first IVF attempt and it took a while for me to recover from the miscarriage. I am pleased to say that 3 years later, we have got a son who is now 10 months old, conceived naturally! That was a bit of a shocker. If the recipient of my eggs was successful, of course I would welcome any child who decided to contact me and explain the reasons behind our decision to egg share.”  
(Respondent 1)

Speaking in a similar vein a respondent said that:

“I felt it was a very good experience although my result was negative I do hope my recipient had a positive result, I do not know the outcome of the recipient because I never phoned to find out, but hopefully will find out before I egg share again. I will be egg sharing again in the near future.”  
(Respondent 4)

It is also evident from the extracts that an unsuccessful cycle of treatment might not always result in a negative experience.

### **Commentary upon these findings**

The findings presented in this chapter illustrate the realities of egg sharing for those who took part in the study, although it is not possible to assess if these findings are generalisable to the population of egg share donors in the UK, because the sample is small. However, the findings, as presented, can contribute to current understandings of egg sharing. As detailed in Chapter Two, there is a limited empirical evidence base that has examined the experiences of egg share donors. I also described the concerns and controversies that were evoked when egg sharing emerged (see pages 44-49). In doing so, I have illustrated that the respondents to the survey considered that they were able to give their informed consent to egg sharing. I have also demonstrated the motivations to egg share as told by respondents. These are influenced by ineligibility for, or restricted access to, NHS treatment and the ability to access cheaper treatment. Respondents also express the desire to help someone in a similar situation to themselves.

I also explored the impact of being an identifiable donor and the potential future implications for egg share donors. The data illustrate that respondents are aware of these implications and that in most cases they had sought to learn the outcome of the recipient's treatment. However, the data also revealed a failed attempt at gaining access to this information, something that should not happen if a request is made.

### **Chapter review**

In this chapter I have presented the findings that emerged during the analysis of the quantitative and qualitative data from the online survey. These findings illustrate the complex processes involved in becoming an egg share donor and will be returned to later in the thesis when data from the e-interviews are merged with the online survey data.

In the following chapter I introduce the findings from the e-interviews. These take the form of case studies and 'I' poems generated from the interviews. This should enable the reader to comprehend the features of egg sharing that were shared with me during the data collection process.

## CHAPTER NINE

### E-interviews: egg sharing stories and 'I' poems

*The relationship has to be maintained throughout the writing, and you don't write over, or voice over, other people's voices...It's an attempt to try to work as a writer would work, by giving people their voice, by giving ourselves a voice in our work, and then thinking very consciously about the orchestration of the pieces we write.*

(Kitzinger with Gilligan, 1994, p.411)

This chapter provides a narrative account of the experiences of the four women who took part in the e-interviews. These contextualised accounts demonstrate how the participants' journeys were individual yet inextricably linked and illustrate the factors that motivated them to become egg share donors.

In documenting the stories of participants using the case studies, I have also incorporated the use of the 'I' poem. This demonstrates how the nuances of the interplay of language change dependent upon which reading is taking place. This is followed with theory relevant to the issues that emerged from the inclusion of the case studies and the creation of the 'I' poems.

#### **Case studies**

The case studies presented in this chapter are those of the women who took part in the e-interviews – Charlotte, Emmeline, Florence and Jayne. Their stories chart the way the narratives unfolded as they were recounted.

In my attempt to remain close to the narratives provided by participants I have used their own words wherever appropriate, indicated by the use of quotation marks. These personal narratives and the way that they are presented highlight the range of issues that may confront egg share donors in their attempts to overcome involuntary childlessness. They are shaped by their experiences of infertility; their attempts to overcome infertility; by their social relations; and by their encounters with medical professionals.

### **Charlotte's story**

Charlotte is married and lives in the South of England, she is 33 years old. When she first made contact with me, Charlotte had no children, and was about to commence her first cycle of egg sharing.

Charlotte had initially realised that she was having fertility problems after she and her husband had been trying to conceive for 12-18 months. She was eventually referred, six months later, to the fertility clinic at her local hospital. Following investigations, Charlotte was diagnosed with PCOS and "some degree of unexplained infertility". When Charlotte initially sought treatment, her local PCT did not fund any treatments. This changed and they were willing to fund one cycle of treatment if certain criteria were met. Charlotte and her husband did not meet any of these criteria as her husband had a child from a previous relationship, so they were going to have to pay for private treatment. At the time Charlotte also had a problem with her weight which she went on to rectify. Charlotte said that "the thought of having to wait because of money was dreadful!!" and she felt it unjust because by then they had been trying to conceive for five years.

Charlotte knew that it would take them some time to save up for treatment so she began searching for cheaper treatment options, including using the Internet to seek overseas treatments. During her searches Charlotte found information about egg sharing. She realised that this was an opportunity to get quicker and cheaper treatment. However, because she had PCOS, she eventually had to travel further than she had anticipated in her search to find a clinic willing to treat her. Charlotte says that she thinks that:

“...many couples are turning to egg share as a means of funding their IVF treatment. I am in touch with lots of people through [name of organisation deleted] who are not eligible for funding from their PCTs and are now egg sharing as a means of reducing the cost...”

Charlotte chose a clinic that had two units that were relatively accessible. She ended up having to travel around 50 minutes (to one unit) for consultations and scans – and for 1 hour and 45 minutes (to the second unit) to have her treatment. She says that she had been speaking to a woman on the support website that had to travel “a whopping 3hr 30mins drive! as she was refused egg share at nearer clinics”.



Charlotte feels that she fully understood the future implications for herself, her husband and family. However, she wonders about the recipient and admits that she was “curious about what she is like” and says that “whatever she is like that she has gone through a similar experience to me and must want this baby very very much”. She also wondered what any child/children might be like if the recipient were successful. She remarked that she was “very grateful to her, as she has given me and my husband this opportunity to have baby together”.

Charlotte admits that she believed that egg sharing was a way that she could help another woman to possibly circumvent her infertility. Yet this was not the initial reason why she decided to pursue egg sharing. Charlotte says that the main reason why she became “an egg donor was financial, although I have always liked the idea that I am helping another couple in a similar situation to have a family”. Overcoming the financial problem meant they were “able to start our IVF treatment sooner. If we had not been able to egg share then it would have taken us several months to save enough money for our treatment”. She did have some concerns regarding the process, including whether she would produce enough eggs to go ahead with the sharing. She says that “I didn't want to let the other couple down”.

Following egg collection all eight of Charlotte's eggs fertilised successfully – however, the following day, there was only one viable embryo which was implanted. Unfortunately, Charlotte's treatment was unsuccessful on this, her first cycle. Despite her own failed cycle of treatment Charlotte intends to go ahead with egg sharing again. She has no idea what the outcome of her recipient's treatment was, or indeed whether the recipient ever received any viable embryos by the time the e-interview came to its conclusion.

### **Emmeline's story**

Emmeline is married and lives in the South of England. She is 31 years old. Born in South Africa, she has spent most of her life in the UK. At the start of the e-interview Emmeline did not have any children. Emmeline had been married for seven years before deciding to start a family. She said that:

“As strange as this may sound I have always thought at the back of my mind that I would have fertility problems as my mum took 7 years to conceive. I thought this might affect me.”

Even though Emmeline thought she might have problems with her own fertility she and her husband did not start trying to conceive immediately. They waited seven years and started trying to conceive in 2007, when they started “charting, temping etc<sup>16</sup>”. This was unsuccessful and Emmeline sought medical advice from her GP. Following referral to a local hospital and investigations, the reasons for Emmeline’s infertility remained unexplained. Emmeline was told that because she had “unexplained infertility” she would not be eligible to go on the NHS waiting list for IVF until she and her husband had been trying to conceive for another two years. Once on the waiting list, she could then expect to wait another year for treatment. Emmeline knew that if she wanted to have a baby then she would have to seek treatment privately; so she started looking for private clinics.

Initially, when she realised the cost that would be involved, Emmeline and her husband considered going overseas for treatment. After researching many countries, South Africa appeared to be the easiest option as she also had family there. Emmeline then found out about egg sharing accidentally during her research on the Internet. Emmeline remarked that she had considered donating eggs in the past, before she knew she needed fertility treatment herself, as she had family members who had used donor sperm in their own treatment. She saw the act of egg donation as an attempt to “repay the gift” which her family members had received. She decided not to go ahead with egg donation, however, because of what was involved and the impact it would have had on her day-to-day life at the time. Therefore, when she found out about egg sharing she realised that not only could she donate and help someone else but that she would benefit as well because of the reduced treatment costs. She “couldn’t believe her luck”.

Emmeline’s main concern, as she waited to commence treatment, was how she would feel if the recipient was successful and she was not. This was during Emmeline’s first cycle of egg sharing and she felt close to the recipient even though she had no idea who she was. Emmeline did not want to know the result of her recipient’s treatment (at this point in time) as she was not herself pregnant. She had a feeling, though, that the recipient was pregnant and she said that “I know this may sound stupid but I believed she was pregnant”. Emmeline thought a lot about her recipient and what she might be like. Yet at the same time she tried not to

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<sup>16</sup> Emmeline is referring to the process of Basal Body Temperature Checking – see Glossary.

concentrate too much on whether the recipient had become pregnant despite her sense that she had.

Emmeline had some of her embryos frozen following her treatment cycle so she was able to undergo frozen embryo transfer<sup>17</sup> (FET) following her unsuccessful first cycle. Her second cycle of treatment was successful and Emmeline conceived twins. She also found out from the clinic that the recipient of her eggs was pregnant, but she did not know whether the recipient was expecting a single or a multiple pregnancy. Emmeline is glad to have shared her eggs but says that she would have found it difficult to do it a second time. During her egg sharing Emmeline had severe OHSS, which made her seriously ill. She wonders if this happened because she was an egg sharer as her cycle had to be matched to that of her recipient, which meant that she had to take some medication longer than she had expected.

Emmeline considered that she knew what she was consenting to, yet she does not “recall anyone explaining the consent process” to her. She says that “I think I may have been more fixated on the ‘when can I start’ question so that the rest is a bit of a blur”. However, she did think that the consent forms were confusing. She comments that “I went through each one with a fine tooth comb but found there was a lot that I didn’t understand”. However, she was able to ask questions and she got the answers she needed. She asked her questions at what she refers to as a “very brief, very odd ‘counselling’ session”. Notably for Emmeline, when she brought up her questions at the counselling session, the counsellor was unable to answer them and had to seek the assistance of a nurse at the clinic who did have the answers.

Emmeline chose to become an egg sharer for a number of reasons. She saw egg sharing as a way of getting quicker treatment. She was also able to help another woman requiring treatment and egg sharing meant that she could get access to treatment that she and her husband could not afford. Emmeline says that:

“...Egg sharing gave me the opportunity to do a round of IVF long before I would have been able to do it if we had had to save up the full price...”

Emmeline does feel that her negative views of the process involved in egg sharing have changed since she became pregnant, particularly her experience of OHSS, and

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<sup>17</sup> See Glossary.

she wondered how she would have felt if she had found out that the recipient had been successful and she had not. She also feels that if she had not gone ahead with egg sharing she would “have had 29 eggs to myself which may have enabled” her “to have quite a few attempts at FET”. However she does follow this statement up by saying that she did not believe that she “would have overstimulated if (she) wasn’t doing egg share so” she “probably wouldn’t have had so many eggs”. Despite these negative views, overall, Emmeline has found the process rewarding.

She was happy that her recipient became pregnant and she hoped that the recipient had frozen some of her embryos, so that she might possibly be able to have another child who would be genetically related to the child to whom she was due to give birth. She also hoped that this would mean that she would not have to “spend possibly years on the egg share waiting list”. She knows that egg share was right for her and she “knew it was something I would be proud to be able to do”. She says that she felt:

“Extremely lucky to have had this opportunity and know my husband and I will be celebrating the date we believe the other ladies baby is due.”

She has no regrets about egg sharing and believes that egg sharing “can be a very rewarding experience”. Emmeline does say, however, that now she is pregnant it is possible that she has “more positive memories than I maybe would have had should I not be pregnant now”.

### ***Emmeline’s update***

Since the conclusion of the e-interview with Emmeline I was privileged to hear that Emmeline had given birth to twin girls in the last months of 2009. Emmeline carried her pregnancy to full-term. Both girls were born healthy two days after their due date and were able to leave hospital after only a few days. Emmeline says that “life is just amazing now”.

### **Florence’s story**

Florence is now the mother of a little girl, following treatment. She is 33 years old, married and lives in the South of England. Florence started trying to conceive naturally in 2004 before seeking treatment in 2005. She had to wait a total of 20 months before receiving help.

Following initial investigations she was diagnosed with “mild endometriosis” and underwent treatment in an attempt to alleviate the problem. Her husband’s sperm was also “sluggish” – this may have also contributed to their inability to conceive naturally. The first treatment they tried was intra-uterine insemination which failed. This treatment was provided by the NHS. Florence and her husband decided to pursue IVF because of the failed IUI. At this point they found out that they did not qualify for NHS-funded IVF treatment because they had been trying to conceive for two and a half years only. Local guidelines stipulated that couples needed to have been trying to conceive naturally for 3 years before being eligible for NHS-funded IVF treatment.

Feeling “desperate” and “depressed” Florence made enquiries at a private clinic. Knowing that they could not afford to fund their own treatment Florence and her husband went to an open day at the clinic. It was here that they found out about the shortage of donor eggs and sperm. They were also told about egg sharing and how, if they decided to use this option, they would receive heavily discounted or even free treatment. They were also told that they would be able to help another couple at the same time. Florence believed that being able to help another couple might prevent them from suffering the “heartache” that she had experienced in her attempts to achieve motherhood.

Florence left her job because she found it impossible to deal with the “grief” associated with her inability to conceive. She found that her support network of friends was unable to provide the support and understanding that she needed. She was careful about whom she told because of possible naïvety and insensitivity. She struggled with depression through her treatment cycles – these were difficult times. She avoided the use of medication and found counselling beneficial.

Initially the couple were going to donate eggs and sperm but following initial assessment at the private consultation problems with her husband’s sperm motility were diagnosed. This had not been diagnosed during their previous NHS-funded IUI treatment. Florence had over-stimulated when prescribed medication during her NHS treatment. This had made her quite ill but she knew that her “body responded quickly and in excess” which she believed meant that she had a good supply of eggs. Despite their previous experience of OHSS, Florence was willing to donate her eggs. Having made the clinic aware of her previous medical history they said that they would adjust the drug they administered accordingly in order to try to prevent repetition of OHSS.

Florence was excited about proceeding with the treatment, yet she was also fearful of the unknown. She also had:

“...a million thoughts about the recipient' and would they look after my eggs?! - as I would do if I were to keep them!, 'concern' for any child born of the result, 'wonder' about what would happen if they turned up in years to come, on my doorstep!, 'confusion' that I was doing the right thing...”.

Florence treated the whole process with “caution” as she wanted to do her best to ensure a positive outcome for herself and the recipient. This put her under pressure and she felt a “burden” because she felt that the recipient would be wondering if she would go through with the egg sharing or whether she would change her mind. She “wanted her to know” that she “wouldn't let her down”.

Counselling prior to the egg sharing helped Florence. She and her husband felt that they were fully informed about the entire process, the potential future implications and eventualities. Yet Florence says that “...you can't fully prepare yourself until it happens...” Florence felt “proud” to help yet nervous at the impending future. Nervousness surrounded both her own and the recipient's treatment. She was aware that they may succeed, and that she may not, or that they might not. Compounding this nervousness was the loss of the pregnancy resulting from her first cycle of egg sharing. Florence refers to this as her “miracle pregnancy” and that they “never got to find out if it was one or two embryo's that implanted”. The loss of the pregnancy was devastating and left the couple “heartbroken”. This was made all the more painful by the realisation that the recipient may have been successful on this cycle. Florence knew that to get any form of closure she would need to find out the outcome of her recipient's treatment. She was not willing, however, to do this until she had been successful herself, which she was on her second cycle of treatment, which was NHS funded. Having been on the waiting list for publicly-funded treatment, the treatment became available after the failed cycle of egg sharing. Florence believes that if she had not undertaken the first cycle of treatment (egg sharing) then she might not be the mother she is now. As it transpired, by staying in the system (private and public) Florence was able to get the treatment she needed. Florence says that her daughter is the result of “four years of hard work” and physical and emotional labour. She is their “everything”.

Florence knew, however, that the outcome for her recipient may bring back a lot of heartache. She knew that, regardless of the outcome, she would need to deal with the complex feelings that she says "... go hand in hand with that information". Having now had her daughter and having her own frozen embryos should she wish to use them in the future, Florence sought the information she needed to know – the outcome of her recipient's treatment. She felt that it was necessary to find out so that her daughter could be told if she had half-siblings. She believed it was important that her daughter was made aware, at some point in the future when she was old enough to deal with the information. She also realised that there may be more than one child born, an issue that had not occurred to her until midway through the interview.

As she vocalises her thoughts about any children who might be born as a result of her egg sharing she says "of the child, if there is one, or more (As I donated **ten** eggs, so more are possible! – only just thought of that today!, - oh god!!....)." Florence is aware, however, that despite her own thoughts on the matter, the recipient couple may never tell any child/children they might have about their conception as a result of the use of donor eggs. Florence is also aware that, if a child is told of their birth through the use of her donated eggs, they may, if they choose to do so, to seek the identifying information held about her. Florence is quite scared about this idea but recognises that it is an outcome over which she has no control. Indeed, Florence articulates well the potential future implications for herself and her family. She hopes that her daughter will understand why she chose to egg share. Florence has been deeply affected by her experience of infertility and feels that this experience has taught her a lot.

As the interview process neared its conclusion Florence got the news she had been seeking – the recipient had been successful – she had had twins. Florence is happy for the couple but sad that they were successful on their first cycle - the cycle where she lost her 'miracle pregnancy'. She wonders 'what if?', but she knows that without egg sharing she would not now be a mother. She feels proud to have helped though; she has to keep reminding herself that she has her daughter because they went to the clinic in the first instance. She believes that if she had not chosen this route then her story might be quite different. Florence is conscious of the fact that she will think about this news a lot.

Florence became an egg sharer for two reasons. The first was financial, in that they could not afford to fund treatment after finding out that they were ineligible for NHS-funded treatment. The second was that she knew that she could help another couple.

The only other option at that stage would have been to have blastocyst<sup>18</sup> transfer. However, this treatment was unaffordable and therefore was not an option for the couple. Florence believed that egg sharing represented “***a silver lining appearing amongst very black clouds***”. For her, “egg share seemed to be on offer when it was most needed”.

### **Jayne’s story**

Jayne is married and lives in the North of England. She had had two cycles of egg sharing – in September 2006 and again in December 2006. At the time she became an egg share donor Jayne was 22 years old. She is now the mother of a little boy. Jayne gave no indication as to how old her son was at the time of the interview.

Jayne and her husband required fertility treatment due to her husband’s failed vasectomy reversal. It later transpired that Jayne had a mild case of PCOS. As a couple they knew that they would require treatment. However, Jayne’s diagnosis came as quite a shock although she says that she did not “think that it affected” her “too much as we’re having IVF anyway”.

Following the medical advice given to them Jayne started a search for local hospitals where they could access treatment. They attended an open evening at a private clinic where they found out the cost of a cycle of IVF and were also told about egg sharing. Prior to this Jayne did not really know much about egg sharing. After reading the information that they took away with them the couple decided that they wanted to egg share.

Jayne felt that egg sharing was really the only option for them. She says that we “...were desperate for a baby and could not afford the full price of IVF”. Jayne viewed the treatment in two ways: first, she was giving another couple the chance to become parents; and second, it was giving her and her husband a chance to become parents as well. Jayne did not feel that she was giving away anything of herself. She believed that as the eggs were not fertilised that “it wasn’t like” she ‘was giving’ her “child away”. Jayne also remarked that she remembered something she had read in a leaflet regarding eggs. She said that it stated “you flush eggs away every month during your cycle”. In essence Jayne felt that the eggs were something of hers that

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<sup>18</sup> See Glossary.



were going to waste each month and that by giving them to another couple she was making good use of them.

When Jayne thought about the eggs she had donated, she did not “let it register” in her head that there was any biological connection, or that any child who might be born would have this connection with her. Her thoughts were that “the lady has grown this child, given birth to it so how can it possibly be connected to me via the same DNA”.

Jayne knew that her own inability to have a child had caused her devastating hurt and pain. She hoped that her donation would prevent the recipient couple having to experience these kinds of feelings. She was also aware that the eggs she had agreed to share may have gone to two couples. Thoughts of the outcomes of the recipients’ treatment have been at the forefront of Jayne’s mind since the birth of her son. Jayne was aware that she had shared her eggs with two recipients.

She wondered if the treatment had worked for the recipients of her eggs and whether they had frozen any embryos. She wondered whether her donated eggs became a boy or a girl and what the child/children might be like. She wondered whether the child/children would have any resemblance to her – to the point where she looks at babies when she is out and wonders, even though she knows that “realistically the chance of that is impossible”, yet she says that “the thoughts always there”. Due to her wondering about the outcome of the egg sharing for the recipients, Jayne had written to the HFEA in an attempt to ascertain whether any children had been born. She contacted the HFEA as she had been told that this was the only way that she could access this information.

Jayne had told her family about the type of treatment she was having. She says that “...most of them don’t really understand and to be honest. Not that interested!”. Her mother supported her decision; however, there had been very little conversation about the treatment after this time.

Jayne fully understands that any child/children who might have been born using her eggs would have the right to contact her in the future if they choose to do so. Jayne also knows that without egg sharing she would not have her son. Yet she does not think that she could do it again. She feels that as a couple they were fully informed and understood exactly what they were consenting to. Jayne is glad that she became

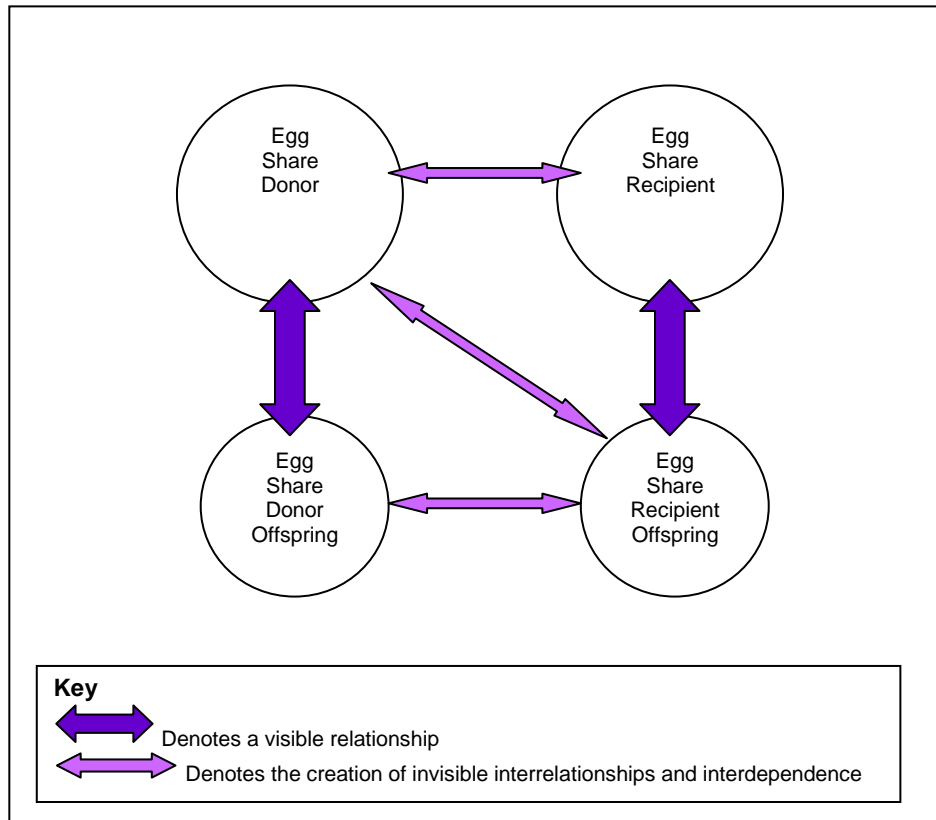
an egg share donor but says that she does not think that "...the reality of it actually hits you until you have your own child...". She believes that she thinks differently about egg sharing since the birth of her son. She also thinks a lot more about any child/children there might be; something which she had not previously done. As the interview came to its conclusion Jayne was still waiting to hear whether the recipients had been successful during their egg share cycle.

### ***Jayne's update***

Jayne recently found out the answers to the information she had sought from the HFEA regarding the outcomes of her recipients' treatment. Unfortunately, one of the recipients with whom she shared her eggs had a miscarriage. The second recipient achieved a pregnancy and had a healthy son; she still has three of the eggs that Jayne shared with her.

### **Case studies: revealing interrelationships and interdependence**

The case studies presented in this chapter epitomise the emergent realities of egg sharing. That is, once a prospective egg share donor proceeds with treatment, the nature of her involvement, identity and own social location changes. Consequently, instead of being independent from wider social relations she places herself in a position that creates both interdependence and the emergence of interrelationships, the creations of which are represented in the diagram overleaf (see Figure 9.1). As can be seen from this schematic representation the emergence of these interrelated aspects of egg sharing begins to change perceptions with regards to family formation and genetic relatedness. This is evidenced in the words of the participants, specifically, wondering about what the other(s) are like; the recipient(s) and the offspring born to recipient(s). Thus, their awareness of the realities of their involvement in egg sharing becomes more apparent than they were prior to proceeding with treatment.



**Figure 9.1** The reality of egg sharing: the creation of visible and invisible interrelationships and interdependence.

Furthermore, the emergence of these visible and invisible interrelationships and interdependence became a focal point of the study. Consequently, this is an aspect of the analytical process that is given more consideration in Chapter Ten (see pages 222-229). However, for the purposes of the current chapter, the final analytical process discussed is the creation of the 'I' poems. In locating the 'I' poems as stand-alone readings I demonstrate how they enabled another layer of meaning to emerge from my analysis of participants' accounts.

### **The 'I' poems**

In the development of the 'I' poems, I chose to create a poem for the entire content of each transcript. This enabled me to maintain a closer proximity to the use of the personal pronoun. In this section I use extracts from the transcripts to demonstrate how the 'I' poems were used in the analysis of the data.

In the first instance, I use Charlotte's poem to demonstrate both the construction of the poem and the analysis undertaken. Typing errors and grammatical errors have been left *in situ* in order to ensure that analysis was undertaken on verbatim transcripts.

In developing the poems, the phrases that include the use of 'I' are underlined. These are then used to develop the lines of the poem; each individual line is then linked up as though they were lines of poetry.

### **Charlotte's poem**

Charlotte describes the route that guided her to choosing egg sharing:

To be honest the whole process of diagnosis and treatment has been very frustrating! everything takes so long and i have felt i have had to push each stage a long. Things are definitely made much harder by that lack of funding available, its just another added worry. I would say 99% of the people i have been in touch with via the website are egg sharing purely for financial reasons. Not to say that, like me, they don't think its a wonderful opportunity to help another women in a similar situation.

Feel free to sent the next lot of questions, i am enjoying answering them and i finding it all quite therapeutic!!

Charlotte's poem emerges from the data as indicated overleaf.

*I have felt,  
I have had to push each stage a long,  
I would say,  
I have been in touch with.*

*I am enjoying answering them,  
I finding it all quite therapeutic.*

In this extract of Charlotte's 'I' poem it is evident that she feels as though she has had to make a concerted effort to get the treatment she needs. I would suggest that this is signified in her use of the phrase "I have" which is used three times in the first four lines of this extract.

In the last two lines of her poem Charlotte is commenting upon the process of the e-interview. Her use of the phrase "I am" is indicative of what she acknowledges as an enjoyable process. Here her switch between the use of "I have" and "I am" indicates that Charlotte is much more in control of the e-interview process than she was with the process of egg sharing. Her words indicate her determined attempts to overcome her infertility. They represent a determination and strength of character that is missing in a later discussion about egg sharing. Here, Charlotte says that:

“I guess the main disadvantage is that i have to give some of my eggs away, which means its possible that the other couple may end up having a child and we don’t”.

In my underlining of the two uses of the personal pronoun it left the following two lines for analysis:

*I guess,  
I have to give some of my eggs away,*

In separating the personal pronoun from the context of the full paragraph it revealed something rather stark. I would suggest that this illustrates that an essence of powerlessness pervades the process of egg sharing. A feature of this phase of analysis is that it revealed a deeper sense of meaning, and a sharper way of focusing upon the actual words of the participant and what they revealed. Set in isolation like this, these two lines of poetry represented a sense of despondency about the process. Here Charlotte shares an air of reluctance, and a realisation that no other viable option was available to her. Hence, Charlotte’s citing of the need to give away “my eggs” as a disadvantage of egg sharing.

### **Emmeline’s poem**

My closer scrutiny of Emmeline’s experiences through the development of her ‘I’ poem revealed nuances of her experiences that may have been missed initially. Emmeline says that:

“I was lead to believe my chances of conceiving would be better after the HSG but still nothing. I was told I had clear tubes and no PCOS. All this took what felt like an eternity. I went back for the next appointment and was given 3 months worth of clomid but no scans. I took the clomid for two months but got increasingly frustrated and depressed with the service, inconsistencies in information and the time delay on the NHS. I was told that because I had ‘unexplained’ infertility I would not be eligible to go on the waiting list for IVF until I had been trying for two years and then the waiting list was about a year. This thought made me aware that if I wanted to have a baby of my own I had to go private”.

By focusing on her use of the personal pronoun in this extract her poem was revealed:

*I was lead to believe,  
I was told,  
I had clear tubes,  
I went back,  
I took the clomid.  
I was told,  
I had 'unexplained' infertility,  
I would not be eligible,  
Until I had been trying for two years.  
If I wanted a baby of my own,  
I had to go private.*

The words used by Emmeline indicate her frustration with the situation in which she found herself. She moves from an acceptance that everything would be alright, to a realisation that it had all gone wrong. Her use of the phrase "I was told" on two occasions appears to represent her accepting the explanations of the people treating her. She then faces the reality that as she has "unexplained infertility" she would have to wait for treatment. Then a dramatic switch takes place whereby it is evident that Emmeline has no intention of waiting any longer than she has to. This is an indication of her possible desperation and frustration with the process, a factor that is evident as being influential in the decision to pursue alternative ways of accessing treatment. In her mind she has no choice or alternative other than to pursue private treatment. Notably, at this stage of the e-interview, there is no mention of egg sharing as a means of accessing treatment. However, this becomes evident in the poem presented below.

*I was not eligible,  
I had been TTC for two years.  
I began,  
I found,  
I researched,  
I researched...  
I came across the concept of egg share.*

Emmeline's poem indicates that she was driven in her attempts to overcome her infertility. Acknowledging her ineligibility for NHS treatment, Emmeline continues to believe that she has no other choice but private treatment. In her determination Emmeline begins to research her options, and even considers returning to South Africa, a factor that demonstrates the range of options that some women will consider in their desire to circumvent their infertility. In her pursuit of other alternatives Emmeline's determination is evident in her researching. This led to her coming "across" egg sharing by chance. Her words also demonstrate her acceptance at being unable to access NHS provision. They also illustrate her personal determination to access

treatment no matter what it took. This strength of character runs through the entire e-interview. Moreover, this strength of character, this tenacity enabled Emmeline to realise her wish of becoming a mother.

### **Florence's poem**

Florence's 'I' poem illustrates the way that she thought about egg sharing. The excerpt presented below demonstrates her awareness of her role in the egg sharing arrangement. Florence says that:

"I was keen to donate my eggs because we already knew I had a good quantity of eggs, and in fact had over stimulated with NHS treatment, of clomid... I was actually quite ill with this, and so was aware that my body responded quickly and in excess!" I needed to produce enough eggs to divide for us and the recipient, and a minimum of eight. If I qualified then it could go ahead...

When converted to an 'I' poem this is how Florence's experiences are portrayed below:

*I was keen to donate,  
I had a good quantity of eggs,  
I was actually quite ill,  
I needed to produce enough,  
If I qualified.*

In converting the text to poetry, features of Florence's experiences become more discernible. In this first excerpt and poem two distinct themes emerge. Firstly, Florence demonstrates control over her reproductive functioning, something that she has lacked because of her need to seek treatment. She regains this control through the knowledge that she had a good quantity of eggs. So whilst acknowledging that she became ill through stimulation treatment previously, the fact that she knows that she can produce a lot of eggs, reinforces her control on her reproductive capacity. However, whilst this awareness exists, her words display also a sense of uncertainty. A sense of powerlessness pervades her thinking; she knows that she can produce a lot of eggs, but she is feeling pressured to ensure that she does produce a lot of eggs when she really needs to do so and she hopes her body responds to this need. This uncertainty and powerlessness filters through in the last line of her poem – "If I qualified". Florence is reinforcing her awareness that this is not a certainty and something outside of her locus of control. In a sense she is at the mercy of her own body, and also of the team of people treating her. In the second poem presented below Florence's experiences

manifest themselves in different ways. It is possible to glean understandings of the impact of egg sharing on Florence.

*I would do everything right,  
I also felt,  
I would go through,  
I wanted her to know,  
I wouldn't let her down.*

In entering Florence's life-world in this way it is evident to see that egg sharing places an immense burden on her. This is acknowledged by her emphasis on "everything"; she knows that in order to obtain her own treatment she has to ensure that she meets her side of the arrangement. Her worry is also evident; worry for herself, but more so for the recipient of her eggs. She wants to make sure that she produces the best eggs and she is also acutely aware of the recipient's needs. Her use of the word "felt" depicts her innermost thoughts, in order to feel, she has to think, by thinking she reflects on her own experiences and how these might mirror those of her recipient. Her recipient is not distant from the process; she is an invisible, anonymous part of the process.

### **Jayne's poem**

Similarly, Jayne's poem provides an awareness of her role in the egg sharing arrangement and what this represented. Jayne believed that the:

"...fact that I would be helping another couple, which I did feel proud of ...I do believe that any couple going through egg share needs to have... I thought about... who need donated eggs, and so I had an idea of how the recipients must feel and knowing that I could possibly help them to get their family, it felt like I was doing something 'good'..."

In her poem these experiences are further highlighted and enable her thinking about her involvement in the process to be further analysed.

*I would be helping,  
I did feel proud of,  
I do believe,  
I thought about,  
I had an idea of how,  
I could possibly help,  
I was doing something 'good'*



It is evident in the way that Jayne vocalises her experiences that she thought quite a lot about the process of egg sharing. Here it is also evident that Jayne thinks about the recipient and what the act of her egg sharing represents to them. The fact that she feels proud reinforces this assertion. In the 'I' poem presented below these feelings are replaced with others that express a different way of thinking about egg sharing.

*I don't really see it as negative,  
I've got to learn,  
I'm never going to know,  
I'm never going to know,  
I could,  
I feel,  
I did,  
I've just got to learn.*

In this extract it is evident that the reality of egg sharing, post-treatment, has become apparent for Jayne. This suggests that a different level of acceptance is taking place. Jayne uses the terms "I've got to learn" and "I'm never going to know" twice in this poem, which suggests that she is trying to become more accepting of the process of egg sharing. She is acknowledging that she has to learn to live with it; whilst her experiences of egg sharing are not negative, they do leave her open to a range of thoughts that she might not otherwise have had. In the final sentence of her poem the word "just" appears which suggests that Jayne is still trying to accept the implications of egg sharing.

### **Egg sharing: the emergence of theory**

In this chapter I have used case studies and the 'I' poems to provide the reader with an insight into the lived experiences of participants. These experiences revealed the need to utilise theoretical perspectives in the attempt to generate a better understanding of their experiences, in keeping with the aims and objectives of the study (see pages 19-20).

As discussed in Chapter One (see pages 17-18) I had an awareness of existing literature that had focused upon egg sharing. Thus, I used this literature, in particular the work of Maggs-Rapport (2001) and the HFEA's stance with regards to the 'gift' within the context of ART provision (see page 29), as the starting point for the present study. This was aided by my readings of philosophical, social anthropological, social philosophical, sociological, and social psychological literature.

These wider conceptual readings enabled me to further contextualise some of the debates surrounding the ability of women to give their 'informed consent' as they proceed to becoming an egg share donor. In doing so, theory demonstrated that the concepts of 'altruism' and 'informed consent' from the perspective of the donor required significant consideration, as did concepts surrounding decision-making and the role this had in relation to becoming an egg share donor.

My integration of theory proceeds with the ethics of informed consent, a concept explored in greater detail in Chapter Eleven (see pages 244-248) as this the central theme of exploration in the study. The following aspects of theory are then addressed in turn: women as autonomous thinkers, rational and moral decision-making, and the concept of the 'gift' relationship in organ and tissue donation, and a brief account of the affect theory of social exchange. Finally, the emergence of my developing feminist perspective is included as this underpinned some of the theoretical thinking incorporated in the thesis.

### **On the ethics of informed consent**

An area that emerged in the presentation of the case studies was that all informants felt adequately prepared to provide their consent and proceed with egg sharing. In my assessment of their ability to 'consent' it was essential to integrate theory pertaining to the ethics of informed consent. Firstly, I outline the historical emergence of ethical codes in society. These codes are then located within conceptual debates pertaining to the giving of 'informed consent' and its potential ramifications.

Notions of ethics, in particular biomedical ethics, can be traced back to the fifth century and Hippocrates (Glannon, 2005), although it was not until the Nuremburg War Trials in 1945 that an understanding of the importance of consent became apparent. This was because some of those on trial included Nazi doctors who were charged with crimes to humanity. In particular:

Being connected with plans and enterprises involving medical experiments without the subjects' *consent* upon civilians and members of the armed forces of nations then at war with the German Reich (emphasis added)  
(Anon, No date)

This unprecedented legal case brought about the inception of the Nuremberg Code. This code specified directives that were designed for those involved in experiments that involved human subjects. Article 1 states that:

The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent; should be situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision.....  
(World Medical Organisation, 1996)

Essentially, this became the basis for the way in which medical research on human subjects is conducted. Nowadays, the guidance runs alongside the Declaration of Helsinki, which was adopted by the World Medical Association in 1964, which added three more principles to the Nuremberg Code (Glannon, 2005). One of the basic underlying principles within the code is that when conducting biomedical research on human subjects “the physician should then obtain the subject’s freely given informed consent” (World Medical Organisation, 1964). Even so, Gorovitz (1998) cited in Bromham (1988, p.230) states that “the complexity of informed consent hangs on the fact that it can go wrong either in the informing or in the consenting”. This view suggests that whilst people may have the relevant information required, thus enabling them to make an informed decision, this may be affected in some way, and could be linked to the quality and clarity of the information being provided. Concerns about consent are based on Westernised cultures and relate also to “research ethics discourses” and “everyday life” (Shaw, 2007a, p.439).

In their discussion of the consent process the HFEA (2006a, paragraph 7) state that “poor information and limited opportunities for discussion lead to problems with properly informed consent”. As alluded to earlier, informed consent may be affected by other scenarios, including external factors, such as unintentional coercion. Internal factors such as having the necessary competencies required to give consent freely, may also factor into decision-making (Glannon, 2005). Additionally, with regard to the donation of human tissue, the European Union Tissue Directive (2004) Article 13.1 states that:

The procurement of human tissues or cells shall be authorised only after all mandatory consent or authorisation requirements in force in the Member State concerned have been met.

In the UK, the Human Tissue Authority (HTA, no date) state that “consent is only valid if proper communication has taken place”. This view reinforces the importance of information provision and communication as central to egg share donor’s ability to give consent.

Significantly, it has been suggested (from a healthcare ethics perspective) that insofar as possible, patients must be supplied with information that is complete; they should also be given a complete set of alternatives (Loewy, 1996). Loewy (1992, p.109) states further that “consent is not merely an explicit agreement between two or more individuals but has to be understood as enmeshed in a particular cultural and communal matrix”. For the purposes of the thesis, the cultural and communal matrices are those that are located and operate within the parameters of the assisted conception centre. However, there is also an acknowledgement that the onus is upon professional responsibility when informed consent is being elicited, since it has been suggested that “coercion can be achieved by the manner in which the information is presented, for instance by the order in which it is given or by laying greater and undue emphasis on one set of side-effects” (Culver & Gert cited in Draper, 1991, p.78). This opinion is in accord with Tong (1996, p.151), who suggests that when counseling gamete donors:

Minimally, the purpose of such counseling should be to secure truly informed consent. Maximally, it should be to help gamete donors explore the nature and consequences of their action for themselves, the gamete recipients, and any child born as the result of their collaborative project.  
(Tong, 1996, p.151)

This was a theme that emerged during the analysis of both the e-interviews and online survey, which is discussed in chapter ten (see pages 222-230). Notably, the ability to provide informed consent was also linked to theories pertaining to decision-making. Particularly those associated with rational and moral decision-making and the autonomy of women.

### **Women as autonomous thinkers**

It is evident in some of the literature pertaining to women’s ability to give informed consent that the opinions presented seem to suggest that women cannot make

decisions that are in their own best interests. These views suggest evidence of patriarchal values and belief systems, which conceptualise women as subordinate beings with no power or control over their lives (Hekman, 1995). Indeed women were once portrayed as timid, helpless, fragile, uneducated beings (Hamilton, 1909). However, this is not the case and women are autonomous individuals. Moreover, if women have autonomy this should be reflected in discussions surrounding their ability to give informed consent, particularly since one of the basic fundamental principles underpinning biomedical ethics is respect for autonomy (Beauchamp & Childress, 2009). The principle of autonomy in this instance is linked to the concept of individual choice and control during the process of agreeing to become an egg donor. Sherwin with *Voices from the Network* suggest that:

Women are placed in subordinate positions with respect to economic, political, legal and social structures.....the nature and degree of women's oppression varies significantly depending on other features of their lives (including race, class, age, sexuality, health, and ethnicity).  
(Sherwin with *Voices from the Network*, 1998, p.2)

They suggest that medicine perpetuates "some aspects of women's oppression while helping to reduce other dimensions of women's oppression" (Sherwin with *Voices from the Network*, 1998, p.3). This view has specific relevance to the field of reproductive medicine, and for women seeking treatment.

For women experiencing involuntary childlessness, oppression may be felt due to the stigma associated with this now medicalised condition (Bryan & Higgins, 1995). The term 'oppressed' is being used here to alert the reader to the fact that society expects women to reproduce and, if this does not occur, they may be viewed as deviant, as society dictates that this is a woman's role and they are not fulfilling it (Miall, 1986; Lasker & Borg, 1987; Bryan & Higgins, 1995; Whiteford & Gonzalez, 1995). However, biomedicine and the emergence of ARTs may have reduced some of the problems faced by the involuntarily childless, in that they offer them hope, but hope that might involve a price. Furthermore, the paternalistic nature of reproductive medicine may in itself oppress the many women who seek treatment.

However, the decision-making process is for many a complex one. In medicine as alluded to earlier, there is a need to respect autonomy so as not to abuse or exploit patients (Sherwin, 1998; Beauchamp & Childress, 2009). The principle of autonomy is

outlined by Sherwin with regards to a patient's decision-making. She postulates the notion that autonomous decisions are ones which are made by a patient if they:

- 1) Are deemed to be sufficiently competent (rational) to make the decision at issue;
- 2) Make a (reasonable) choice from a set of available options;
- 3) Have adequate information and understanding about the available choices;
- 4) Are free from explicit coercion toward (or away from) one of those options.

(Sherwin, 1998, p.26)

This latter point is the central focus of the following analysis.

Becoming an egg share donor may be viewed as a legitimate way of attempting to achieve a pregnancy. In doing so, a woman is choosing to do something which she believes is in her best interests, particularly if this is the only way she can access treatment. At the same time she is attempting to help another woman who is experiencing difficulty conceiving naturally. This may be a purely altruistic act, or it may be an act that has been influenced by wider factors, such as the desire to help, or the offer of cheaper, quicker treatment. Thus, Sherwin's point regarding 'free from explicit coercion' is applicable to the analysis of donor motivations. However, decision-making can be framed in a number of ways. Thus, my integration of rational (consequential) and moral decision-making (later in this chapter) is linked to 'if then' logic. This became applicable to the study, because as I described in chapter two, the existing empirical studies on egg sharing assert that donors' decisions are affected by the drive to conceive. Consequently, if they want to try to conceive, then egg sharing represents an opportunity to do so. Thus, the applicability of this position is that the emphasis is placed upon women having the necessary capacity to make the right decision.

### **On decision-making**

In the current study, as evidenced in the case studies presented in this chapter, egg share donors' decision-making processes have been explored. As they described how and why they decided to pursue egg sharing it became clear that this was not a split second decision. Furthermore, the data collected depicts (to a certain degree) how and what was influential in their decision-making. Thus, in my assessment of the motivations to become an egg share donor, I applied a number of theoretical positions in my analysis of decision-making. In doing so, I integrate a brief exploration of rational and moral decision-making.

### **Rational decision-making**

In locating decision-making within the study I was guided by the work of Crosbie (1986) who cites the work of Lee (1971). Crosbie suggests that the philosophical writings of Adam Smith, Thomas Hobbes and Jeremy Bentham (as discussed by Lee, 1971) qualify for inclusion in discussions pertaining to rational decision-making in reproductive medicine. Crosbie states that these early philosophers suggested that:

Humans act by anticipating the consequences of their decisions, and that humans would act best if they directed their decisions towards achieving the maximum consequential satisfaction or happiness.  
(Crosbie, 1986, p.31)

Thus, it is essential that the consequences of one's actions are evident prior to the decision being made. Crosbie (1986, p.31) concludes that this is the basis of decision-making and that "contemporary rational man (or woman) is informed, and contemplates his or her decisions". Subsequently, decisions are influenced by internal motivations. The theory pertaining to 'rational' decision-making stems from microeconomics, and the notion of the consumer in society. Decisions are made based upon the allocation of limited resources in a manner that achieves optimum satisfaction (Crosbie, 1986). However, as suggested by Blyth and Golding (2008), the implications of one's decision are not always evident at the time the decision is made. Consequently, decisions may be regretted at a later date; however, this does not invalidate the original decision. Nor does it provide a legitimate reason for not making the decision, or being allowed to make the decision, in the first place. In the analysis presented later in the thesis (see pages 238-242), I illustrate, through the application of this concept, how this perspective was influential to the development of understanding about egg share donors' decision-making.

### **Moral decision-making**

As Thompson et al (2000, p.306) point out "moral decision-making is undertaken by people who act freely and *understand* what they are doing" (emphasis added). Here I emphasise understanding as being about the potential consequences of one's actions. Thus, it could mean that the ability to make a morally sound decision may become problematic. Consequently, it may be affected by wider, mediating factors which, it could be argued are underpinned by society's ethical codes. However, a moral decision is not governed by a framework or general definition. It is framed by the moral agent

(the person) making the decision. Thus, the decision taken will be determined by the individual's independent, moral thinking with regard to what best suits their situation.

Furthermore, in relation to egg sharing, moral decision-making may be affected by the internalised, associative stigma of involuntary childlessness (Raphael-Leff, 2010) that may pervade women's inner thinking. Thus, the capacity to make a decision may be influenced by women's own biological desire to have a child.

### **Analysing the gift relationship**

My integration of the 'gift' relationship stems somewhat from Emmeline's reference to the 'gift' within the context of her becoming an egg share donor, and the HFEA's reference to the 'gift' (see pages 29 and 168). However, as the concept of what constitutes a 'gift' have emerged from a number of discourses, some of these discourses are explored to assess whether egg sharing can be described and located within the context of the gift relationship. This begins within the locating of 'gift' within the context of a legal framework.

Laurie (2002) introduces a legal perspective into the debates about what constitutes a gift within the context of genetic research. Laurie states that English law defines the 'gift' as follows:

A gift... may be defined shortly as the transfer of any property from one person to another gratuitously... It is an act whereby something is voluntarily transferred from the true owner in possession to another person with the full intention that the thing shall not be returned to the donor.  
(Halsbury's, 1993 cited in Laurie, 2002, p.313)

In Scottish Law the gift is referred to, more appropriately, Laurie suggests, as a donation (Laurie, 2002, p.313). In his analysis he notes that the use of the gift analogy in relation to donation of human tissue and body parts for research has led to confusion about what constitutes informed consent. He acknowledges that the use of the gift model creates a:

Normative appeal in lay terms, not least because it is seen to be a laudable act, demonstrating the virtues of altruism and beneficence, and untainted by the twin evils of self-interest or exploitation.  
(Laurie, 2002, p.312)



He notes that unconditional gift giving can serve a number of valuable social purposes, “including advances in medical research and the development of therapeutic agents or cures” (Laurie, 2002, p.313). However, Speirs (2007) asks us to consider whether a gift, within the context of the donation of bodily material, should be viewed as a gift, or whether it should actually be referred to as a commodity, a theme explored later in the thesis (see pages 205-209).

Utilising these positions as the basis of my integration of theory I drew extensively upon the works of Mauss (1954, 1990), Schwarz (1967), and Titmuss (1970, 1997). This enabled me to both contextualise and conceptualise the concept of the gift. In their works, each author espouses their theoretical position pertaining to the concepts of the gift, gift giving, and reciprocity. Titmuss’ theory, in particular, is used in some instances as an ethical model for the framing of understanding about transplantation and organ donation (Shaw, 2010). I have used it in the thesis in order to draw out the issues surrounding the motivation to donate eggs. In Titmuss’ essay on blood donation it is evident that there are distinctions to be made regarding what constitutes a ‘gift’. Thus, the multifaceted nature of the gift needs to be examined from a variety of perspective.

In his analysis of the social psychology of the gift Schwarz (1967, p.1) states that “a gift is an imposition of identity”. That is, the gift transmits pictures of ourselves to others, and it is the gift that defines who we are as moral beings. Schwarz (1967, p.2) goes on to propose that “gifts reveal an important secret: the idea which the recipient evokes in the imagination of the giver”; [it is through this perception of the] “other” [that enables the gift to become] “self-defining”. Subsequently, Schwarz (1967, p.6) suggests that the “gift giver and receiver evaluate presents according to some frame of reference”. This analysis implies that in order to give a gift, one has to have some perception as to why one wishes to give that gift, to that particular person. However, it is also acknowledged that gift giving is linked to reciprocity (Levi-Strauss, 1957; Schwarz, 1967). Consequently, the application of gift theory implies that gifts are given but that a reciprocal act is required. This led to my exploration of affect social exchange theory.

### **Affect theory of social exchange**

Social exchange theory works on the assumption that it is “self-interested actors who transact with other self-interested actors to accomplish individual goals that they cannot achieve alone” (Lawler & Thye, 1999, p.217). The central properties of social exchange theory are interdependence and self-interest (Lawler & Thye, 1999). That is, “two or more actors, each of whom has something of value to the other, decide whether to

exchange and in what amounts” (Lawler & Thye, 1999, pp: 217-218). They go on to suggest that these actors are normally unemotional, and that they use cognition to process information in order to reach a decision. The authors propose, however, that rather than relying on cognition alone to understand social exchange, the role of emotion and its impact upon social exchange is warranted (Lawler & Thye, 1999). Thus, Lawler (2001) advocates a move away from the Skinnerian concept of exchange, proposing his own theoretical position of “affect theory of social exchange” to illustrate the relational nature of exchange and “focuses exclusively on the emotional/affective process in order to broaden and deepen theorizing of the emotional effects of exchange” (Lawler, 2001, p. 322).

In the current study emotions were a significant part of the research and the premise that “emotional dynamics have a more central role in social exchange than typically assumed” (Lawler & Thye, 2001, p.218) has been acknowledged in my assessment of the motivations and the ability of women to consent to become egg share donors. In particular, the idea put forward by Lawler and Yoon (1996) that describes exchange as a process that enables individuals to feel satisfied, excited, good and relieved, soon became very significant. Lawler and Thye (1999) note that the vague nature of ‘emotions’ within the exchange tradition perpetuated the view that emotion is a phenomenon that cannot be understood within rational or behavioural choice principles. Subsequently, much of the literature that referred to emotion was not theorised to any extent until recently (see for example Hochschild, 1979; Malacrida, 2007; Hunter & Deery, 2009). It was readings such as these that led to me revisiting my theoretical position within the context of the research.

### **Developing a feminist perspective**

At the start of my journey into theory I was a researcher with no leanings towards any particular theoretical position. Yet as I charted my progress through my work and began to reflect on my readings it became self-evident that I was erring towards feminist attempts to examine women’s reproductive health and well-being, infertility, childbirth and motherhood. These readings represented quite a dominant stance from a cultural and critical realist position regarding the issues women face when attempting to overcome involuntary childlessness. This was an illuminating moment and I went on to view this study, not only as a female researcher, but through the eyes of a woman who could attempt to comprehend the lived experiences of the women who took part in the research. Thus, I was entering into the feminist tradition of doing research on women, as a woman, for the benefit of women (Stacey, 1991, p.111).

Furthermore, notions of male dominance, patriarchy and the role of men in the medical profession guided me to critically re-evaluate my own location in the study. As I did I began to realise that I was developing as a feminist with a critical stance and view. Through reflecting upon my development as a feminist phenomenologist I acknowledged that the development of my feminist thinking stemmed from my readings of works by Mills (1971), Oakley (1982), Gilligan (1983), Stanley & Wise (1983), Corea (1987), Spallone (1989), Brown & Gilligan (1990) and Rich (1990). In essence I re-visited myself, as expressed by the feminist author Rich who defines re-vision as ‘the act of looking back, seeing with fresh eyes, of entering old text from a new critical direction’ (Rich, 1990, p.483-484). This re-visioning incorporated a “radical feminist critique of the literature” (Crotty, 1998, p.107).

However, whilst acknowledging that I developed as a feminist, with a particular theoretical viewpoint, I chose not to embed a purely feminist position in the study. Rather, I use this position later in the thesis during the analysis of the experiences of egg share donors. As I have illustrated in this chapter, the use of feminist methods of analysis enabled me to examine, evaluate, analyse, and give ‘voice’ to the women who participated in the study. Moreover, in my quest to decipher and understand the meaning of experiences as recounted, I further located myself in relation to the study (see pages 253-256). Subsequently, by becoming reflexive I was able to undertake a more rigorous analysis of the data. In doing so, I incorporated the work of Hochschild (1979) and the theoretical concept of ‘emotion’ and ‘emotion work’ in my attempts to extrapolate and elucidate the experiences of egg share donors.

### **Chapter review**

This chapter has presented my analysis of the findings from the e-interviews. I have used the case studies and the ‘I’ poems to demonstrate the features of the analysis process employed. I also located the emergent findings within the context of an emergent theoretical framework. This was undertaken to demonstrate how the wider theoretical literature integrated into the study were pertinent to the debates surrounding egg sharing.

In doing so, I based the beginnings of the theoretical framework around the ability to give informed consent, as the accounts provided by participants illustrate how the consent process was dealt with, and how they felt that they were able to consent to being an egg share donor. Thus, the role of decision-making from a theoretical context was also considered. This integrated a number of contrasting positions in order to

contextualise decision-making. Specific attention was also given to the concept of the gift, the gift relationship, and altruism in breast milk and blood donation. In my analysis I illustrated how there are conflicting accounts of what constitutes an altruistic act in relation to the donation of bodily material. I also briefly introduced the affect theory of social exchange as it, too, became relevant to the context of the research. Finally, I introduced a feminist theoretical position in my attempt to illustrate how my theoretical thinking developed whilst undertaking the study.

Significantly however, the accounts that emerged from participants revealed a number of discourses. These relate to motherhood and the decisions made in the attempt to achieve motherhood status. The accounts provided also highlight the reality of egg sharing, for some women, both during and after treatment. The women's stories demonstrate how the experience of becoming an egg share donor is complex, and this complexity will be addressed in more detail in Chapter Ten, when the findings from the e-interviews and the online survey are combined.

## CHAPTER TEN

### **Egg sharing: putting the donors' accounts together**

*If you want to know me, then you must know my story, for my story defines who I am. And if I want to know myself, to gain insight into the meaning of my own life, then I too must come to know my own story.*  
(McAdams, 1993, p.11)

This chapter describes the nature of egg sharing from the donors' perspectives. In doing so it details the main findings that emerged from the two phases of the study, the online survey and the e-interviews. Interwoven throughout the findings presented are my personal reflections and reactions to the emergent issues. These are set alongside relevant evidence from existing literature, to demonstrate the varied discourses of egg sharing that emerged in the study.

#### **Combining the data from phases one and two**

As the study utilised two different methods of data collection, data were combined for the final stage of analysis. This facilitated a more rigorous and overarching analysis of informant accounts. It also illustrates how the underpinning methodological framework enabled the 'lived' experiences of egg share donors to be revealed (see Chapter Three). Additionally, since the e-interviews and the online survey questionnaire were similar because the areas covered were linked to existing literature and research, the complementarity of the chosen methods is also demonstrated.

In the study, both methods of data collection provided sufficient scope for respondents and participants to provide their thoughts about other areas not explicitly included in either the interview schedule or the online survey. The five emergent themes outlined in this chapter: (1) the motivation to egg share, (2) egg sharing as a helping relationship, (3) egg sharing as a complex, psychosocial treatment option, (4) egg sharing as control and being controlled, and (5) egg sharing as motherhood, are discussed in turn. This demonstrates further the multilayered journey to becoming an egg share donor, using the informants' own words, in order to remain as close to the narrative account of the lived experiences as possible.

### **The sample population**

In my introduction I provided statistics that demonstrate the number of women who enter into egg sharing as donors (see page 18). This means that a limitation of the study is that the views of informants may not be representative of the entire population of egg share donors, as discussed in Chapter Eight (see page 142). Thus, if the current study were to be replicated using a sample of women who had not self-selected into the study, the findings might be somewhat different to those reported here. However, the characteristics of participants and respondents were examined to assess whether women from different ethnic, social and economic groups had responded to my call for informants.

I was able to conclude that in terms of age, there were some variations in the characteristics of informants. However, the sample was as homogenous as I had anticipated. I would suggest that this is because of the specialised nature of the study and its focus upon the experiences of egg share donors. Thus, I am able to demonstrate the similarities that became evident in my presentation of the detailed analysis of the merged data.

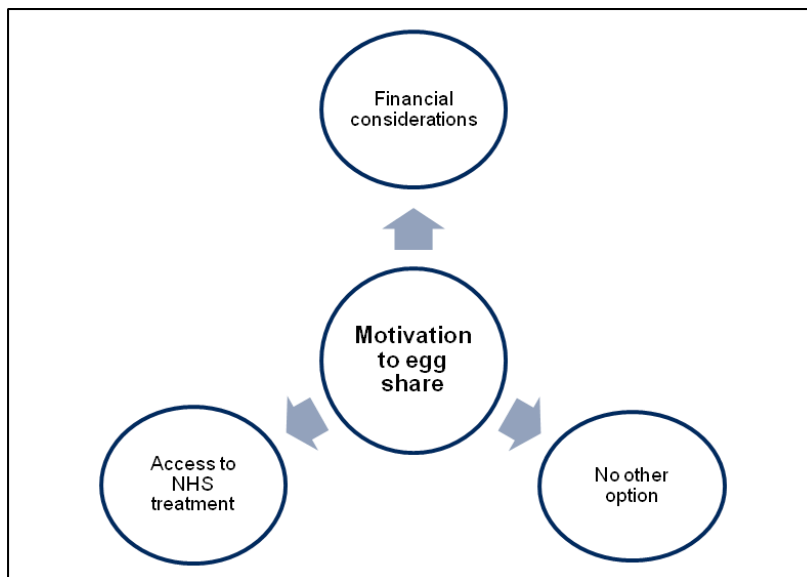
### **Motivation to egg share**

In the study a main theme to emerge pertained to the complex nature of motivation to egg share. In addition, the multidimensional nature of egg share donors' experiences and the inextricable link created between them and the recipient became very apparent. That is, the emergence of an invisible relationship between the donor, the recipient(s), and the potential (in some cases, actual) donor-conceived children, because egg sharing contributes to new family formation and donors have to contend with the existence of genetically related offspring being raised, from birth, in another family. In locating the donor in this distinctive new relationship, I suggest that the decision to provide informed consent and proceed with egg sharing becomes more complex post-treatment. Thus, the reality that children exist from this arrangement (or 'invisible' relationship), is intangible, however, it may become tangible in the future. Consequently, donors know that the donor-conceived child may choose to seek them out once they have reached the age of 18. In some cases this is welcomed; in others there is uncertainty (see pages 161-163 and 166-176).

As I demonstrate further the multilayered nature of the motivation to donate, I illustrate how the location of the informants enabled the relational nature of egg sharing to be made explicit. Thus, the intricacies associated with being an egg share donor are

further revealed. I have chosen to integrate diagrammatic interpretation to demonstrate the emergent themes, and their sub-themes.

In describing the motivation to egg share, Figure 10.1 depicts the aspects associated with the theme; 'motivation to egg share'. Four sub-themes emerged which are: financial considerations, a helping relationship, no other option and access to NHS treatment.



**Figure 10.1** Motivation to egg share

The diagrammatic representation of this theme illustrates the interwoven features of the decision to proceed with egg sharing and the motivations to do so. These findings accord with those of Rapport, who states that the:

Motivation to egg share is multi-dimensional and all dimensions are inextricably bound together, having no order of precedence or focal point. Indeed, their relationship to each other cannot be measured or predicted, and yet it is this relationship which makes motivation to donate so complex.  
(Rapport, 2003, p.32)

However, for the purposes of the ensuing discussion I have chosen to separate the ability to help as a motivational factor and instead discuss it on its own merit. This is because a further two sub-themes emerged with regards to the helping relationship. For this reason I give this theme (a helping relationship) specific attention as determined by my analysis of the data and emergent themes. I now demonstrate how the three sub-themes depicted in the diagram related to egg share donor motivation.

### **Access to NHS treatment**

A major theme to arise from the study was the level of dissatisfaction with NHS provision and the levels of care experienced. In three of the in-depth interviews and 10 of the survey responses it was clear that access to NHS treatment was an overarching issue. It was cited as an influential factor that underpinned the decision to seek treatment in the private sector. Participants also conveyed their thoughts about issues related to waiting times, eligibility, and IVF provision in their locality. In explaining why they chose to become an egg share donor there were issues related to how long they would be required to wait to access NHS treatment. Subsequently, the possibility of escaping a lengthy wait for NHS treatment, assuming, of course, they were eligible for NHS treatment in the first instance, represented another choice. Emmeline elucidates her experiences and says that she:

“Got increasingly frustrated and depressed with the service, inconsistencies in information and the time delay on the NHS. I was told that because I had ‘unexplained’ infertility I would not be eligible to go on the waiting list for IVF until I had been trying for two years and then the waiting list was about a year...”

In the same vein, a respondent to the survey reported that when she attempted to access NHS treatment she found that the:

“Waiting list was 3+ years, we would have got 3 cycles but had just had my twins when we reached the top of waiting list.”  
(Respondent 11)

Circumventing the waiting list by choosing egg sharing reinforces the concept discussed in Chapter Two (see pages 44-49) that egg sharing represents a tangible opportunity to achieve parenthood without a lengthy wait for NHS treatment. Florence voiced similar experiences and it is clear that this had impacted on her greatly. She says of her attempt to access NHS treatment that:

“You have to ‘**Qualify**’ under the PCT for IVF and we didn’t at that stage because we had ‘**only**’ been ttc<sup>19</sup> *for two and a half years at this point. They insist it’s three years before you get a look in!*”

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<sup>19</sup> (ttc) Trying to conceive – participant’s own use of the acronym.



Charlotte found that her local PCT did not fund IVF. Although they subsequently began to fund a single cycle of treatment, the eligibility criteria were stringent and Charlotte found out that she was ineligible for two reasons:

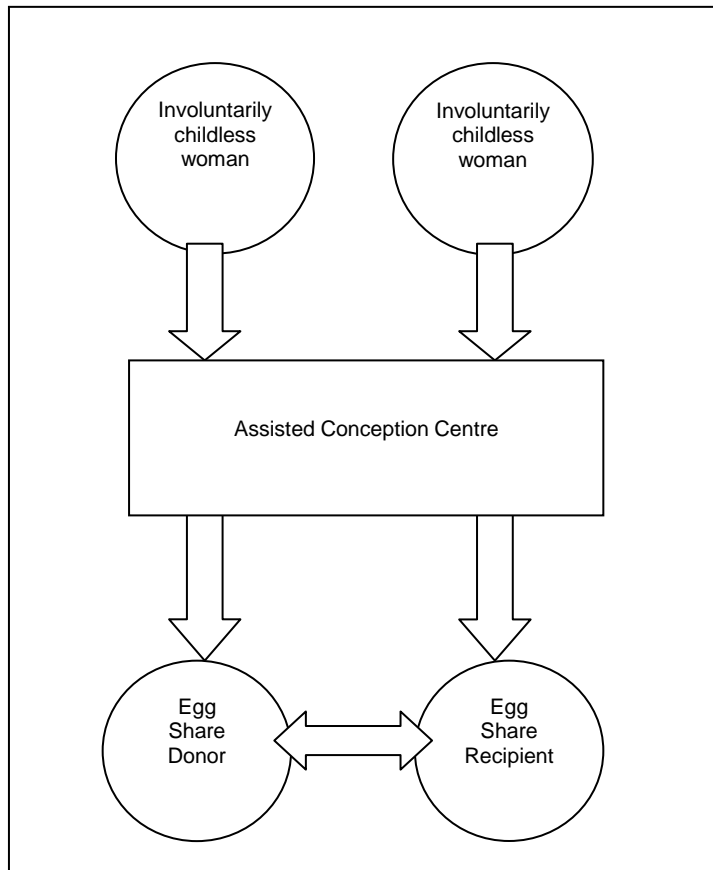
“Unfortunately my husband and I didn’t meet the criteria as my husband has a child from a previous relationship and my weight was an issue...”

What she also found difficult to understand were the guidelines related to smokers. She commented that smokers were ineligible for treatment, although she was aware of a couple who both smoked, yet had been able to access treatment. She could not comprehend this fact and saw no justice or equity in service provision. What these findings appear to exemplify is that these experiences reinforce the opinion that NHS treatment provision is inconsistent and that, for those participants who had problems accessing NHS treatment, the main issue was the timescales involved. The thought of having to wait so long for treatment, in addition to the length of time they had already been trying to conceive a family, were influential in their decision to seek private treatment, and to subsequently become egg share donors.

The disenchantment and disillusionment experienced by participants is evident in the way Florence vocalises her thoughts about the process. She says that she:

“...was desperate and very depressed. I found out about a private clinic and although we couldn’t afford their prices went along to an open evening.”

Similarly, Emmeline said when she realised that she would not be able to get NHS treatment: “if I wanted to have a baby of my own I had to go private”. These are views that further exemplify the problems some women face gaining access to NHS treatment. Consequently, it results in a situation whereby independent women in need of ARTs become dependent upon a private assisted conception centre (see Figure 10.2). This results in the creation of mutual interdependence on one another as the only way they can receive the treatment that they require.



**Figure 10.2** From independence, to dependence, resulting in the concept of mutual interdependence.

### **The only option**

It became apparent in my analysis was that women felt that egg sharing represented the only way of getting treatment. Difficulties accessing NHS provision, because of waiting times, ineligibility or restricted provision, prompted participants to find other ways of overcoming their childlessness. In the current study, the main method of finding different ways of accessing treatment was to use the Internet as a search facility.

Three of the four participants who were e-interviewed for the study said that they had found out about egg sharing by chance, via the Internet; this was in addition to two survey respondents who also indicated that they had found out about egg sharing from an Internet search. A further two respondents indicated that they found out about egg sharing via an Internet support group. Prior to finding out about egg sharing in this way, they had no prior knowledge that the treatment existed. For these women, egg sharing became the treatment of choice. This highlights that, in the absence of alternatives, some women will potentially pursue any treatment if they believe that it may alleviate their involuntary childlessness, including treatment overseas. I described this theme in Chapter Two with reference to the works by Rapport (2003) and Blyth (2004), who

found that egg sharing represented the only choice in the attempt to circumvent involuntary childlessness (see page 44). However, there is no evidence provided in the data as to why these avenues were never pursued as an alternative to egg sharing.

### **Financial considerations**

In the study, it was evident that the offer of reduced price treatment was a motivating factor. However, there was no evidence that informants felt that they were exploited because of their financial situation, although financial issues were cited as a primary motivating factor associated with the decision to become an egg share donor. This was expressed by four e-interview participants and seven of the survey respondents (11 out of 17 informants), who said that they could not afford to fund their own treatments. Thus, it could be argued that decision-making is in part, financially motivated. For example, Jayne, said that:

“Without sounding selfish, egg share was really the only option for us. We were desperate for a baby and could not afford the full price of IVF... the main reason for egg sharing was the financial side of things, its cut our costs down dramatically.”

Florence said that she and her husband chose egg sharing as it meant that they could get:

“Access to the treatment we needed as it was beyond our reach financially and the NHS wouldn't allow us treatment at that time.”

One respondent said that for her, “doing egg sharing dramatically reduced the cost of IVF” (Respondent 10), and Respondent 11 commented:

“Happy to find a way the help us finance ivf without spending all the money we had saved up for the baby it would hopefully result in.”

These shared opinions demonstrate that the ability to access cheaper treatment was influential in egg share donors' decision-making, insofar as informants acknowledged that this was a motivating factor.

This finding is in accord with one of the criticisms of egg sharing that I alluded to earlier in the thesis (see pages 44-49, 151-152 and 166-176). This was with regards to the concerns that have been expressed about access to cheaper treatment and whether this constitutes an inducement to egg share. The major concern expressed was that

women are coerced in to becoming an egg share donor because of the financial incentive that can be attributed to accessing cheaper treatment (Johnson, 1999; Brazier, 2003; English, 2005; Blyth & Golding, 2008). This is a theme explored by Pfeffer (2010) in her analysis of older mothers and the global context pertaining to egg donation. Pfeffer suggests that:

In the UK, the prohibition on buying and selling human body parts remains, but is circumvented for gametes by claiming they are 'donated' altruistically and any money 'donors' receive is not payment, but reimbursement of expenses incurred.  
(Pfeffer, 2010, paragraph 5)

Pfeffer is of the opinion that permitting egg sharing, as discussed in Chapter Two (see pages 44-49), is controversial because of the financial incentives associated with the schemes. Significantly, she asserts that, by no stretch of the imagination, can access to reduced price treatment be called 'expenses'. She also suggests that access to cheaper treatment exploits women who are economically disadvantaged. The findings presented tend to support this analysis. However, as I have demonstrated, the decision to become an egg share donor is not that straightforward, and is not based solely on financial considerations. Nor was there any intimation that informants believed that they had been exploited. Hence, the findings support the multifaceted nature associated with the motivations to become an egg share donor.

### **A helping relationship**

The ability to help someone else was a theme that ran through all the data. Here the perception of the 'infertile other' was evident. So whilst, as illustrated previously, women were motivated to egg share because they faced difficulties accessing treatment, or previous treatments had failed, egg sharing represented the only real option due to financial restrictions. Nevertheless, the final decision to egg share is not solely based on these reasons. Informants also expressed helping as a secondary motivating factor, based on altruism and empathy. Reproductive 'gift' giving also became evident during analysis, as illustrated in the diagrammatic representation provided in Figure 10.3.



**Figure 10.3** A helping relationship

### **Altruism and empathy**

In the study, all e-interview informants, and 12 of the 13 survey informants indicated that helping someone else was an important aspect of egg sharing. This suggests that egg share donors display altruistic tendencies. Importantly, the concept of ‘helping’ was related to informants being told that this is the ascribed benefit of egg sharing. Subsequently, whilst egg share donors wanted to help, I would suggest that the way that the treatment was framed by others, such as clinic staff, could have been influential in their decision-making. For example, Florence explains how egg sharing was described during her consultations:

..." You are only donating eggs, which is in fact a bunch of cells, when put together with the man's sperm, whom is not your partner/husband's. It could tango, it could not, but it is only 'your baby' in the making when it's with your partner/husband. In this situation you are half that person, in terms of their make up, but you have no part in their life, or how they are brought up. They may never have any of your characteristics of personality, or they may have some, or many. They are themselves a person within their own right."

She states that it was this information that enabled her to proceed with egg sharing, a concept I return to later in this chapter in my discussion of the concept of dissociation. That is, the discourse of language might act as a vehicle that promotes egg sharing. The choice of language and the way messages are framed provides a concept of egg sharing that is driven by those promoting the treatment. I explore this concept further in

Chapter Eleven, as the discourse of language was a salient feature of the study. Consequently, it permeated through some of the accounts provided by informants. However, regardless of the way information was framed, a helping role was described by other informants. In explaining her motivation Jayne said that with egg sharing:

“There was also the fact that I would be helping another couple, which I did feel proud of, but unfortunately money was a great issue.”

Thus, she could empathise with the recipient’s situation in order for her to respond. A similar theme was evident in the response provided by Respondent 3, who said that her immediate perceptions about egg sharing were that:

“It would help us financially and also give us the chance to help another couple who were struggling to become parents.”

Others stated that:

“I felt good that I could try and help another couple in the same situation as me as well as helping myself.”  
(Respondent 6),

“It seemed like an ideal way to have treatment and also to help others at the same time.”  
(Respondent 12)

Similarly, Respondent 10 acknowledged that she:

“Could also help somebody who was in a worse position than me to become a parent.”  
(Respondent 10)

Commenting upon her decision, Florence said that “I also felt a huge urge to help another couple, if it could prevent further heartbreak”. Notably, Florence had had a difficult time during her attempts to conceive which may have influenced her choice of the word ‘heartbreak’, as elsewhere she indicated this had been her own experience. Emmeline said that, for her, being an egg share donor was linked to “the thought of doing something great for a woman going through the same as me and giving her a chance that I would want if I was in her shoes”. Charlotte spoke in a similar vein when she said that:

“We would be able to have treatment sooner (not have to wait and save several thousands of pounds) and in the process help another woman to have a child.”

These opinions indicate, in some instances, an altruistically motivated decision. Notably, in his analysis of the motivations to donate blood, Titmuss explored the concept of altruism within society. Altruism is defined by Macaulay and Berkowitz (1970, p.3) as “behaviour carried out to benefit another without anticipation of external reward”. Additionally, Batson (1991), whose work is discussed by Scott & Seglow (2007, p.68, emphasis added), argues that empathy is induced if “a person’s experience of another’s suffering will, *if they are altruistic*, evoke in them an empathetic desire to relieve it. He proposes the “empathy-altruism hypothesis” as a model of altruism from which a social-psychological understanding of altruism can be developed (Batson & Shaw, 1991, p.162). The model suggests that an “altruistic act can reliably occur if someone feels empathy towards another human being” (Maggs-Rapport, 2001, p.17). However, as discussed earlier, the ability to help followed the decision that had already been made, a decision that in eleven out of seventeen cases, as demonstrated earlier in the chapter (see pages 201-202), is primarily, motivated by access to reduced price treatment.

### **Reproductive ‘gift’ giving**

The concept of the ‘gift’ as discussed in Chapter Nine was one that underpinned the study. Yet my analysis of the data yielded only four direct references to a ‘gift’. Emmeline, on learning of her recipient’s successful pregnancy, used the word “gift”; however, the term was brought into the conversation by a member of the clinic where she had sought treatment. Florence’s use of “gift” was in association with the recipient thanking her for giving them the chance at the “gift of life”. Only one of the interviewees and one respondent mentioned the word “gift” spontaneously. Commenting upon egg sharing, Respondent 9 said that she was “excited that we could afford IVF and give such a precious gift to another couple in the process”.

This reference to the gift indicates that the gift as perceived is closely aligned to the value attributed to the ability to access treatment which otherwise was unaffordable. Thus, this analysis fits with the concept “to give is to receive”, hence, the reciprocal nature of gift exchange (Shaw, 2007b). However, what constitutes gifting is subject to social and cultural constructions.

This is a theme explored by Speirs (2007) in her study of anonymous sperm donation. She asserts that the difficulties associated with the discourse surrounding the 'gift' is because the concept of the gift is different, in that it is socially and culturally located; therefore the reference point for the understanding of what constitutes a gift will vary. This variance is reliant upon the social and cultural location of the person gifting. Thus, there are no assurances that when we are talking about the gift, we are discussing the same thing. Consequently, the 'situatedness' of the gift is determined by the context within which it is located. Speirs (2007) cites the work of Derrida (1994) who suggests that the word 'gift' is simply that; it is merely a word, and not a social phenomenon. Extending this concept further Speirs (2007) says that Derrida (1994) believed that the use of the word will represent different types of sociality and social practices: a theme espoused by Mauss (1954, 1990) in his analysis of the gift-exchange system in archaic societies.

In his essay Mauss (1954, 1990) makes reference to the North American potlatch. Douglas (1990, p.viii) suggests that to Mauss, potlatch represented an example of "a total system of giving"; a system that is found in different societies throughout the world in different forms. It literally means that "each gift is a part of a system of reciprocity in which the honour of giver and recipient are engaged" (Douglas, 1990, p.viii). The reciprocal arrangement works on the premise that as gifts are given; gifts are given in return, leading to the development of a perpetuating cycle whereby the principles of gift exchange become a part of society's practices (Douglas, 1990). Mauss extends Durkheim's view that serious philosophical endeavours should have public policy at their core. Thus, the notion of the 'gift' in society is one that constitutes a "theory of human solidarity" (Douglas, 2000, p.viii). Consequently, gifts are not merely economic transactions; they also represent acts of politeness (Mauss, 1954; 1990), a theme utilised in Titmuss' work *The Gift Relationship* (1970; 1997).

In his analysis of different types of blood donation systems, Titmuss identifies a typology of donors: Type A (paid donor system), Type B (the professional donor), Type C (paid-induced voluntary donor), Type D (responsibility fee donor), Type E (family credit donor), Type F (captive voluntary donor), Type G (fringe-benefit donor), and Type H (the voluntary community donor). His comparative analysis included the 'altruistically' motivated donation system in the UK and he "presents a powerful indictment of the commercial health market systems" (Rapport & Maggs, 2002, p.496), a system that Rapport and Maggs (2002) suggest is one that rewards the donors, at the expense of the recipients who pay in kind or cash, whilst it maintains a lucrative



practice for the third party. This tri-partite arrangement, which I suggest is similar to that within egg sharing arrangements, (and to which I return later in the thesis - see page 207), is one that, it could be argued, erodes the concept of 'altruism'.

Titmuss conveys the point that the ability to make a free choice, a decision not affected by factors that may be indicative of coercion – such as payment – ensures that people choose voluntarily to donate to an unidentifiable stranger. He refers to this concept as 'creative altruism', which he defines as being:

Creative in the sense that the self is realized with the help of anonymous others; they allow the biological need to help to express itself. Manifestations of altruism in this sense may of course be thought of as self-love. But they may also be thought of as giving life, or prolonging life or enriching life for anonymous others.  
(Titmuss, 1970, p. 212)

Titmuss believed that the blood donation system practised in Britain represented an acceptable system, free from inducement to donate. It is a system that is "free from human exploitation, commercialisation or risk" (Maggs-Rapport, 2001, p.28). Titmuss concludes, with regards to blood donation programmes that for a society to exist healthily altruism must play a part in it. Subsequently, the integration of altruism within donation programmes creates both social wealth, and social cohesion, making it economically efficient, and therefore, a morally sound system (Maggs-Rapport, 2001). These views are explored further in the revised edition of Titmuss' work published in 1997.

The new edition includes a chapter that analyses the concept of breast milk donation and the role of milk banks. In the analysis undertaken by Weaver and Williams (1997) it is made evident that parallels can be drawn between blood and milk donation practices, neither of which were included in Titmuss' earlier work. The editors Oakley and Ashton (1997) assert that this was omitted purposefully, although they do not indicate why this happened. Speirs (2007, p.25), however, suggests two possible reasons. First, this may be linked to the social climate at that time; it may have been perceived as improper for a male researcher to exhibit an interest in breast milk, unless socially sanctioned to do so, "for example; as an obstetrician". Second, breast milk donation is gender specific, unlike blood donation which is gender neutral. Speirs asserts that this earlier omission may be due to the fact that:

Titmuss did not have the benefit of later anthropological analysis of human milk as a substance with much broader and deeper connotations than just as a source of nourishment for a baby.

(Speirs, 2007, p.25)

Nevertheless, despite Titmuss' omission of breast milk donation, a type of donation that "predates the gift of blood" (Weaver & Williams, 1997, p.319), there is a tension evident regarding what constitutes a gift, the role of altruism, and the commercialisation and commodification of body tissue and parts. Furthermore, there are distinctions to be made as to the nature of the gifting of bodily tissue, and parts, which are, in some instances, gendered.

Historically, accounts of wet nursing occur in the Bible (Exodus 2:7 and 2:8). Wet nurses are responsible for nourishing infants requiring breastfeeding (Weaver & Williams, 1997). However, it needs to be acknowledged that being a wet nurse is not always a voluntary act and some women may receive payment (Groskop, 2007a). Additionally, wet nursing has cultural and historical histories; it sometimes "involved the structural provision of a service between persons of unequal social standing and frequently entailed exploitative power relations" (Shaw, 2007a, p.442). Shaw suggests that perhaps the most dominant image of this exploitative practice is evident in the record of Black women slaves. These women were responsible for the suckling of White children in eighteenth century USA (Baumslag & Michels, 1995, p.51). Despite this somewhat tarnished historical context, wet nursing, or what is referred to in contemporary society as cross-nursing, shared breastfeeding or cross-breastfeeding (Shaw, 2007a) creates a situation where two women can choose to help one another without the intervention of a third party. Thus, it enables a gift relationship to flourish. In her analysis of cross-nursing Shaw (2007a, p.444) asserts that unlike the historical context of wet nursing, that involved power relationship, contemporary cross-nursing creates "mutual gift-giving".

In the UK the first milk bank was set up in 1939; initially donors were paid. Nowadays there is no payment for donation. Similar schemes exist in Brazil, Germany, France, USA and Canada. In contrast to blood donation, women undertake the somewhat arduous task of pumping and collecting breast milk, which is much more time-consuming and labour intensive (Weaver & Williams, 1997). Speirs (2007) notes the parallels between donation of milk, sperm and blood, as renewable bodily materials that can be gifted. The ability to gift such material is dependent upon age, gender,

hormonal status, and health. Titmuss suggested “that the gift of blood has certain unique attributes which distinguish it from other forms of gift” (Titmuss, 1997, p.127). It has the capacity to maintain or prolong life. It could be argued that donated breast milk also has the propensity to maintain life, as it might be given to premature infants. Sperm and egg donation do not possess entirely the same qualities. Whilst both blood and breast milk are ‘bodily fluids’, breast milk can be substituted, however, blood cannot. Sperm, whilst reproducible, does not maintain life, though it contributes to the development of new lives.

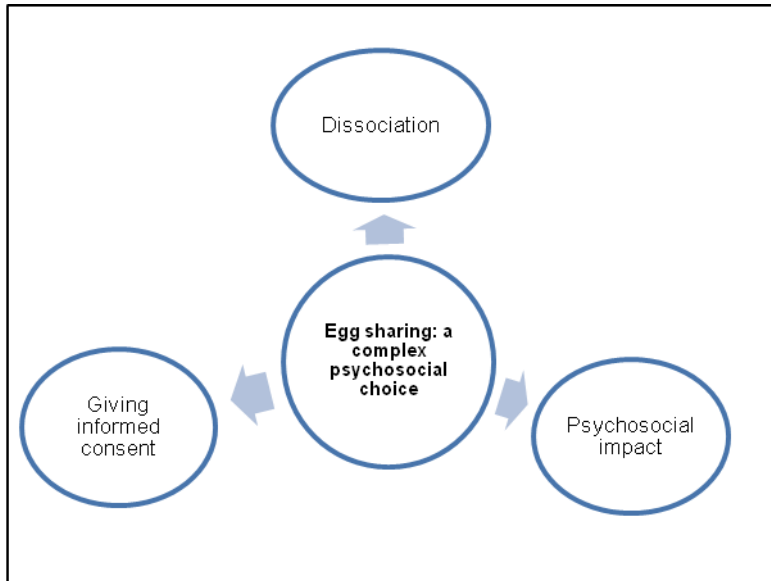
In contrast to blood, milk or sperm the gifting of non-renewable, non-regenerative parts of the body including organs, limbs, or eggs is different as they are not reproducible. For this reason, they are a finite resource central to a woman’s reproductive capacity. Once they are gifted, unless the arrangement is stopped, eggs are lost to the donor forever because their life giving capacity is transferred to the recipient. However, what I would suggest makes egg donation different to other bodily gifts is that the donating of eggs may lead to the creation of new life.

I therefore suggest that the concept of the gift is in keeping with the theoretical analysis of what constitutes a ‘gift’ *per se*. However, whether, this type of ‘gifting’ is undertaken because of the anticipated return (subsidised treatment), it is difficult to qualify, due to the lack of substantial data that referred to the act of giving. Significantly, in contrast to literature on reproductive gift giving, the majority of informants did not associate their donation with the giving of a gift.

### **Egg sharing: a complex, psychosocial treatment option**

Involuntary childlessness impacts on every aspect of life for those that it affects, as demonstrated in Chapters Eight and Nine, when I explored the narrative accounts and data provided by study informants. The women who shared their stories with me by e-mail, or through the completion of the online survey, made me even more committed to ensuring that I accurately and fully represented their views, in order to address our limited knowledge of donor perspectives.

Further analysis of the combined data highlighted in Figure 10.4 identifies three elements to this process, each demonstrating the relational complexities involved in egg sharing. The focus is on: the giving of informed consent, dissociation and the psychosocial impact of egg sharing.



**Figure 10.4** Egg sharing: a complex, psychosocial treatment choice

Thus, egg sharing is not a ‘quick fix’ or instant solution to overcoming infertility, but rather it is a process fraught with complex issues related to informed consent and decision-making in relation to wider mediating factors.

### **Giving informed consent**

As the focus of the study was to explore informed consent, an assessment of egg share donors’ ability to provide informed consent was integral to the research. Responses provided by the seventeen informants indicated that they all considered that they were able to give informed consent. In providing this evidence in the study, various accounts were given with regards to understanding the context of informed consent. Emmeline said that:

“I believe I did fully understand what I was giving consent to and was quite surprised how much the consent forms covered and how many there were.”

However, Emmeline’s experience of the consent process was affected by the fact that she was unable to get the answers she required from the counsellor. She felt that:

“If I hadn’t been assertive enough to say I want an explanation I am not sure someone would have volunteered to give me one.”

The account provided by Florence focused upon her understanding of the consent process. She states that she:

“Was fully aware that her treatment was hers, once I had signed over half the eggs, I had no jurisdiction over the eggs donated to her.”

Similarly, Charlotte understood the consent process to mean that:

“I have to give some of my eggs away, which means its possible that the other couple may end up having a child and we don't.”

Here, Charlotte’s response provides a stark reminder of the reality of egg sharing for some women. The fact that their own treatment might be unsuccessful, in my estimation, reinforced the perception that at the time of giving their consent, informants understood what they were consenting to (see pages 244-246). Furthermore, the accounts also provide a powerful reminder that the implications for those pursuing egg sharing are central to their cognitive processing, in that they understand and comprehend what the treatment actually means. However, as illustrated, Emmeline used the phrase ‘I believe’ in her account, which suggests some ambiguities related to the provision of consent, which might merit further research.

The justification underpinning this proposal emerges from the theoretical basis upon which informed consent is founded. This is aided further by the view enunciated by Gorovitz cited in Bromham (1998) regarding the complexity of informed consent and the process of informing (see pages 184-186). An area that is discussed further in Chapters Eleven and Twelve (see pages 244-246 and 263-264).

### **Dissociation**

Informants conveyed their thoughts about the concept of eggs and the menstrual cycle. This was despite not being asked specifically about their perceptions of their eggs in relation to their reproductive journeys. Nevertheless, the language they used, in relation to their eggs, was thought-provoking and evocative; and this prompted me to re-evaluate my own conceptual understanding of eggs, reproductive capacity and menstruation. It also made me re-evaluate the discourse of language and mental cognition processes with specific regard to the act of dispelling an egg.

In the study, the way these experiences were relayed suggested some level of dissociation from their eggs. For some, the dispelling of an egg represented lost opportunities and the wasting of a valuable resource. I cannot ascertain fully whether

participants arrived at this conclusion on their own or whether this was influenced by 'relational' aspects of their treatment. However, the findings are indicative that message framing played a role in the decision to pursue egg sharing (see pages 243-244). Thus, two of the three informants who spoke of their eggs in this way indicated that their thoughts had been influenced by something that they had read or had heard at a counselling session. These factors resulted in changing connotations and associations with their eggs. Subsequently, eggs became a highly valued resource because they could be put to a purposeful use; they were going to waste anyway, so sharing them represented doing something meaningful with them; reducing and preventing waste occurring. Speaking of her experiences of egg sharing Jayne remarked that:

"It was just eggs if that makes sense... I kept remembering something I'd seen on a leaflet saying you flush eggs away every month during your cycle so instead of mine going to waste, I gave them to another couple."

This thought was reflected in the qualitative data captured in the self-completion survey. In response to a question asking about her initial thoughts of egg sharing, Respondent 10 wrote:

"My thoughts were that you lose an egg every month during the cycle so why not help somebody who hasn't got their own eggs."  
(Respondent 10)

When Florence spoke of her experience of egg sharing she said the way that the counsellor spoke made her realise that she could go through with egg sharing – a comment which suggests that she may have been indecisive at the time of the consultation. In her portrayal of the session she was led to understand that:

"You are only donating eggs, which is in fact a bundle of cells ... In this situation you are half of that person, in terms of their make up, but you have no part in their life, or how they are brought up. They may never have any characteristics of personality, or they may have some, or many. They are themselves a person within their own right."

Florence went on to say that when she remembered this conversation she knew "I wasn't giving away my babies". This was a particularly insightful comment that revealed

further the reality of egg sharing. I suggest that despite Florence not referring to her eggs as things which are wasted; her narrative reflects an association with, and then dissociation from, her eggs. Moreover, it was apparent, not solely from the words cited here, but from her overall portrayal of her experiences, that she thought about the act of 'giving' in relation to the 'sharing' of them with another woman. Furthermore, her representations of her eggs as cells indicated that her perception of what she was sharing changed. Florence knew that her 'eggs' represented potential children, yet by dissociating herself from this fact, and distancing herself from the act of giving them away, she was able to reconcile herself to the act of sharing. Her eggs did not represent children because they had not been fertilised; therefore, she was not giving away "our child" because at the time she shared her eggs they were indeed only cells. The findings presented here alongside my personal reflections had congruence with theory and other empirical studies. Egg share donors interviewed by Maggs-Rapport (2001) made similar comments, and in a later article she notes that dissociation from the act of donation was signified by the use of "amorphous terminology" (Rapport, 2003, p.34).

This theme was also reflected in a study undertaken by Orobitz and Salazar (2005) who investigated egg donation at a clinic in Barcelona. Though their study focused upon the views of patient donors as opposed to those of egg share donors, several donors reiterated the view that eggs signified something that they did not need because they wasted them every month. Similar findings were echoed in a Finnish study by Söderström-Anttila regarding the motivations of volunteer oocyte donors post treatment, in which donors expressed a desire to help, although:

Many donors emphasized that they regarded their oocytes as cells which they would not need and were nothing that connected them to a child.  
(Söderström-Anttila, 1995, p.37)

In her analysis of the motivation of known egg donors in the UK, Martin (2008, p.149) suggests that 'the donor may perceive her egg as a cell, akin to any other cell in the body, and the donation as an impersonal endeavour'. This point is illustrated by one participant, who states that:

...just a cell, just like you know, a skin graft or anything erm...I think if I'd given away my hand or my eye or...my ear would feel more personal, you know, if somebody was grafting it onto somebody else's body, that would be horrible but an egg I don't, it doesn't matter really.  
(Hayley cited in Martin, 2008, p.149)

The similarities in the findings from my own and these studies led me to question what an egg actually was. I suggest that the concept of eggs changes for those undergoing fertility treatments, a theme expanded upon in the findings presented here. Suffice to say, though not comprehensive (in terms of the number of participants who spoke of their eggs in this way), this theme highlights one possible aspect of the decision-making process – dissociation. I put forward the suggestion that dissociation may be brought about by external influences, be that egg share donor recruitment information, past egg share donors, through counselling provision, clinical consultation, or other influencing media, which may then be internalised by the donor. Moreover, infertile women may be highly sensitised to aspects of their fertility prior to undertaking IVF. Thus, they may be primed to accept the discourses offered by those they come into contact with as they seek treatment.

Specifically, as discussed in Chapter One (see page 20), I chose to use the word 'egg' as it could be argued that it portrays something of a more personal approach (Boden et al., 2002) when discussing reproduction and the act of egg sharing. Furthermore, Boden et al., (2002) assert that egg talk is synonymous with the infertile and their interactions with fertility clinics. Thus, clinicians speak of eggs rather than using medical terminology such as 'ova' (Boden et al., 2002). Hence, I would suggest that the discourse of language (eggs instead of ova) might be used as a script that makes the process of donating easier.

The discourse of language is a theme discussed by Rhonda Shaw in her analysis of surrogacy and egg donation, altruism and reproductive gift-giving in New Zealand. Shaw suggests that the language used in clinics provides "a ready-made frame of reference for lay people to understand and make sense of the practices and procedures they are engaged in" (Shaw, 2008, p.18). This she says arises from the discourses used by clinics in information sheets, in their work with prospective donors, and by ethics committees (Shaw, 2007b). She later asserts in her commentary on New Zealand fertility clinics, that it is the clinics that perpetuate the promotion of altruistic acts. Thus, it is this dominant discourse and the language used that propels some



women to become surrogates or egg donors (Shaw, 2007b). This analysis fits with my overview of the possible impact of language use on egg share donors. For example, the fact that 'egg sharing' is described as such implies that it is a very personal act, rather than as an impersonal medical act that might be conveyed by a term such as 'ova sharing'.

I also suggest that the use of clinical terminology is closely related to the physiological aspects of infertility, a theme represented by the biomedical model. Although, it attempts to create a holistic approach to the concepts and experiences of health and illness, the biomedical model has been criticised because it creates a mind/body divide. The possible application of the biopsychosocial approach (Engel, 1977) to the health experience, within the context of the biological, psychological and social experiences of egg share donors, presents a more accurate representation of their experiences. I would also concur with the suggestion posited by Boden et al., (2002, p.47) who note that within the context of this principle, language discourses change; an issue which may 'predispose particular outcomes'. Consequently, if the language used is more personable, and the donor believes she is being treated as a whole person, and not merely as a body with a health problem, this may be sufficient to affect decision-making.

Thus, the concept of something that is lost or wasted indicated that informants create meaning in relation to their eggs. I would suggest that this meaning is context driven and value laden. Referring to a point made earlier with reference to the concept of eggs, Boden et al., suggest that to discuss eggs in a meaningful context women need to recognize that they have eggs before meaning is constructed:

All women are familiar with the process of menstruation, and this is subject to change in meaning by context: from the 'curse' to an overt indication of womanhood. Certainly primitive tribes, and many women in developed societies, do not relate menstruation to eggs. But some women, notably those seeking to conceive a child, may make this association.  
(Boden et al., 2002, p.48)

It could therefore be suggested that this use of language reinforces the women's personal relationship to their eggs. These representations imbue a certain level of understanding amongst women seeking fertility treatment. Subsequently, it is these understandings that quite possibly develop directly from the attempt to overcome

involuntary childlessness. Therefore, eggs need to be understood as representing potential life before that potentiality can take place. Yet within these frame of reference women's perceptions also sometimes change (see pages 203-206). That is, the interplay between the use of language and the decision to become egg share donors was evident in the way participants spoke of their experiences. Indeed I would concur with Boden et al., (2002) who suggest that menstruation for many women is merely a physiological process to which women of reproductive age are used. Here I acknowledge that parallel literature exists about the concept of menstruation and its social construction. This has implications for understanding women's health and the way that menstruation is perceived as it will vary in different societies and also the time period in which these discourses occur.

However, for the purpose of the thesis, I merely allude to the existence of other literature to demonstrate that the concept of menstruation changes and is dependent upon social and cultural contexts. For example, for women who are experiencing infertility their perception of menstruation may represent a disproportionate significance. That is, menstruation may be perceived as the 'loss' of a potential child or the waste of a resource that has the potential to create life. Hence, menstruation may become significant because of this alternative discourse as voiced by participants such as Jayne, who said that "you flush eggs away every month during your cycle so instead of mine going to waste, I gave them to another couple". Thoughts such as this by Jayne and others (see pages 243-244) I would suggest reinforce the dissociation concept, as revealed in the study.

### **Psychosocial impact**

In the study four informants said that they had experienced stress, anxiety and depression. Here I focus on the impact of treatment on egg share donors, and the psychosocial impact of their journey to egg sharing and upon finding out the outcome of their recipient's treatment. A response to the survey illustrates the post-treatment effect for an egg share donor whose own treatment was unsuccessful. She says that:

"It is a easy decision to make at the time, however in retrospect had any woman got pregnant it would have haunted me..."  
(Respondent 6)

In contrast the reality of successful recipient treatment compared to the donor's unsuccessful outcome is illustrated in the following excerpt. This reveals her opinion about egg sharing. She says that she had:

“Mixed feelings to be honest. I am happy for whoever my eggs went to and can imagine how hard it is for somebody waiting for eggs and then finally getting them and it working out for them. I think I would have been happier if I had conceived.”  
(Respondent 10)

Consequently, there is what the respondent refers to as ‘mixed feelings’, I would suggest that it is clear that this situation is tinged with sadness, acceptance, and a less than complete sense of fulfilment. Additionally, this donor has to live with the knowledge that she has contributed to the existence of a child with a genetic bond to her (a theme addressed in Chapter Eleven; pages 250-251). This is an issue reflected upon by another informant who says that she:

“Found out for first recipient, not sure about second yet. It made me sad that it didn't work for me first time, but also glad that I knew there was a woman somewhere who had desperately wanted children who might now have that dream realised.”  
(Respondent 8)

With regard to egg sharing there was also a commonly held opinion that donors might suffer psychologically from the thought that the recipient of their eggs had become pregnant whilst their treatment had failed (Ahuja et al., 1996; HFEA, 1996). Ahuja and his colleagues suggested that there was no evidence to support this claim, substituting a counter-claim that “for some donors the distress of an unsuccessful treatment is eased with the thought that the recipient may have been successful” (Ahuja et al., 1996, p.1129), although they acknowledged that women may become distressed if they had unsuccessful treatment.

Although at first glance, participants’ opinions seem to support Ahuja et al.’s (1998) view of the “sanguine donor” (as discussed in Chapter Two; page 36), dissenting views were expressed by some, highlighting the disadvantages of egg sharing. Charlotte said that:

“I guess the main disadvantage is that I have to give some of me eggs away, which means its possible that the other couple may end up with a child and we don't.”

Similarly, Florence says that for her the disadvantage was that:

“If the recipient got pregnant and I lost a baby or had a negative result, the first of which DID happen... That I will always be wondering if a knock on the door will ever come.”

Emmeline recounted that:

“I worried about her success and felt for some reason responsible for her success or failure. I can’t explain why but felt it was a pressure although at that point I had no plan to find out if she was pregnant or not unless I was pregnant.”

I propose that these opinions illustrate that egg sharing is not always perceived favourably by donors. This is regardless of whether there has been a positive or negative result. What the data exemplify is a psychosocial implication of egg sharing. The fact that the treatment might work for the recipient and not the donor can be difficult to contend with. It also illustrates that in some cases, women are willing to forego ‘finding out’ until they have achieved success. This raises the issue as to what happens if the donor never conceives, as the long-term future implications might be different (pages 235-237 and 266-268).

Additionally, when explaining her journey to egg sharing, Florence gave a graphic account of her experiences prior to egg sharing; exemplifying that infertility is a stressful life event. Furthermore, her narrative incorporates the social aspects of her attempts to achieve motherhood, as documented in her case study. Brief reference to her narrative is made here to illustrate the emotional and social aspects of her journey. Florence said that:

“It became evident to those around me that something was **very wrong**, yet as it’s such a personal issue, I had to be careful who I told and what I said”.  
(Florence)

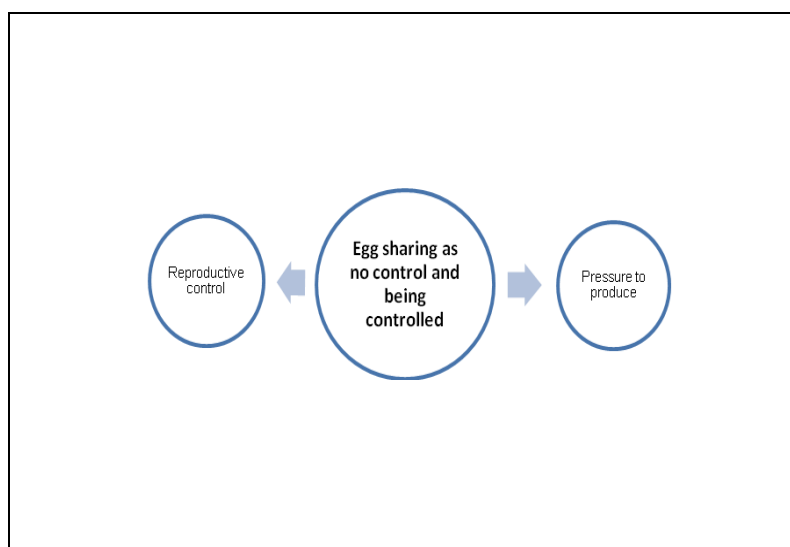
Here Florence was commenting upon the impact of needing treatment to assist conception and the toll this had on her socially and emotionally. Speaking in a slightly different tone, Florence explains how taking part in the study has enabled her to re-examine her own narrative. Her comments illustrate that her memories of her journey to parenthood will not diminish. She says:

“It’s amazing how much you remember about each stage of the journey – *it will never leave me*, its ‘scars’ are imprinted there, in my mind”.  
(Florence)

However, in the absence of longitudinal data, it is impossible to assess the long-term impact of egg sharing, either for successful or unsuccessful donors, hence the need for more research.

### **Egg sharing as no control and being controlled**

This theme emerged from informants’ narrative accounts of treatment, discussions of reproductive capacity, and the sharing of experiences of treatment (see Figure 10.5). From the overarching theme, two sub-themes emerged (reproductive control and pressure to produce) that highlighted unanticipated findings. Since these themes emerged from the experiences shared by only six of the seventeen informants, they cannot be generalised to the entire sample, although they provide an alternative way of considering the debates surrounding egg sharing.



**Figure 10.5** Egg sharing as no control and being controlled

#### **Reproductive control**

During analysis of the data the theme of reproductive control as an element of the lived experiences of informants emerged. This was in relation to the control that informants felt that they had over their eggs and their potential to create offspring. Commenting upon the quality of her eggs, a survey respondent said that she:

“Found out for first recipient, not sure about second yet. It made me sad that it didn't work for me first time, but also glad that I knew there was a woman somewhere who had desperately wanted children who might now have that dream realised. Plus it meant I knew my eggs worked!”  
(Respondent 8)

Similarly, Respondent 9 said that her successful treatment meant that:

“As well as getting our own good news we also helped someone else have a family and although we would have been disappointed if we hadn't got a positive result ourselves, the news that we had helped someone else's dream come true would have spurred us on to have another go as it meant my eggs were good quality.”

Respondent 10, who learnt that her recipient had been successful, highlights an important aspect of the study, the psychological impact of a failed cycle of egg sharing. She adds:

“I am feeling a little down that its not worked for me but at least I know that I have good quality eggs.”  
(Respondent 10)

Conversely, Florence was more enthusiastic about the process and said that:

“I was keen to donate my eggs because we already knew I had a good quantity of eggs.”  
(Florence)

These excerpts illustrate that in the absence of control over their reproductive functioning, as it is in the hands of the medical profession, these women viewed the capacity of their eggs to create life as evidence that they were in control of at least one aspect of their reproductive functioning. Specifically, they were able to produce eggs, thus providing evidence of their reproductive capacity. It might also be an additional motivating factor since for some women they have the knowledge that their eggs work. This analysis is in accord with the work of Blyth (2004, p.159) who illustrated how finding out that her donated eggs achieved a successful conception for the recipient was received by an egg share donor. She comments that the news meant that she had not “been a total failure. That’s how I look at it”. This view, I suggest, indicates that the donor in question feels a sense of reproductive control, in that whilst she might require IVF treatment, something that is outside her locus of control, she is in control of her

eggs as indicated by the recipient conceiving. However, this news is akin to a 'two-edged sword' in that her treatment has failed.

### **Pressure to produce**

The egg sharing arrangement is a complex situation that would appear to place pressure on donors. This experience was recounted by more e-interview participants (3 out of 4), rather than survey respondents (2 out of 13). This highlights the different levels of information captured by the two different methods of data collection. However, I can demonstrate how the perception of the waiting recipient places external pressure on donors, which is then internalised. Additionally, the necessity to produce a minimum number of eggs prior to proceeding was also somewhat disconcerting for informants. This is evidenced by Charlotte:

“My main concerns were regarding what would happen if I didn't produce enough eggs, as I didn't want to let the other couple down.”  
(Charlotte)

Jayne expressed a similar opinion when she considered the implications of not producing sufficient eggs. She explains how she dealt with this factor when she says:

“Before my eggs were removed, I did think, what if they wasn't enough, id have to decide weather to keep them for myself, or give them all to the recipients. But I decided I would cross that bridge if/when came to it.”  
(Jayne)

Similarly, Emmeline described how she and her husband decided how they would deal with not producing sufficient eggs. She explains that:

“I remember being told that I had to produce a minimum of 8 eggs or I would have to choose whether I wanted to donate my eggs to the recipient or pay for the cycle. We had decided that we would pay for the cycle but the pressure to produce 8 was quite scary.”  
(Emmeline)

Florence expresses a similar opinion and said that she:

“Also felt a ‘burden’ too about this last bit, that that person was waiting and hoping I would go through with it right to the bitter end.”  
(Florence)

Respondent 10 explained that she thought:

“About my recip alot and how she would have felt getting the call from {treatment centre} to say they have found a donor.”  
(Respondent 10)

These findings serve to exemplify the view that egg sharing is not undertaken in isolation, but rather that it signifies a relational bond with the invisible other: the recipient. It impacts upon the donor as they know they have to produce sufficient eggs to share, or accept the consequences of not producing enough. The consequences of these are: not being able to proceed with egg sharing, or having to donate all the eggs from the cycle to the recipient. The donor would then have to undertake another cycle of treatment, and its associated risks, in the hope that she then produces enough eggs to proceed with her own treatment.

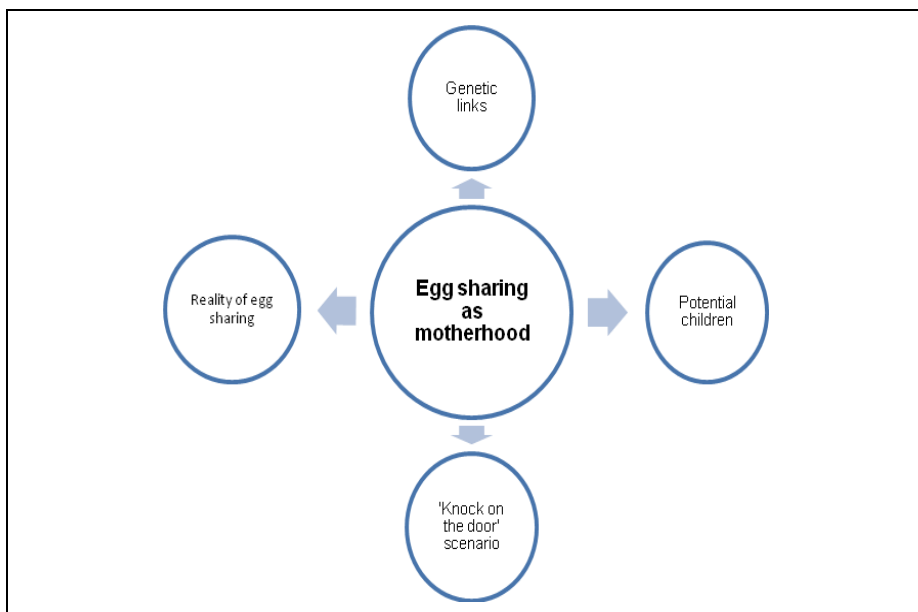
Significantly, Florence said that prior to treatment she had decided to retain all her eggs for her own use if she were unable to produce sufficient numbers to share. This was because she and her partner were in a position to fund a cycle of treatment should they have needed to. However, she decided to proceed with egg sharing and noted that if it became apparent that she could not share her eggs, she would have dealt with that situation if it arose. It transpired that Florence produced enough eggs that enabled her to go ahead with the sharing arrangement. This, I would suggest, may be a good example of altruism or it might be linked to the way that egg sharing is framed by those promoting the arrangements, in so far as egg sharing is promoted as helping and - as evidenced - donors want to help (see pages 203-206).

### **Egg sharing as motherhood**

As demonstrated in my earlier analysis (see pages 148-149 and 197-199), informants had, in most cases, accessed a range of treatments prior to choosing egg sharing. Thus, egg sharing represents a means to a potential end. However, as illustrated in Figure 10.6, egg sharing and motherhood are inextricably linked to the relational aspect of egg sharing – the recipient and her potential offspring. This aspect was raised by 13



out of the 17 informants. The sub-themes that emerged focused upon potential children, genetic links, the 'knock on the door' scenario, and the reality of egg sharing.



**Figure 10.6** Egg sharing as motherhood

In Chapter Two I described family formation in relation to gamete donation (see page 31). In extrapolating motherhood as a theme I am able to further contextualise the debates pertaining to egg sharing. Whilst mothers have always existed, motherhood is a relatively recent societal invention, based upon the imposition of terms and expectations of mothers. Significantly, Kitzinger proposes that there is an advantage to be had from:

Seeing mothering from a cross-cultural vantage point is that the observer quickly realizes that instead of one ideal of mothering there are many permutations of the motherhood role. No one of these is universally right. Each is the product of women's empirical experience in a specific culture and is finely adjusted to the value system of that society.  
(Kitzinger, 1978, p.273)

It is these permutations that fit with the analysis presented here, in that motherhood is perceived as the "rite of passage invariably equated with 'womanhood' and glorified as women's chief vocation" (Letherby, 2010, p.31), while Oakley states that:

Women give birth to children, anchoring motherhood firmly in what we think of as nature: but both women and motherhood are subject to the complex formulations of culture.  
(Oakley, 2005, p.118)

As such, the ideal is still based upon the concept that women become mothers; if this does not happen women may experience exclusion from societies that place an expectation upon women to become mothers (Letherby, 1994), an issue relevant to informants in the study who did not want to face a childless future. They wanted to overcome this, if possible, in order to achieve motherhood. However, in their attempts to circumvent involuntary childlessness they invariably created a different permutation of motherhood, evidenced through their thoughts about potential children.

### **Potential children**

In the study donors were not asked expressly about their thoughts about future children. However, it became evident that informants were aware of the potential consequences of egg sharing in this regard. Speaking about the outcome of the recipient's treatment, Jayne said that:

"I constantly think of the eggs I donated, if treatment worked for them, 'have they had a boy or a girl'... And the sorry part is, if im out shopping say, and I look at babies, there's always the thought there is my head. I know realistically the chance of that is impossible but the thoughts always there."  
(Jayne)

Jayne demonstrates that egg sharing is not straightforward. Nor is it possible (not withstanding my discussion earlier about dissociation in relation to giving away eggs), to totally dissociate oneself from the potential or actual implications of the outcome of an egg share arrangement. Indeed, Jayne later comments that:

"I think differently now... Then I didn't really think too much about the possibility of any potential children, where as now I have my child I think about it quite often."  
(Jayne)

It was evident that this was a central theme in the counselling experience for Emmeline, who says that the counsellor:

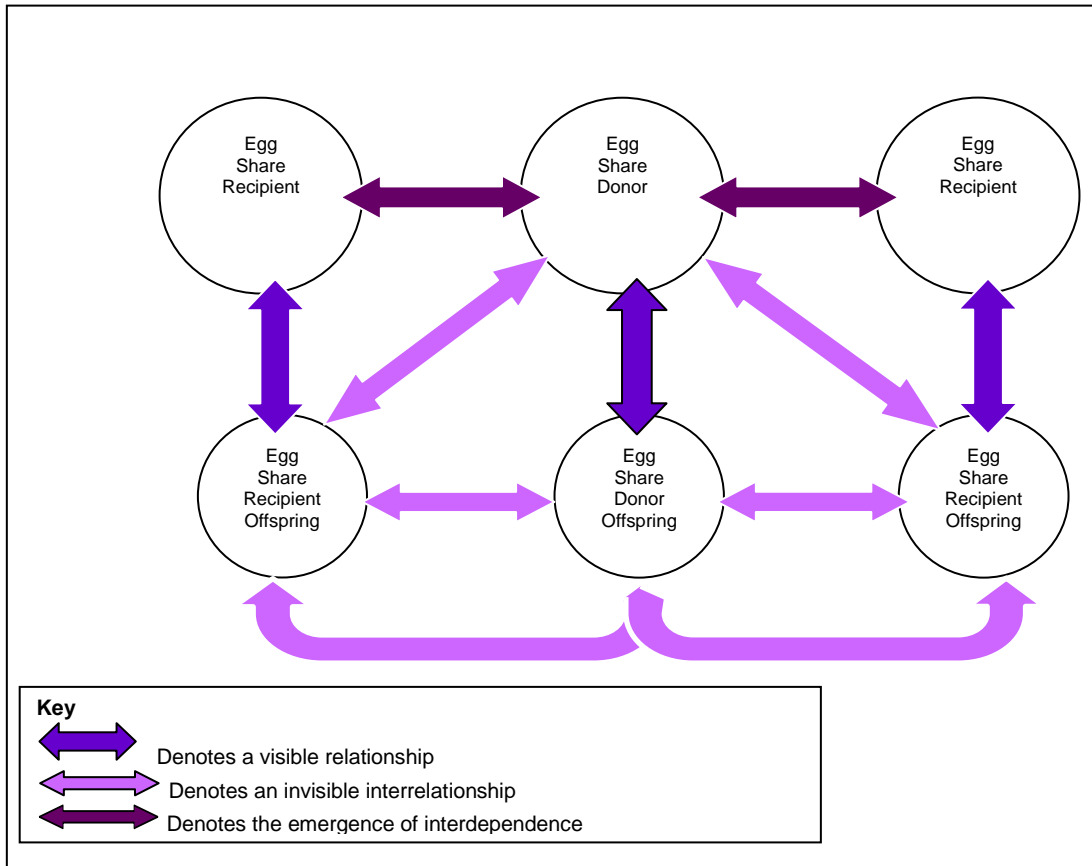
“Repeated about three times the fact that it would be a good idea to tell any children we have in the future about the fact that we had egg shared. I hadn’t thought of this and said I thought it was a good idea.”  
(Emmeline)

Emmeline further qualifies this point when she discusses her wish to know more about the recipient’s outcome – she knew she had conceived. Florence expressed a similar desire and wondered if any potential children would be told about their donor conception. In her own observation she stresses the importance of knowing, now that she has her own child:

“I feel it necessary to know, not only for own curiosity and own piece of mind, but for that of our daughter. If she has a half brother or sister, I feel it only just she be made aware of the fact in the future, when she is of age to understand.”  
(Florence)

This view epitomises the eventuality that a (recipient’s) child/children may result from the egg sharing arrangement. This is the ideal outcome of the treatment, however, it means that there is a separation of biological, gestational, genetic, and social parenthood as described on page 31 (Blyth & Landau, 2004; Daniels, 2005).

Thus, by locating the potential child in relation to her own – she is re-creating the genetic link, which is ‘invisible’ (see Figure 10.7), as she cannot see the offspring, and may never do so. However, the genetic link will become visible, because she will share (in the future) the information with her own child.



**Figure 10.7** The more complex interdependence and interrelationships that emerge if two recipients are involved.

This, I suggest, reinforces the view that people have the right to access information about their genetic origins (see pages 250-251). In this instance, even though the genetic link has been separated, it will exist because of a live birth that might pervade the reality of what it means to be an egg share donor, and may necessitate the need to acknowledge, and anticipate, a possible contact with a genetically related child, as illustrated below.

### **Genetic links**

Egg donation transcends the boundaries of what constitutes motherhood. As illustrated in Chapter Two, it changes the concept of traditional family formation. In relating this concept to the study, I refer back to the perceptions of the egg that is donated, as described earlier in this chapter (see pages 211-206). Consequently, if a donor allows herself to think of her egg as a potential child, this might make the decision to share her eggs more problematic, and weaken her resolve to proceed with egg sharing – a view reflected by Jayne:

“I never let it register in my head that if the other couple did go on to have a child with my eggs, that the child would have biologically come from me... I didn't allow myself to think too much into things.”

(Jayne)

In this way, Jayne appears to distance herself from what the egg might become through denying the potential biological connection. In contrast, Emmeline said:

“Very briefly I had a thought about if it is right that someone else may have a child with my genes before me and how would I feel about it.”

(Emmeline)

The fact that Emmeline acknowledged thinking about the outcome of her treatment was what I had expected, as women should be counselled about the fact that the recipient might conceive. This should make explicit the potential implications of the so-called ‘knock on the door’ scenario, as discussed below.

#### **The ‘knock on the door’ scenario**

Informants were asked about their understanding about the removal of donor anonymity and what it signified. All informants said that they were aware of the removal of donor anonymity, and its potential future implications for them. Some spoke favourably about future contact with any offspring, while others admitted ambivalence. Furthermore, informants noted their lack of control regarding whether recipients would share information with their offspring regarding their origins.

Three informants said that they would welcome any future contact. Jayne stated that she was unsure how she felt about a possible future meeting. While Florence acknowledged that she would always be wondering about the child/children, she was unsure whether the recipient family would share this information:

“If they do, that the child has the right as 18, to search for me and ask information about me from the HFEA form, that I filled in. It is a very real possibility now and that's quite scary... That I will always be wondering if a knock on the door will come.”

(Florence)

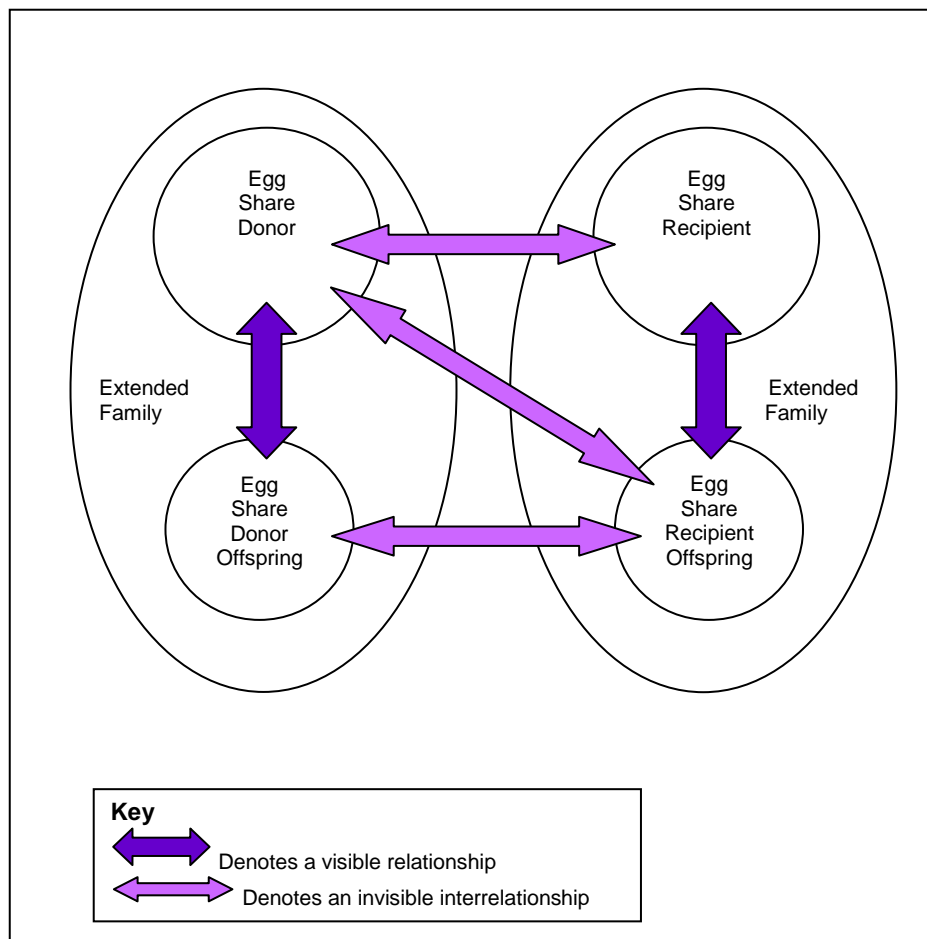
Similarly Emmeline comments about future meetings, though she expresses familial concern:

“And the only thing I thought that may be a problem was how my husband felt about the possibility of any child born of my egg would feel if in 18 years time he or she looked for me.”  
 (Emmeline)

Emmeline provides a contrasting, more positive, account:

“I also look forward to the day that (if it happens) I get a knock on the door and get the opportunity to meet the child born and hopefully the mother too.”

Thus, mixed reactions are evident from contrasting accounts of the potential “knock on the door”. The full extent of the consequences of the decision to proceed with egg sharing have yet to be revealed, and will need to await not only the coming of age of individuals conceived as a result of egg sharing, but also their decision to seek out their genetic mothers and other genetic relatives (see Figure 10.8), where they are knowledgeable of the method of their conception.



**Figure 10.8** The creation of interdependence and interrelationships between the donor, the recipient, offspring, and the wider familial network.

Thus, the reality for egg share donors is that the 'knock on the door' will materialise only if recipients tell their children about their conception or the children learn of their conception another way. Recent evidence from a Finnish study suggests that more parents of children conceived through egg donation are planning to tell their children at some point than did so in the past (Söderström-Anttila et al, 2010), although, it is not necessarily the case that similar findings would be found among British parents of children conceived through egg donation, or whether findings relating to egg donation are transferrable to egg sharing.

Significantly, in the study, one e-interview participant said that she would use the interview transcript to help her begin to share information with her daughter when she felt that the time was right to do so. She was hopeful that her daughter would understand her motivation for egg sharing. This highlights another focus for future research into egg sharing; the experiences of the children of both egg share donors and their recipients. At the same time, it needs to be noted that, to date, there have been no published studies of the views or experiences of the children of either men or women who have donated gametes or embryos for family building.

### **Reality of egg sharing**

As evidenced earlier in this chapter, decision-making by egg share donors is inherently complex. As discussed in Chapter Nine, I described how moral and rational decision-making became integral features of the analysis (see pages 188-190).

In the study, informants provided conflicting accounts of egg sharing. These provide further insights into the reality of egg sharing and potential future implications. Therefore, I suggest that the realities of egg sharing manifest themselves in a number of ways. Egg sharing may have a compelling nature (for donors and possibly recipients) in that it provides an opportunity to potentially change women's parental status. Thus, when faced with the decision to proceed as an egg share donor, it is evident, as illustrated already (see pages 196-209), that there are a myriad of complex decisions to be navigated. Once the decision has been made, donors are faced with the reality of their decision. For some, this is largely positive, as encapsulated by Jayne:

"I'm glad I did it, and ive never wished I hadn't, but im not sure if I could do it again... but I don't think the reality of it actually hits you until you have your own child. I think differently now, than what I did after the 1st egg share."  
(Jayne)

However, Florence provides an alternative interpretation:

“It’s a Russian roulette wheel – success brings happiness but loss and a negative result could be the twist of the knife.”

Furthermore, as summarised earlier in this chapter (see pages 224-227) egg sharing raises continuing questions in the minds of those who pursue it. For example Emmeline commented, “I did find myself wondering things”, while Jayne said:

“I think then at least I will know, and just maybe stop these questions in my head. Or it could have the reverse affect!!”

These quotes represent, to some extent, the reality of egg sharing for egg share donors. This is evidenced through the change over time in their perception about egg sharing, thus further reinforcing the complex nature of decision-making within the context of egg sharing. This analysis has parallels with the work of MacIver:

In the process of making a decision, some desire, some valuation, simple or complex, has become dominant for the time being, as a determinant of action within the individual’s scheme of values.  
(MacIver, 1957, p.229)

He goes on to postulate that ‘at every moment of deliberation or decision the individual is faced with alternatives. He has not one desire but many, and they are not independent but interdependent’ (MacIver, 1957, p.233). This view supports the constant theme that emerged in the study, that of utilitarian decision-making (see pages 240-242).

### **Chapter review**

As demonstrated in the chapter, egg sharing is a ‘relational’ treatment choice, insofar as the motivations to donate, the giving of informed consent, and the decision to pursue egg sharing involve the relational other(s) - the recipient and the potential child/children. Moreover, in my analysis I used diagrammatic representation and textual accounts to illustrate the multilayered, interdependent and interrelational nature of the egg share arrangement. This is demonstrated through the documented accounts of the themes that emerged from the study and analysis of the decision-making process with



regards to the provision of informed consent. In doing so, the findings were explored using existing theory to contextualise the analysis.

In the following chapter I discuss the findings from the study, and demonstrate their application to what is currently known about egg sharing. I also provide suggestions regarding the reconceptualising of informed consent within the context of egg sharing.

## CHAPTER ELEVEN

### Egg sharing: a psychosocial and ethical discussion

*“The one thing that is paramount you express in your studies of this subject, is how **profoundly** infertility affects **every** aspect of your life.”* (Florence)

In this chapter I advance the ideas put forward in the earlier analysis provided in the thesis and extend them significantly. Specific reference is given to the psychosocial and ethical debates surrounding egg sharing. I document how the research has broader implications than previously envisaged and how it contributes to the critical debate concerning egg sharing. I begin by revisiting the research process and the aims and objectives of the study (see pages 19-20). This demonstrates how the study has led to the development of a new conceptual understanding of the experiences of egg share donors. In expressing the emergence of these new understandings I document how they also revealed previously unknown aspects of the experiences of egg share donors. In so doing, I illustrate how I was able to answer the central question posed in the study – can women consent to share their eggs?

The chapter explores the following areas: (1) the emergence of helping as opposed to gifting; (2) egg sharing and the applicability of affect social exchange theory; (3) the influence of wider mediating factors upon egg share donor decision-making, which includes a number of sub-sections that reassess utilitarian decision-making, the role of empathy, empathy-altruism and dissociation within the context of decision-making; (4) informed consent provision and the need to reconceptualise informed consent within the context of egg sharing; (5) revisiting my development as a researcher with a leaning towards feminist viewpoints, and (6) a discussion of the ethical and psychosocial implications of egg sharing, including new family formations and the policy implications associated with egg sharing. Finally, it revisits my personal biography and its impact on my analysis of informants' accounts. Thus, the chapter demonstrates how the study's findings contribute to, and advance, what is currently known about the ethical and psychosocial debates pertaining to egg sharing.

#### **Returning to the beginning...**

Faced with the prospect of remaining childless, some women seek alternative solutions in the quest to achieve motherhood (Rapport, 2003). The accounts of informants articulated in the study illustrate that the experience of failed treatment or the inability to

access NHS treatment led to them choosing egg sharing. Most informants had attempted to circumvent their infertility in other ways prior to becoming an egg share donor. The majority of the 17 informants had met some form of resistance in their attempts to circumvent their involuntary childlessness, either because they were ineligible for NHS treatment, or previous treatments had proved ineffective (see Chapters Eight, Nine and Ten). Moreover, as illustrated (see pages 253-256), involuntary childlessness had impacted on most aspects of their lives – as so emphatically recounted by Florence, cited at the beginning of this chapter. Thus, informants showed great fortitude in their determination to overcome their situation with – at the time of interview – successful outcomes for some but not for others. Their journeys to egg sharing were tinged at times with melancholic reflections upon what might have been.

Additionally, the study integrated critical accounts from existing literature that suggest that women cannot consent to share their eggs because of the inducements involved in the arrangement (Shenfield & Steele, 1995; Johnson, 1997; 1999; English, 2005; Lieberman, 2005). It also considered whether egg sharing is akin to the commercialisation and commodification of body tissue, because egg sharing involves a financial incentive attributed to the provision of subsidised treatment (Johnson, 1997; Lieberman & Brison, 2003; Lieberman, 2005). These concerns underpin the work presented in the thesis.

The evidence provided by informants indicates that they believed they were able to consent to becoming an egg share donor, and all except one were clear that they understood what they were consenting to. However, inevitably their ability to provide consent was mediated by a number of factors that I discuss below. By doing so, I assert that the multidimensional nature of informed consent provision and the impact of wider mediating factors inevitably influence decision-making by egg share donors.

Significantly, it was evident that financial considerations are a motivating factor in becoming an egg share donor. In essence, and in line with the concerns raised by critics of egg sharing, (Johnson, 1997; 1999; English, 2005; Lieberman, 2005) financial considerations act as an inducement to proceed.

In Chapters Nine and Ten (see pages 165-176 and 201-202) I have highlighted the significant impact of financial considerations in relation to egg share donors' decision-making; the decision to pursue egg sharing stemming from restricted choice and

financially adverse circumstances. Consequently, as demonstrated (see pages 150-151) egg sharing facilitates the pursuit of treatment that informants could otherwise ill afford.

However, it is significant to note that even though the majority of informants cited financial motivations, for example Respondent 10 commented that “egg sharing dramatically reduced the cost of IVF”, Respondent 11 said that she “was happy to find a way the help us finance ivf” and Florence stated categorically that egg sharing represented the opportunity to access “the treatment we needed as it was beyond our reach financially”, the emphasis given to the ability to help someone whom informants believed was in a similar position to themselves must be acknowledged. While other research has highlighted that not all women choose to proceed with egg sharing, even if it is a means of accessing otherwise unavailable fertility treatment (Rapport, 2003; Blyth, 2004), the choice of foregoing treatment was not one that informants for this study were prepared to contemplate. At the time of completing the thesis Görtin-Broadbent commented on the restricted choice faced by women typically participating in egg sharing, by suggesting that:

If almost all egg-share donors resort to the schemes as a final option, unable to access treatment in any other way, than [*sic*] concerns for their ability to exercise real choice would be justifiable.  
(Görtin-Broadbent, 2010, p.61)

The data presented in the thesis demonstrate that these concerns are warranted.

### **Aims and objectives revisited: integrating theory**

In my introductory commentary, I described the main focus of the study as an exploration of whether women can willingly provide informed consent to share their eggs. In my examination of the key research question I employed a hermeneutic phenomenological position and the VCRM approach to data analysis. This has enabled me to explore the ‘lived’ experiences of egg share donors who participated in the study. Egg sharing was located within the theoretical framework explored in Chapters Nine (see pages 183-193) and Ten, to aid the conceptualisation of egg sharing from the donor’s perspective. Thus, I have been able to document, through the combination of the narratives provided by participants and the data collected from the survey respondents, egg share donors’ motivations and their abilities to provide informed consent.

As discussed in Chapter Two (see pages 32-34), egg sharing enjoys an equivocal legal and ethical status globally. It is not practiced at all in most countries and is formally prohibited (along with other forms of commercial gamete procurement) in others. On the other hand, it is permitted in some countries and in a few of these it is the only form of egg donation that is allowed (Blyth & Golding, 2008). Furthermore, egg sharing has been advocated as an ethically superior form of egg donation compared to obtaining eggs from non-patient donors. It has also been suggested that women choose egg sharing because of altruistic motivation as opposed to them being motivated by the ability to access cheaper, quicker treatment (Ahuja et al., 1996; 1997; Simons & Ahuja, 2005). However, as informants' accounts have demonstrated, the motivation to pursue egg sharing is not borne directly of an altruistic desire to help someone else, but stems from the ability to access treatment that informants would otherwise be unable to obtain, primarily because of reasons of affordability. Pivotal to this is the ability to access treatment more quickly than through the NHS. That is, if informants were eligible to access publicly-funded NHS treatment in the first instance.

Consequently, as indicated (see pages 196-209), the motivations to pursue egg sharing are multifaceted and as such cannot be expressed exclusively as 'altruism' or even as the 'pragmatic altruism' suggested by Ahuja et al (1999). Hence, the study has revealed a number of implications for practice on both ethical and psychosocial grounds. However, before addressing the implications for practice, the following section revisits the theoretical underpinnings of the study.

### **Revisiting the gift relationship: helping as opposed to gifting**

Titmuss' conceptualisation of the 'gift relationship' was based upon eight donor typologies. The principles and application of the 'gift relationship' are still used and, as such, dominate social understandings within the context of organ, sperm, blood, milk, and gamete donation. However, from the analysis presented in the thesis, it is evident that while egg sharing has similarities with blood, sperm and milk donation, it is also significantly dissimilar. I highlight these differences with regards to eggs being non-reproducible, thus a finite form of body tissue; whereas blood, sperm and milk are reproducible. A further distinguishing feature of eggs is their ability to create life – which other than sperm when combined with eggs, none of the other bodily materials are able to do this (see pages 205-209). Additionally, as the 'gift' and its role in reproduction have been widely contested, one could argue that the concept of the gift, in the reproductive context, is value laden and framed in a manner that enhances the 'feel-good factor' (Blyth & Golding, 2008) associated with the 'gifting' of one's eggs to

another (see pages 202-209). Shaw discusses this theme in her analysis of the motivation of surrogates and egg donors in Aotearoa/New Zealand. Shaw states that “concomitantly, donors and recipients need to be clear about whether gifts and donations are the same thing” (Shaw, 2008, p.24). She later asserts that “the language of the gift separates the act of donation from that of commerce and the commodification of tissues” (Shaw, 2010, p.612). While Shaw’s analysis was presented in relation to perceptions about organ and tissue donation, it has similarities with the findings relating to egg sharing that emerged from the study.

The language of the gift enables a positive message regarding the merits of donation to be transmitted. However, Shaw’s analysis of the views of intensive care workers and donor and recipient coordinators in Aotearoa/New Zealand, regarding their perception of the gift relationship in organ donation provides an alternative view. She says one participant indicated the need to address the concept of gift giving in relation to the way that donors and families frame the act of giving: “if families and donors do not identify with the word gift, then perhaps we should embrace and move away from language as indicated or cued by that group, the donor group” (Shaw, 2010, p.615). Significantly, this model may be a more appropriate approach to egg sharing in the UK. That is, rather than the concept of the gift being applied to the schemes, as is currently done; it may be pertinent to explore how egg share donors themselves express what the act of donation represents to them. I would concur further with Shaw’s analysis regarding the discourse of the gift relationship within the context of egg sharing.

In the study, the concept of the ‘gift’ was not a dominant theme. Significantly, only four informants spontaneously used the term ‘gift’ in their accounts, intimating that donation was not always perceived as a gift. Hence, few egg share donors equated the donation of their eggs in accord with ‘gifting’ when elucidating their experience about participation in egg sharing. Consequently, it became evident that egg sharing cannot be subsumed into any of the donor typologies proposed by Titmuss. Instead egg sharing is more closely aligned to helping. When informants referred to their involvement they predominantly talked about the ability to help, 16 out of 17 informants citing the ability to help as a factor in their decision-making, as illustrated in the following excerpts: “I would be helping another couple” (Jayne), “It would help us...” while representing a “chance to help another couple” (Respondent 3), and “I could try and help” (Respondent 6).

### **Locating affect social exchange theory**

In my integration of affect social theory it became evident that it was relevant to the context of egg sharing as it involves a system of exchange. The importance of this theory to the study stemmed from the argument that egg sharing may be akin to (affect) social exchange, in that the principles of social exchange are about maximising benefits whilst minimising associated costs. If risks are too great, then a relationship may be abandoned (Homan, 1958). This concept is pertinent to the current study, as egg share donors attempt to maximise their opportunities to conceive and endeavour to minimise the costs involved. This is evidenced in the way they discussed their involvement in egg sharing and their perception of the other(s), the recipient(s) in need of donor eggs.

Additionally, the integration of the 'affect' dimension enables emotions (empathy) to become incorporated in the exchange process. This is evidenced in relation to the way that informants described how they came to be involved in egg sharing. Significantly, it is their awareness of other(s) in need (of donor eggs) that acts as the driver towards donation. That is, informants in the study could relate to how the recipient(s) felt about their own attempts to conceive and how this might have affected them. For example, Respondent 1 comments that "It would help us financially and also give us the chance to help another couple who were struggling to become parents". Similarly, Respondent 4 states that she "felt good that I could try and help another couple in the same situation as me as well as helping myself" while Respondent 11 says that she "was happy to be able to help a lady who would have been through as much heartache because of infertility that I had". These excerpts epitomise the relational nature of egg sharing and the influence that their perceptions about the other parties involved, combined with empathic awareness that enable the exchange (donor eggs for the subsidised treatment) to take place. However, I suggest that the inclusion of a 'third' party changes the 'social exchange' to a 'social transaction' that is mediated by another, who ensures that the 'best' interests of all parties are represented, including their own.

More specifically, the parties requiring treatment; the donor and recipient(s) are able to access the treatment required, regardless of the outcome, while the clinics benefit as they are able to provide the treatment and for which they receive a fee. Hence, all parties appear to have their best interests served. However, the reality is that only the clinics may benefit since egg sharing does not always lead to a successful conception and birth for either the egg share donor or recipient.

### **Egg share donor decision-making**

The majority of informants had no means of paying for their own treatment, thus egg sharing was pursued, as elucidated by Charlotte:

“...many couples are turning to egg share as a means of funding their IVF treatment. I am in touch with lots of people through [name of organisation deleted] who are not eligible for funding from their PCTs and are now egg sharing as a means of reducing the cost...”  
(Charlotte)

Moreover, Charlotte is supported by other contributions, such as, Respondent 10, who commented that “doing egg sharing dramatically reduced the cost of IVF”, and Florence who said that egg sharing represented an opportunity to “access to the treatment we needed as it was beyond our reach financially”.

Consequently, the complex nature of egg share donor decision-making should not be downplayed. The decision to participate in egg sharing is made in conjunction with relational aspects of donors’ ‘lived’ experiences. This meant that decision-making and the ability to give informed consent were affected by both intrinsic and extrinsic factors.

In evaluating decision-making I concur with the analysis by Broadstock & Michie who state that “decisions are not taken in a vacuum, but in a social context with varying degrees and types of social influence” (Broadstock & Michie, 2000, p.192). Consequently, decision-making is affected by external influences, such as the way “information is framed” (Broadstock & Michie, 2000, p.192). As identified in Chapters Nine and Ten (see pages 188-190), rational decision-making is a feature of the process, yet decisions have the potential to generate both positive and negative outcomes. Concomitant with egg share donors’ decision-making is their tacit understanding of the impact of their decision, based on their desire to achieve a conception, and the role that the input of ‘relational’ others has on the process.

Informants were in effect, attempting to manage what could be perceived as a disrupted biography caused by their inability to conceive naturally. Attempts to overcome this challenge led to medical intervention that, in some cases, had caused anguish and distress. Consequently, in the attempts to transform their biographies from unmother (incomplete woman) to mother (complete woman) (Chester, 2003), informants encountered difficulties and complexities in their relationships with others.



In some instances, being the infertile other caused consternation, as women attempted to explain the gravity of the situation in their lives. In vocalising, through their narrative accounts, the multidimensional nature of egg sharing, it was clear that infertility was disrupting their vision of their life course. This is attributed to the use of a relational methodological approach to analysis, which revealed their relationships with significant others. For example, Florence wrote:

“Some friends seemed shocked that I could contemplate or consider it, but then when I explained our predicament and the treatment we needed they kind of understood.”

She also said “I couldn’t see them through their pregnancies, and became quite a recluse”. Similarly Jayne stated: “I don’t think anyone else really understands what it entails”. These quotes epitomise the relational nature of the attempts to achieve motherhood. Moreover, they signify the impact that infertility had had upon these women. As Exley and Letherby state:

In a society where individuals are encouraged to value procreation (albeit in the ‘right’ social and economic circumstances)... people who have difficulty having children... are likely to experience some disruption both to their lifecourse expectations, and to their everyday life and relationships with others.

(Exley & Letherby, 2001, p.128)

Contending with the consequences of an infertile future, and non-motherhood, informants chose to redress this through treatment. Thus, they attempt to avert the path that nature had tasked them with. Therefore, in their attempts to navigate their biographies, from unmother (incomplete woman), to mother (complete woman), the informants pursued egg sharing. This was not the first treatment of choice (for most informants). Nevertheless, egg sharing represented a tangible means of achieving motherhood. However, egg share donors are not always successful. Consequently, in terms of outcomes there are six possible typologies that can emerge from egg sharing. These are: (1) donor successful – recipient successful; (2) donor successful – recipient unsuccessful; (3) donor unsuccessful – recipient successful; (4) donor unsuccessful – recipient unsuccessful; (5) donor successful – recipient outcome not known; and (6) donor unsuccessful – recipient outcome not known. Each of these typologies raises different implications for all those involved. Accordingly, there is a need to ensure that the needs of both egg share donors and their recipients are met based upon these

outcomes, specifically, as each typology presented different issues for donors in the study.

In the current study, most informants' treatment was successful (10 out of 17), thus their disrupted biography was realigned. In achieving a conception they were subsumed into the following typologies: type 1 (7 out of 10), type 3 (2 out of 10), type 4 (1 out of ten). The six informants who had been unsuccessful fit typology 6, while the final informant was still awaiting her own result and could therefore not be subsumed into any of these typologies at the time of writing. What these findings identify are the degrees to which post-treatment implications will vary. Moreover, they reinforce how egg sharing can lead to the construction of new biographies. In highlighting this finding the study reveals how type 1 egg share donors, had constructed other biographies; a biography as mother (own offspring), and as 'genetic' mother (recipient's offspring), as had the one type 4 egg share donor. Thus, in circumventing their infertility, and contributing to the circumvention of the invisible other's infertility, a new story is written, and a new invisible 'social' relationship emerges. This relationship becomes intertwined with the concept of the 'invisible' other(s), the recipient, and the potential or actual, 'genetic' child born into another family (see pages 222-230). It is also epitomised in the way that egg share donors reflect upon their involvement in egg sharing. For example, Jayne comments that "I constantly think of the eggs I donated", going on to state that:

Then I didn't really think too much about the possibility of any potential children, where as now I have my child I think about it quite often."  
(Jayne)

In a similar manner Florence notes that she feels that it is "necessary to know, not only for own curiosity and own piece of mind, but for that of our daughter". In essence, these views serve to typify the post-treatment impact of egg share donor decision-making, demonstrating further the concept that decision-making is imbued with complexity and, as such, a number of factors were vocalised by informants. Notwithstanding this fact, decision-making also appeared to be guided by a particular theoretical concept, that which can be observed from a utilitarian perspective.

### **Utilitarian decision-making and egg sharing**

In Chapter Nine I introduced the utilitarian ethical position (see pages 188-190) alongside moral and rational decision-making, specifically the work of Bentham and Hobbes. My discussion addressed the issue of rational decision-making, a concept

based upon consequentialist or utilitarian ethics. The key principle underpinning utilitarianism is the achievement of the “greatest happiness/good for the greatest number” (Bentham, 1962; Mill, 1962). As a theory it is based on the principle of maximising welfare, and comprises a complex cluster of moral theories (Gillon, 1985). This position suggests that decision-making is not based on absolutes, but rather that decisions are relative. Specifically, decisions are made based upon what appears to be the most appropriate action, in relation to the possible perceived outcomes, at that point in time.

When applied to egg sharing it is evident that it provides a (potential) practical solution to a problem. Indeed, the documented accounts that emerged from data analysis demonstrate that not only is egg sharing representative of a practical solution, but the decision to pursue egg sharing is mediated by what appears to represent the best option. Moreover, in describing why they chose to pursue egg sharing, informants spoke of their motivations to egg share that are primarily influenced by the overwhelming need to circumvent involuntary childlessness. Consequently, when faced with the inability to afford treatment lengthy waiting lists, egg sharing represented not merely a solution, but an expedited solution. At the same time, other than to forego fertility treatment altogether, these decisions were constrained to the extent that egg sharing represented the only real option available to them, as elucidated by Jayne: “without sounding selfish, egg share was really the only option for us. We were desperate for a baby and could not afford the full price of IVF”. Moreover, the fact that informants thought about the potential future consequences of egg sharing demonstrates that they undertook a full consideration of the benefits and associated personal costs, such as, biological connectedness, as illustrated by Emmeline:

“Very briefly I had a thought about if it is right that someone else may have a child with my genes before me and how would I feel about it.”  
(Emmeline)

Yet, despite these misgivings, she still deemed egg sharing as the most favourable option and proceeded with treatment. Admittedly, this analysis appears to lean towards the opinions of Ahuja et al., (1997; 1999) that when the potential benefits and potential costs of egg sharing have been sufficiently weighted, the decision to share becomes the course of action. This illustrates Bentham’s principle of utility, which states that when choices need to be made, the ethical choice is the one that is perceived to have the best outcome for those involved (Rachels, 1998, cited in Houser et al., 2006;

Glannon, 2005). Consequently, the decision to egg share is made because it is perceived as offering the chance of the best possible outcome, and the preferable option, given the alternative of no access to treatment. Hence, egg share donors' motivations and the desire to achieve a conception are inherent features of their decision-making.

### **Altruism and empathy-altruism**

Advocates of egg sharing suggest that women are motivated by altruism and the desire to help someone in a similar situation (Ahuja et al., 1996; 1997; 1998; Wilcox, 2001; Simons & Ahuja, 2005). According to Ahuja et al., (1997), egg sharing enables 'altruistic reciprocity' between two (possibly three) couples in need of otherwise unobtainable IVF treatment. Evidence of altruism exists in the study as 16 out of 17 informants cite the ability to help someone else as a motivating factor. This is because they could empathise with the recipient(s)' situation as they knew how it felt to be involuntarily childless. Consequently, their perception of the 'infertile' other enables (through the perceived commonality of experiences) the arrangement to proceed. Thus, empathy represented this commonality of experience and motivated informants to help the infertile other(s). This is evident in the accounts provided by informants whereby they vocalised their thoughts about the other(s). This is illustrated by Emmeline who commented that she decided to egg share because of "the thought of doing something great for a woman going through the same as me and giving her a chance that I would want if I was in her shoes", thus personifying the relational aspects of egg sharing that emerged in the study. Moreover, they serve to embody the concept that informants' insight into how it feels to be involuntarily childless is an important factor within the context of decision-making.

Significantly, donors' perception of the other (the recipient) framed the context of their reproductive decision-making (see pages 203-205). Thus, they become motivated by the desire to alleviate their own circumstances and those of the invisible other. This concept is described by Fox (1992) citing Lugones (1987), highlighting the importance of the ability to perceive something through the eyes of the other. In this way it is possible to share their construction of the world, to come to know the other, and to know their way of thinking about the world. The study provides evidence that supports this concept as informants expressed their awareness of the recipient (see pages 224-225 and 250-251). They acknowledged thinking about how difficult it must be for someone who is both involuntarily childless and also in need of donor eggs.

Accordingly, this awareness of someone in need (empathy-altruism) was influential in the decision to proceed with treatment.

### **Egg sharing as dissociation**

An alternative discourse using the language of egg sharing emerged from the analysis - the concept that some women put some distance between themselves, their eggs and any potential child/children. For example, when I read Jayne's account I looked closely at the language she used. Evident within her use of language is the fact that she takes ownership for her eggs ("my eggs"), yet when it comes to thinking about the outcome of the donation of her eggs, she distances herself ("I didn't allow myself to think too much"). Indeed, Jayne's use of language indicates that not only did she dissociate herself from her eggs, but that she did so in a manner that I interpreted as a method of self-protection. Moreover, if she did not have to think about her eggs and the act of sharing them, this put her, in some way, in a safe place, at a distance from her eggs, where she might not be affected by her decision. This theme has similarities with existing studies into the experiences of both egg share and known egg donors (Rapport, 2003; Blyth, 2004; Martin, 2008).

Martin's (2008, p.149) study of known egg donation revealed that some known donors perceived their eggs in different ways. She notes this as being in accord with other studies into known donation. Martin (2008) describes how some informants referred to their eggs as 'waste products' or 'just a cell'. In making this reference it would appear that some known egg donors were able to emotionally detach themselves from their eggs. Similar, themes emerged in the accounts provided by egg share donors in studies by Rapport (2003) and Blyth (2004). Comparable findings emerged in a study by Kirkman (2003) in her analysis of egg and embryo donation in which some informants equated an egg as something that is lost. Consequently, it may be that it is distance (the ability to dissociate from the concept of the egg as a potential life) that facilitates the conditions within which the decision to go ahead with egg sharing is made, a distance socially constructed through language. Data included in the current study tend to support this analysis.

Significantly, the way informants vocalised decision-making made it evident that two dominant discourses prevailed; association and dissociation. These may be influenced by the language and particular discourses applied in egg sharing information and counselling. I posit that if egg share donors view their eggs as 'cells', 'waste products', or of 'no significant value' to themselves, then the decision to egg share may be easier,

as they do not equate the egg with the potential to become a life. Thus, clinics benefit as they are possibly able to overcome the lack of donor eggs, and are able to treat both the donor and the recipient. When both parties (donor and recipient(s)) are successful then it can be the “win-win situation” described by Simons and Ahuja (2005, p.116). However, the clinic is missing from the situation described by Simons and Ahuja. Consequently, if the clinic were to be added to this equation it would mean that rather than it being a “win-win situation”, it would become a “win-win-win” or even a “win-win-win-win” situation. That is, the clinic becomes a visible entity within the concept of the egg sharing arrangement, as they are the third-party intermediary (“win-win-win”) described earlier in the chapter (see page 237). The latter situation would arise when there are two recipients involved in the egg sharing arrangement. If all of these parties achieve a successful conception and live birth, then it is “win-win-win-win”. However, I would argue, and based on the evidence provided (see pages 155-156 and Chapter Nine) that, clinics always “win” since they get paid regardless of the outcome for donor or recipient(s). Thus, clinics are placed in a position where it “wins” as a result of the provision of treatment to the donor and the recipient(s). Conversely, egg sharing is not always a “win-win”, “win-win-win” or even a “win-win-win-win” arrangement, for donors or recipient(s) as treatment for either – or all – may fail (see pages 232-233). Consequently, I would suggest that if this discourse were to change to one whereby the egg was perceived as representing a potential child, then the act of egg sharing may be much more difficult.

### **Informed consent within the context of egg sharing**

In my review of the criticisms of egg sharing I explained why egg sharing has been contested, the suggestion being that women’s consent is fettered and diluted by the offer of access to cheaper, expeditious treatment. If the criticisms advanced by English (2005) and others (see for example, Shenfield & Steele, 1995; Johnson 1997; 1999; Lieberman, 2003; 2005) are correct, then women simply cannot consent to share their eggs. The key reasons supporting this contention are that: 1) donors may change their mind later, and 2) their own treatment might be unsuccessful while the recipient might be successful. However, the reality is that, in life, decisions have to be made and sometimes their full implications only become apparent afterwards – or circumstances may change that generate a reconsideration of an earlier decision.

My reference to changed circumstances is not being advanced to challenge the validity of decision-making in other arenas; it merely serves to highlight the impact that reflection about decision-making can have on people. This challenge is illustrated using

the opinion expressed by Respondent 6 who said that “it is a easy decision to make at the time, however in retrospect had any woman got pregnant it would have haunted me..”. Consequently, what the study does is challenge the concept that women cannot consent to share their eggs.

In order to contextualise the challenge, I refer to Chapter Nine (see pages 188-190) where I explored moral decision-making, autonomy and principles of informed consent, to demonstrate how these concepts might enable an understanding of egg share donors’ experiences to be evidenced. The principle of informed consent relies on the autonomy of the individual. To be autonomous one must be able to make a decision that is not influenced by offers or incentives (Cook et al., 2003; Beauchamp & Childress, 2009). However, autonomy is mediated by circumstances and as such one has to question the extent to which egg share donors are able to be autonomous.

The autonomy of women entering egg sharing schemes may already have been compromised, in the first instance, by their need for ARTs. However, it is evident that egg share donors manage to retain some autonomy in their reproductive decision-making, even if this is affected by financial considerations combined with the desire to achieve motherhood. As the study demonstrates, most informants understood what egg sharing entailed and to what they were agreeing. This finding is symbolised by Emmeline when she reflected on the consent process; she explained that she knew what she was consenting to, yet she did not have any recollection of “anyone explaining the consent process” to her. Similarly, Florence remarked that she felt that as a couple they were fully informed about the entire process, the potential future implications and eventualities. Significantly, though, Florence added: “...you can't fully prepare yourself until it happens”. These excerpts serve to personify the fact that informants felt able to give their consent. However, as discussed in Chapter Ten (see pages 229-230), the reality of egg sharing only became apparent post-treatment.

This is evidenced by data from the study confirming that egg share donors can consent to share their eggs. However, the decision to share is influenced by wider mediating factors; these include the offer of cheaper, expeditious treatment and the ability to help someone else. These factors indicate that the provision of informed consent by egg share donors merits further scrutiny. However, as the thesis emphasises, the provision of informed consent by egg share donors is complex and the realities post-treatment are not always what they might have been anticipating. For example, Jayne remarked that when she is out she looks in prams and wonders about whether that child might be

the offspring conceived from her eggs, something she is not likely to have anticipated when she decided to proceed with egg sharing. Jayne is also of the opinion that the reality of egg sharing does not take effect until after treatment. Notably, the reality became more apparent after she had her own child, and she knows that the questions she has may remain with her for the rest of her life. Similarly, Emmeline comments that she wonders about the other(s); the recipient(s) and offspring. These findings both demonstrate and reinforce the concept that egg sharing is not undertaken in isolation. Instead, it creates a situation whereby the egg share donor is left with a myriad of thoughts and feelings about their involvement that tend to be brought to the fore following their own cycle(s) of treatment. These findings lead to the proposal that informed consent within the context of egg sharing arrangements needs reconceptualising to allow for the making of ethically-valid decisions on the basis of less than “complete” information, but the best available information at the time.

### **Reconceptualising informed consent**

My proposal for reconceptualising informed consent is located within the context of current policy for egg sharing in the UK. This should enable the reader to understand the context underpinning this proposal.

Currently, the HFEA code of practice asserts that:

The person obtaining consent should ensure that an egg provider’s consent is recorded so that different conditions can be placed on: (a) the use of eggs and the use and storage of embryos created for the egg provider’s own treatment, and (b) the use of eggs and the use and storage of embryos created for the treatment of the recipient(s).  
(HFEA, 2009b, 5.21)

The guidance also recommends that “the centre must offer anyone intending to participate in an egg sharing arrangement the opportunity for counselling” (HFEA, 2009b, 12A) and this should be undertaken in accordance with the guidelines set out by the British Infertility Counselling Association (BICA) (HFEA, 2009b). It is stipulated by BICA that a minimum of two sessions of counselling should be offered to people considering the use of third party ARTs including egg sharing (BICA Working Party, 2007). Specific guidance for those considering surrogacy, sperm, egg and embryo donation and egg sharing should enable them to reflect upon the following situations:

a) Their reasons for wanting to provide gametes/embryos or act as surrogates;



- b) Their attitudes and possible feelings towards any resulting children;
- c) The implications for any current or future partner they may have;
- d) The needs of resultant children for full biographical information and the importance of providing such information on the HFEA register form;
- e) The needs of such children when they reach adulthood and the possibility of future contact;
- f) The importance to their own existing or future children of information about the donation or surrogacy and these children's potential needs;
- g) The importance of sharing information wherever possible with their own parents and wider family;
- h) The possibility that treatment will fail or that other, pregnancy-related difficulties will arise (Adapted from BICA Working Party, 2007, p.6).

These comprehensive guidelines illustrate the complex considerations that should be discussed with those considering third-party ARTs. However, despite these guidelines there are further issues, specific to egg sharing, that need to be discussed prior to the formal giving of consent. Hence, the proposed model of informed consent and issues that should be included in counselling. These should focus upon enabling ethical decision-making to be undertaken by egg share donors in relation to the proposed additional information. This should include (but is not limited to) informing them that:

- a) We do not currently know the long-term implications of egg sharing for anyone involved and that it will be some time before we do;
- b) Concerns have been raised by critics of egg sharing about women's ability to give informed consent due to the influence that access to cheaper, quicker treatment has on decision-making processes;
- c) The HFEA Code of Practice (2009b) states that a woman may vary or withdraw her consent to treatment at any point before the embryo that was created with her eggs is transferred to the recipient. There may, however, be consequences (for example, fee

implications) if a donor withdraws or varies her consent that may dissuade women from withdrawing their consent. Consequently, egg share donors should be advised that it is possible they might wish to change their mind at a point when there is no opportunity to do so. They may regret their decision later, especially if their own treatment is unsuccessful and they learn that their recipient's was;

d) It is important that donors update the information they provide to the HFEA, even if they are unsuccessful in conceiving a child. This is especially important if their recipient was successful;

e) We do not know how genetic offspring will regard the arrangement or their conception as a result of the donor's involvement;

f) We do not know whether genetic offspring will ever seek to make contact with their donor, so we cannot yet provide much guidance as to what to do if this happens;

g) We do not know how donors' own child/children will feel about the arrangement, or learning that they may have half-siblings who are about the same age as them and who are being raised in a different family;

h) We are not fully aware of how donors will feel about egg sharing after the treatment. It is important that if a donor experiences adverse psychological effects that she seeks appropriate support, advice, and guidance.

The rationale for these areas to be covered in depth, as part of the consenting process, is based on the findings to emerge from the study that informant's perceptions about egg sharing changed following treatment (see pages 227-230). Thus, my suggestion that the potential future ramifications of being an egg share donor needs to be discussed in greater detail. Donors should then be asked, on the basis of this additional information, whether they are still willing to consent to being an egg share donor. I suggest that it is only then, following the integration of this model for obtaining consent, that consent can be validated. Principally, if emphasis is also given to the negative aspects of egg sharing, donors may be more fully informed about potential future implications. They are also being made aware that there is no way of knowing, just yet, what the future might hold for them.

### **Revisiting my feminist development**

In Chapter Nine (see pages 192-193) I explained how my readings of feminist critics of the medicalisation of reproduction and the patriarchal influences attributed to medicalisation, on a number of levels, led me to re-vision myself as a developing researcher with a leaning towards feminist thinking. As such, as I approached the end of the study I believe that I have become more closely aligned to a feminist position. This led me to re-visit the data using a different lens.

Having listened to and observed the data provided by informants, there are, I argue, questions that remained unanswered which I pursued using the lens of a developing critical feminist, thus affording me the opportunity to gain a further insight into the challenges faced by women attempting to circumvent involuntary childlessness, in this instance the experiences of egg share donors. Moreover, I was able to delve deeper into the experience shared by the informants in the study.

This created a tension in the findings I have presented in the thesis and the thought process underpinning them. I have struggled with this tension as I feel that there is another aspect of egg sharing that might have emerged from the research had I employed a purely feminist approach. This is based on the observations I have made which are that: (1) egg sharing in the UK is predicated on a business model that enables clinics to profit from their mediation between egg share donors and recipients; (2) within this system it would appear from the accounts provided by informants that they are encouraged to view egg sharing positively both for themselves and for others; (3) women do not dwell on the negative or morally questionable aspects that are associated with egg sharing. If they did then they might not feel comfortable with becoming an egg share donor and (4) women's biological, social, and cultural needs are being manipulated by the only health service available to them.

However, for the purposes of the thesis I did not undertake a complete analysis from a critical feminist viewpoint. Instead, based on the observations above, I allude to the fact that a feminist critique of egg sharing may have revealed an alternative layer of meaning. Hence, my justification for not including an analysis of the data based entirely on the critical lens of a developing feminist researcher.

### **The ethical and psychosocial implications of egg sharing**

At the beginning of this chapter I asserted that women can consent to share their eggs. However, the decision to do so is framed within the context of wider mediating factors. As highlighted in my earlier analysis, the study has revealed an aspect of egg sharing not considered by previous research, since this is the first study of egg sharing to be undertaken following the removal of donor anonymity in the UK in 2005. Previous research therefore, (such as that of Rapport (2003) and Blyth (2004), was unable to take account of the impact of the loss of donor anonymity on egg share donors' decision-making and experiences – a deficit that this study begins to address. Thus, while the research further contributes to what is currently known about egg sharing, it also provides important empirical evidence about the experiences of egg share donors who have donated as identifiable donors. Little is still known about the experiences of egg share donors and it has been acknowledged that it is important that more evidence about the feelings and experiences “specifically of egg-sharers” is required (Gürtin-Broadbent, 2010, p.36). The current study provides some of this missing evidence.

### **Egg sharing and new family formation**

While informants were never asked directly about their thoughts regarding the other child/children, it emerged as a feature of their ‘lived experiences’. Informants acknowledged the existence of the others: the recipient, the recipients' child/children, and the way that the child might be brought up. Informants wondered about the other family, and hoped that the child would be looked after, and raised in a way that they would wish. I would concur with Raphael-Leff (2010, p.128) who asserts that donation of the egg “acts as a catalyst, impelling all members of the triangle towards mental preoccupation with each other”. It is this preoccupation with the other that emerged from the findings presented in the thesis.

Herein lie potential future implications regarding a lack of information, the child's ability and right to know their genetic origins, and the impact on all those involved. Egg sharing is not a treatment undertaken in isolation. It involves a minimum of two parties, two (possibly three) childless families, who combine their resources (eggs and money), in the attempt to overcome involuntary childlessness. In doing so, the reality is that in some cases both parties are successful. Alternatively, the donor may be subsumed into typologies 3 or 6 (see pages 239-240). Consequently, some egg share donors have to contend with the existence of a child/children genetically related to them being raised in the recipient(s) family.

Thus, egg sharing creates new family formations and importance needs to be attributed to the ensuing social, gestational, psychological, genetic, and familial roles. In determining how their own offspring's conception came about, donors need to (in some cases) introduce the concept of the existence of genetically related half-sibling(s), the relational 'invisible' other(s), who may, or may not, introduce themselves to the family in the future. Hence, the association with the other is made evident and had congruence with the existing empirical literature on egg sharing. Notably, in the study by Blyth (2004) several respondents indicated that if they knew that a recipient-conceived child lived in the same geographical area this would influence information sharing. In contrast Rapport (2003) notes that potential donors expressed doubts about potential future meetings with donor-conceived offspring.

Markedly, the accounts presented in the thesis portray the experiences of egg share donors post 2005. As such, the study is the first to report on the views and perceptions of identifiable gamete donors following the change of legislation in the UK in 2005 permitting a donor-conceived person to learn the identity of her or his donor. This legislation makes it more likely than previously, when donor anonymity was protected, that a donor-conceived person may seek information about, and possibly make contact with, their donor in the future.

Significantly, the study also provides data regarding egg share donors' response to the HFEA's change of policy, allowing them to learn the outcome of their recipient's treatment, and evidence that some donors (the majority in this study) chose to seek this information (7 out of 13 survey respondents and 3 out of 4 e-interview participants) or indicated that they would do so in the future (2 out of 13 survey respondents). Although three survey respondents indicated that they had not found out this information at the time they participated in the study, this does not equate to them never finding out. Notably, one clinic would not provide the requested information, which is not in compliance with the current guidelines (HFEA, 2009b). However, informants also express a lack of control over potential future consequences, illustrating further the complex nature of egg sharing.

### **Policy implications**

Findings from this research have led to the emergence of new ways to explain the experiences of egg share donors and implications for policy. Thus, the study has raised the following points for consideration:

1) Do the accounts of these egg share donors provide sufficient evidence to propose that egg sharing should be prohibited? I do not believe that findings from this study provide sufficient evidence to support this proposal. Moreover, the accounts provided by unsuccessful egg share donors in the study do not provide any evidence that egg sharing should be curtailed. However, the provision of subsidised treatment is subject to further scrutiny as part of the HFEA review of donor compensation, and which could result in a clampdown on egg sharing. On the other hand the evidence is that the HFEA is concerned about donor supply, as it has been reported that waiting times for egg donors can be as long as 3-5years (Hamm et al., 2010), and egg sharing comprises a significant element of egg donation in the UK at the present time. The review could result in a more generous system of compensation for inconveniences for donors – as permitted under the EU Tissue Directive (see page 37). This could lead to a decision that egg sharing is acceptable – or it could lead to a decision that egg sharing will be prohibited and all egg donors receive the same levels of compensation for inconvenience.

2) If egg sharing is allowed to continue how might women be better prepared? Both responses to the online survey and the accounts provided by e-interview participants illustrate the need for a more detailed and comprehensive discussion of consent to be undertaken in counselling and consultations with clinic staff. For example, Florence referred to the consent process and the fact that “you can’t fully prepare yourself until it happens”, whereas Emmeline commented that she was more fixated on starting treatment and therefore could not fully remember having the consent process explained to her. She also noted that there were a lot of forms and they were actually quite complex. Similar thoughts were expressed by Charlotte (see pages 210-211), hence the proposal for the reconceptualising of informed consent as detailed on pages 246-248.

3) The evidence presented in the study emphasises the significance of both financial considerations and restricted access to treatment. Twelve of the thirteen respondents who completed the survey had experienced difficulty accessing, or were ineligible for, NHS treatment. This is in accord with previous UK research that indicated that egg sharing thrives in a context of restricted access to NHS-funded fertility treatment and that women would be less likely to choose egg sharing if there were no NHS rationing (Rapport, 2003; Blyth, 2004). Furthermore, recent evidence to emerge in the UK has shown that there has been an 80% reduction in the numbers participating in egg sharing, in one locality, following the availability of more IVF cycles on the NHS (Avery

2010 cited in Guy). These views and evidence are supported by Belgian research (Pennings & Devroey, 2006) showing that the number of egg share donors in Belgium fell by 70% following the Government's decision to reimburse the cost of six cycles of IVF treatment. Pennings and Devroey assert that this finding confirms that restricted access to IVF treatment because of affordability leads women to become egg share donors.

Thus, the study provides support for the suggestions made by Rapport (2003), Blyth (2004) and Pennings and Devroey (2006) and reinforces the view that motivations to share eggs are multidimensional rather than being borne from exclusively altruistic intentions, as summarised by Maggs-Rapport:

A strong desire for a child, spurs women on to describe egg sharing in positive terms. Drawn to a programme that avoids lengthy NHS waiting lists and the cost of private treatment, egg sharing is an enticing solution to a long-term problem.  
(Maggs-Rapport, 2001, p.229)

Based on the evidence presented in the study, the opinion expressed by Maggs-Rapport (2001) is a compelling one. It supports further the concept that the desire for cheaper, expeditious treatment, when faced with restricted choices or no alternative, is influential in egg share donor decision-making. Therefore, inevitably, these factors affect egg share donors as they attempt to circumvent their involuntary childlessness, as evidenced in the study.

### **My biography and its impact on my analysis of participants' stories**

As I conclude this chapter I end with an account of the emergence of similarities with my own biography that became apparent during my analysis of informants' accounts, in particular those involved in the e-interviews. In presenting my final reflections on the study I refer back to the underpinning reflexive approach taken during the research (see pages 67-69). The ability to be reflexive and to locate myself as a female researcher within the context of the study meant that I could begin to appreciate the experiences that informants shared with me. Moreover, it made me revisit my choice of research area within the context of who I am as an individual but also in relation to my wider family unit (see pages 14-19). This enabled me to locate my own experiences as a child, sister, half-sister and mother in a manner appropriate to the context of the research. It also enabled me to comprehend egg sharing from the position of those who know it best: the egg share donors themselves. Consequently, I suggest that for

those who have achieved a pregnancy, egg sharing has proved to be a practical solution because they have been successful. Yet their success is complicated by other aspects of feeling and emotion that may not have been evident to them at the start of the egg sharing process (see pages 229-230).

As I communicated with the participants who had taken the time to be involved in the study, I was captivated by their stories as they were displayed on the computer screen. I was fascinated by the way their personal narratives started to unfold and I knew that I had to make discernible the distinct voices that could be heard as they recounted their stories. As I read their personal accounts of their struggles to overcome infertility I was left with a multitude of feelings. As Florence recounted her story, for example, I realised that she had started trying to conceive at 29, the same age when I had my son. Unlike me, though, her journey had been long and torturous. I could see with clarity how difficult the last few years must have been. Indeed, I felt a sense of frustration at the complexities of participants' situations.

As I listened to the stories it was almost as if I could feel what their experiences portrayed. As participants spoke of loss, of despair, of desperation and yearning, I could comprehend the extent of the anguish they expounded. Those periods of depression, grief, desperation and, in some cases, isolation made vividly explicit their experiences. As they charted their journeys, I travelled with them and I felt some of those feelings for them. Although my own family loss was distinctly different (see pages 17-19), the features of the grieving process were very familiar. I also realised that I shared a common theme with participants: the loss of reproductive capacity although, in my case, this was brought about by my perception of the biological clock ticking away.

When participants spoke of their negative experiences of infertility, even though I could not fully comprehend how these must have made them feel, I could understand to a certain degree. When Florence and Jayne spoke of their joy of finally becoming parents I was thrilled that they had achieved the desired outcome. Emmeline commenced her treatment at the beginning of the interview process and became pregnant with twins, midway through the study. As we talked about morning sickness and her scans (she sent me her scan photos by e-mail), I could begin to understand why some women would choose to become egg share donors, especially if the outcome was a positive one. I remembered being overjoyed when I got the news from Emmeline that she was now a prospective parent.



As I concluded the interviews with participants I began to appreciate the impact that their stories had had on me. I also think it is fair to surmise that I got close to these women over a period of weeks and months as they told me their stories and shared their journeys with me. At times this was difficult and very emotional. I empathised, at times I felt like I counselled, and at times I felt like a confidante. It also became a process that made me think about my own reproductive capabilities and biological heritage, something I found quite uncomfortable. It also made me question whether I could ever share my eggs with another woman or, indeed, donate them at all.

For me, age was against me so my chances of donating or sharing eggs were now non-existent and I was grateful that I did not have to make a choice. Although, I remembered that many years ago I had seen an advertisement about egg donation and thought that it seemed like a useful and caring thing to do. This was a fleeting thought and something that I never pursued. To be honest I am glad that I never did, because, at that time, I had no concept of the genetic link involved, nor was I a parent. I merely thought that the act of donation might help someone have a baby. At no time did I think about what the future implications might have been for me, for the recipient of the eggs to whom I might have donated, or for any child who might be born from the eggs, or even for my own child.

These thoughts made me feel quite guilty because I had interviewed women who had shared their eggs and who may not have been aware of these implications, either, at the outset, although they did now. These women had had to accept that genetically related child/children may be, or indeed had been, born because of the choice they had made. They knew these would be children who would be brought up in another family. I found this hard to comprehend. It was not that I could not understand entirely, but it made me think more about the implications of their treatment for them, and the recipient families. It also made me realise that I would have found it difficult to pursue egg sharing myself because of the genetic link implications (see pages 226-227). As I attempted to make sense of my own feelings during the research in relation to the stories I heard, I looked at my son in ways that I had never done before. I began to appreciate the strength of the genetic link between us. On the other hand, I saw him as I always do, as the most precious person in my life, and I understood why the women in the study had pursued egg sharing regardless of the potential future implications.

I also thought about my relationships with my genetically related half-siblings and realised that I was glad I knew of their existence, something that might not always be

possible for children conceived using third party reproductive treatments. The onus is on parents to share knowledge about the genetic link with other children, to respect their right to know who they are, and their genetic blood line, a theme I discussed in Chapter Ten (see pages 226-229). Fortunately, the issues for me are different and as far as I am aware, there is no need for me to wonder. However, this is not the same for those involved in the study, which promoted the discussion of potential future implications and the child's right to know, a finding that I revisit in Chapter Twelve (page 260).

### **Chapter review**

This chapter has concentrated on discussing the findings that emerged from the research. By returning to the beginning of the research I have demonstrated how egg share donors can consent to share their eggs. In answering the primary research question, the chapter illustrates the complex issues that emerge for egg share donors post-treatment. This was aided by a re-visitation of the methodological, philosophical and theoretical underpinnings of the study. The ethical and psychosocial implications of egg sharing were also discussed. This led to the suggestions regarding the policy implications associated with egg sharing. Finally, I reflected upon my own location as a researcher within the context of the study. I described how this had impacted on my analysis of the accounts provided by informants'.

The following chapter returns to the work undertaken in the study and explains how this contributed to new knowledge formation. It illustrates how the recommendations for future research arose directly from the work undertaken in the study. It also describes the limitations of the current study. Finally, the thesis is brought to its conclusion with my recommendations for future research.

## CHAPTER TWELVE

### Concluding comments

*“I am happy for whoever my eggs went to and can only imagine how hard it is for somebody waiting for eggs and then finally getting them and it working for them. I think I would have been happier if I had conceived” (Respondent 10)*

The aim of this chapter is to present the overall conclusions that emerged from my research into egg sharing. Conclusions are drawn from the analysis of the ‘lived experiences’ of egg share donors about their motivations to donate and their ability to give informed consent. This highlights how the work undertaken in the thesis has enabled a further understanding of egg share donors’ experiences post-treatment to be revealed.

Drawing upon the accounts given by e-interview participants and the online survey respondents I reflect upon how I was able to explore the meaning of their experiences. This meant locating egg sharing within a theoretical framework. This enabled me, as demonstrated in Chapter Eleven, to propose an alternative conceptualisation of informed consent within the context of egg sharing. This was mediated by the findings presented in the thesis.

This chapter also demonstrates how the study has the potential to impact on the current review of donor remuneration policies being undertaken by the Human Fertilisation and Embryology Authority. I also highlight how the potential long-term implications of egg sharing provide a focus for future research.

I address the implications that have arisen from the research for those working with egg share donors, in light of my proposal for the reconceptualisation of informed consent provision. Set alongside these discussions I also describe the potential implications for health and social care professionals who may come into contact with women who have been, or are currently, an egg share donor.

I describe the limitations of the study prior to explaining how the findings presented in the thesis might be transferable to the wider population of egg share donors. Finally, I present my recommendations for future research into egg sharing.

### **Can women consent to share their eggs?**

At the beginning of the study I set out with clearly defined aims and objectives, specifically, to enable the voices of egg share donors to be heard. In Chapter Four I described how I meticulously developed and designed a prospective study, with the intention that I would seek to interview approximately 20 egg share donors after they had shared their eggs, but before they had received the result of their pregnancy test. However, as highlighted towards the end of Chapter Four, there was a need to thoroughly revise the focus of my study, as access to potential participants, via private fertility clinics, could not be gained. This meant that while the underpinning concepts, aims and objectives, and the philosophical approach of the study remained the same (see Chapters Three and Five), the context changed. The study became retrospective in its orientation, thus generating a greater heterogeneity among participants than originally envisaged. Hence, participants who volunteered to be involved were from the early post-donation period, undertaking egg sharing as the interviews progressed (Emmeline conceived her twins while Charlotte had been unsuccessful), through to those who had either conceived, not conceived or who had undertaken more than one round of treatment prior to taking part in the study (see Chapters Eight and Nine).

### **Informed consent and egg share donors**

The emphasis on establishing whether women can willingly consent to share their eggs or whether they are coerced to do so has been a central feature of the thesis. This study demonstrates that women are autonomous thinkers and decision-makers. Thus, they are able to give their informed consent in advance of undertaking egg sharing. However, as I detailed in Chapters Ten and Eleven (see pages 196-209 and 244-246), giving consent is affected by wider mediating factors, including the opportunity to access cheaper, expeditious treatment and the ability to help other involuntarily childless women. I now document how I was able to evaluate egg share donors' decision-making by returning to the aims and objectives (see pages 19-20) of the research.

### **Returning to the research questions**

In my three analysis chapters (Chapters Eight, Nine, and Ten) I have explained how the experiences of study informants led to them becoming egg share donors. The impact of their involuntary childlessness was such that engaging with egg sharing was pursued because it represented the last resort for family-building. Informants explained how frustrated they had become in their attempts to access NHS treatment, even if

they were eligible, only to find that there were lengthy waiting lists. Furthermore, when describing their experiences of involuntary childlessness, it was evident that this delay in accessing treatment contributed to them feeling disheartened, distressed and, in some cases, depressed. Consequently, it was not surprising that egg sharing represented a way of circumventing their infertility. However, as I discussed in Chapter Ten, egg sharing is not a 'quick fix' solution to involuntary childlessness. Instead, it became apparent in the accounts provided that egg sharing is for most informants, a last resort for those who wanted to pursue conceiving a child.

Furthermore, in Chapter Ten, I explained how most informants had exhausted all other treatment options before participating in egg sharing (see pages 200-201). Hence, it is clear that in the absence of realistic alternatives, other than remaining childless, egg sharing is seen as a viable option. Significantly, they came across egg sharing by chance during the search for ways to access treatment rather than being a possible option about which they were aware at the outset of their treatment. However, when they discovered information about egg sharing, it was clear that it offered them hope.

Based on the information available to them at the time, informants reported that they understood the implications of the treatment and its potential impact on them and their families before they agreed to go ahead with egg sharing. However, in reflecting back on their experiences it was apparent that this understanding became more comprehensive following treatment (see page 179). For those who had achieved a conception, they had the child/children that they had hoped for, as had their recipient(s). Others had not been successful, and some of these were having to contend with the knowledge that their recipient(s) had been successful rather than this being merely an abstract possibility (see page 156-157).

Additionally, as discussed in Chapter Ten, the motivation to become an egg share donor was associated with three factors: access to NHS treatment, no other realistic option for family building, and financial considerations. An additional factor which I introduced separately was the ability to help, which emerged as a separate theme and incorporated the concepts of altruism and empathy, and reproductive gift giving. These themes served to highlight that when there is an absence of alternatives, and when egg share donors' perception of the infertile other are merged together, these act as the vehicle that propels them towards becoming an egg share donor.

My final aim was the assessment of informants' perceptions and understandings of informed consent. It was clear from the accounts provided that most informants understood what it entailed. Hence, other than the single informant who notes that she did not really understand what she was consenting to (about which she did not inform the clinic), informants knew what they were consenting to and were happy to proceed. However, it was evident that informants had experienced disparities in the way ensuring their informed consent had been implemented. Some were simply provided with information sheets that they took away to read, while others felt more able to ask questions in order to obtain any necessary clarification. This demonstrates that while informants were able to provide their informed consent, there appeared to be a lack of uniform discussions that explored the wider potential ramifications of egg sharing. It was this analysis, combined with the revelation of the implications of egg sharing, that contributed to my proposal for reconceptualising informed consent (see pages 246-248). The study also revealed a novel aspect of egg share donors' experience that was related to their thoughts about the invisible other(s).

There was clear evidence that they thought about this quite a lot, thus reinforcing the concept of the relational link with the invisible others, the recipient(s) of their eggs and in some cases, the resultant child/children. Notably, some informants explained that they thought about how genetically related offspring might be raised in recipients' families. Informants commented on their thoughts about the existence of genetically-related offspring. They also expressed interest in what the recipient(s) of their eggs might be like, and whether any child/children may resemble them. This highlighted the relational nature of egg sharing. Consequently, through informants' attempts to navigate what I have described as a disrupted biography, from unmother to mother, they also create, in some instances: new biographies (see pages 250-251).

Since 2005, gamete donors in the UK have donated with the knowledge that any donor-conceived offspring reaching the age of 18 years may be able to learn their identity and may also attempt to contact them. Some informants, like Emmeline, welcomed any future contact, while others were more cautious. Hence, this led to the emergence of a further layer of understanding about egg share donation.

The emergence of these findings was greatly aided by my integration of theory discussed in Chapter Nine and revisited in Chapters Ten and Eleven. These underpinning concepts enabled me to contextualise the experiences of egg share donors. However, it became evident that not all of the theories that I had explored were

relevant to the analysis and findings presented in the thesis. As discussed in Chapter Eleven, egg sharing is a complex, multidimensional process that some women consider to be right for them. It would appear that it is more closely aligned, conceptually, to a helping relationship rather than as a gift relationship.

### **Main findings**

As noted previously in the thesis (see Chapter Ten) egg sharing is context laden, and the reality for those pursuing treatment is complex. However, the study demonstrates that the accounts of egg share donors provide a valuable insight into their experiences. I have identified long-term psychosocial implications of egg sharing that have implications for policy and practice in a number of health and social care contexts. I would envisage that this will include the work of infertility counsellors, as I have identified the need for more consideration of the needs of egg share donors prior to, during, and following treatment. This is illustrated in my discussion of the complex relational experiences of egg share donors (see pages 250-251). That is, the impact of egg sharing upon themselves, their immediate families, and the 'invisible' others; the recipient, the recipient's offspring and the recipient's wider familial network. Consequently, the study raises the following points:

1) There is a need for all those involved in the provision of egg sharing to make available in-depth information to women considering sharing their eggs. This should be provided by key identifiable fertility centre members and should consistently explore all the potential future implications of egg sharing. This proposal is for comprehensive counselling to be provided to egg share donors, prior to, during, and post-treatment. I would also suggest that in the long-term, there may be a need for additional post-treatment support, especially for type 1, type 3, type 5 and type 6 egg share donors, for whom the ramifications of egg sharing may be particularly problematic (see pages 239-240). Significantly, what the study highlights is the potential need for counselling support for egg share donors and their families, specifically, when donor-conceived offspring begin to seek contact.

2) Informed consent provision by egg share donors merits further scrutiny because, as the thesis shows, the decision to share is influenced by wider mediating factors: the offer of cheaper, expeditious treatment combined with the ability to help someone else. Thus, an alternative model of informed consent has been proposed in Chapter Eleven (see pages 246-248).

3) An egg share donor who is successful in her own treatment and whose recipient has also been successful will need to renegotiate her biography to account for the existence of genetically related offspring living in another family. The donor's children will also need to assimilate information regarding their genetically related half-siblings(s), and other family members may require counselling and support.

4) Additional support may be required for any unsuccessful egg share donor whose recipient has been successful, particularly where the donor is aware of the outcome of treatment for her recipient(s), since she will have to acknowledge the fact that child/children genetically related to her are being raised in one or more other families.

5) A donor who has not ascertained the outcome of her recipient's treatment may not be best prepared for contact from any offspring who may attempt to contact her in the future. She should be given the opportunity to consider the implications of not seeking this information.

6) The study identifies the need for a range of health and social care professionals, for example: midwives, health visitors, educators, early years workers, and social workers to be sufficiently knowledgeable about egg sharing and sources of specialist help to ensure that any woman with whom they become involved who is – or has been – engaged in egg sharing receives any support she may require.

7) The study raises a number of policy implications. These focus upon the need to further examine the context of egg sharing and donor remuneration. The current study highlights that egg share donors' decision-making is constrained by restricted choice. Hence, they choose to become egg share donors primarily because of financial considerations, combined with the ability to access treatment expeditiously. More specifically, these findings may be relevant to the current review of donor remuneration, including egg sharing, that is underway in the UK, as it demonstrates that financial considerations factor into the motivation, and the decision to become an egg share donor.

8) The study indicates that more generous and uniform provision of NHS-funded ART would expand the range of choices available to involuntarily childless people. This could result in fewer women opting to become involved in egg sharing. However, the reality is that current NHS funding cuts are having a disproportionate impact on the funding for fertility treatments (see pages 198-199) and there is already less generous



NHS provision of fertility treatments than that experienced by the informants in the study. Consequently, assuming that (1) egg sharing is not outlawed as a result of the HFEA donation review and (2) NHS funding for infertility treatment is not reinstated, it is possible that there could be an increased recourse to egg sharing in the future.

### **What this study adds**

The study makes an original contribution to the social science evidence base regarding the motivations of egg share donors and their ability to give informed consent. The research has the potential to contribute evidence that might be of interest to policy makers, specifically, the current review of sperm, egg and embryo donor remuneration policies in the UK.

Additionally, this research extends the empirical studies undertaken by Rapport (2003) and Blyth (2004), and is the first to report on the experiences of identifiable egg share donors in the UK. Informants divulged that prior to donation they understood the implications of what being an identifiable donor meant, and went ahead on the basis of this understanding. However, it became evident that this understanding changed after treatment. That is, the knowledge – or lack of knowledge – of the recipient's treatment creates an invisible interrelationship between the egg share donor and the genetically related other(s), the recipient(s) offspring. Where the donor also has children, a further invisible link is established between the genetically related offspring in each family.

Subsequently, some egg share donors in the study had to acknowledge the existence of a child who may choose to make contact with them in the future. Significantly, the study revealed that some egg share donors used the change in HFEA policy to find out the result of their recipient's treatment. Thus, it appears that egg share donors considered the policy change to be beneficial. However, what is currently unknown is how this information is dealt with, and how the future implications associated with egg sharing might impact on the donor and her family.

### **Providing informed consent**

The primary objective of this research was to assess whether women can consent to share their eggs. As demonstrated, the documented analysis presented in the thesis indicates that women can consent to share their eggs, at a given point in time. However, as I have explained in Chapter Ten (see pages 218-219), further implications of that decision become evident following treatment. Consequently, I have proposed a model of informed consent that better fits the context of the egg sharing arrangement

and which enables egg share donors to make ethical decisions based on having, not necessarily “complete” information, but the best available information at the time. This information should include not only the positive elements, but also ensuring that potential egg share donors are aware of what is currently not known about the longer-term implications of egg sharing, and what may be deemed the more contentious aspects that have been subject to vigorous debate on moral, ethical and psychosocial grounds (see pages 44-49). This will contribute to helping ensure that the consent provided is both valid and informed.

The proposal for reconceptualising informed consent also builds upon the previous limited empirical evidence regarding egg sharing, indicating that egg share donors feel able to make valid choices regarding their decision about, and participation in, an egg sharing arrangement (Blyth & Golding, 2008). For example, Blyth states that all respondents in his study “considered that they had been adequately prepared” (Blyth, 2002, p.158) for egg sharing with regards to counselling and information provision. This finding accords with the studies undertaken by Ahuja et al., (1996; 1997; 2000) and Rapport (2003).

However, as Gorowitz (1988) suggests, the consent process can go wrong in the informing. In the study, some informants indicated that they were given numerous forms about the consent process (see pages 210-211). Hence, the suggestion that more emphasis should be given to providing an opportunity for in-depth discussions of the positive, negative and the unknown elements of egg sharing.

### **Advancing asynchronous e-interview methodology**

The thesis makes an additional claim to originality through use of asynchronous e-mail interviewing to gather qualitative data (Chapter Five). The efficacy of asynchronous e-mail interviewing has been demonstrated previously (Donath, 1999; Illingworth, 2001; Bampton & Cowton, 2002; McAuliffe, 2003; McCoyd & Kerson, 2006). However, in this study it was used for the first time with individuals undergoing fertility treatment, specifically, egg sharing. I further explained that if ethical and rigorous planning is undertaken this method can be used successfully to gather rich, in-depth qualitative data about a sensitive topic.

Additionally, asynchronous e-mail interviewing proved to be an appropriate method for gaining access to a sample population when face-to-face access to participants had proved impossible.

I have also explained that the disadvantages of asynchronous e-mail interviewing can be overcome with planning and some careful consideration. Furthermore, as a method of data collection it enabled rapport to develop with informants. This yielded comments from participants about the benefits of being involved in research using this method of data collection, such as affording them the time to think before conveying their thoughts. Participants also indicated that they experienced it as a cathartic process. As noted earlier (see page 92) the use of e-interviewing initially created a tension with the underpinning philosophy of hermeneutical (interpretive) phenomenology (see pages 61-64). However, as I have demonstrated, it was possible to overcome this tension in order to collect e-interview data. Thus, in advancing e-interviewing methods as a claim to originality, I also advance the use of e-interviews as a research method that works within the underpinning philosophy of hermeneutic phenomenology.

The rationale underpinning this advancement is that hermeneutic phenomenology enables an understanding of a phenomenon to emerge during the interpretive process of data analysis. Significantly, the method of e-interviewing captures the written word during the process of data collection. Thus, it enables the interpretation of the text to take place. Thus, I would suggest that the application of asynchronous e-mail interviewing has both informed and contributed to current understandings within phenomenology.

### **Limitations of the study**

Notwithstanding the original contributions the thesis claims to make, there were a number of limitations to the study. Some of these have been described as the thesis progressed (see page 196). However, others became more apparent as the work drew to its conclusion. These are related to the sample population and the methods utilised in the research.

As the revised study was primarily reliant upon recruiting a self-selecting sample population drawn from two infertility support websites and a charitable organisation, findings are based on the accounts of a small number of women (accounting for less than 1% of the population of egg share donors). Furthermore, women who may not have had regular access to the Internet and these Internet forums may have been excluded from participating. Within resource and time constraints, additional efforts were made to draw the study to the attention of women who may not have had regular access to the Internet and these Internet forums, through distributing a publicity poster to fertility clinics (see pages 107-108).

Nevertheless, the study failed to recruit any women who identified as being in a same sex relationship, and recruited only one single woman – and provided limited information regarding informants' ethnicity. Whether these potential deficits are *actual* limitations or not is open to speculation since there is no information available regarding these demographic characteristics of egg share donors.

While the availability of such information would be advantageous to facilitate more refined research in the future, it should be noted, as indicated in Chapters Ten and Eleven, that the composition of the study group is similar to those in previous studies (Rapport, 2003; Blyth, 2004). Furthermore, the findings presented here are similar to those discussed in the unpublished study by Maggs-Rapport (2001), and the published studies by Rapport (2003) and Blyth (2004). Thus, the research contributes to the limited evidence base about the experiences of egg share donors.

The study specifically provides further evidence that egg sharing is pursued in the absence of alternatives; a decision linked to financial considerations and access to cheaper, quicker treatment, in addition to being able to help someone else. While extrapolation of these findings beyond the study population should be undertaken with caution, I would argue that the proposals regarding reconceptualising informed consent and information provision prior to consent being given (see pages 246-248), are sufficiently well grounded in the evidence to make a new and significant contribution to the limited evidence base about the experiences of egg share donors.

### **Recommendations for future research**

The findings presented in the thesis provide an illustration as to why further research needs to be undertaken with egg share donors. As proposed in Chapter Eleven, there is a need to reconceptualise informed consent based on the findings presented in the thesis (see pages 246-248). This should take place prior to, and following treatment, to critically examine whether opinions about informed consent provision change over time.

This highlights the need for close attention to be given to the well-being of egg share donors as they navigate their life course. This may involve them being either an unmother (who may be aware, or unaware, of their recipient(s) being mothers), or they may be a mother (successful conception and live birth), and also the genetic mother (in some cases) of the relational other; the genetically related offspring (see Chapter

Eleven). There is a need to establish a robust empirical evidence base upon which to explore these complex scenarios. Future studies should focus upon exploring:

1) The long-term psychosocial implications for egg share donors and their families. Specifically, how do egg share donors feel about their involvement in egg sharing, and what impact has it had on their families since their treatment? For example, have relationships been affected by egg sharing? Additional questions that might be asked include, but are not limited to:

a) Do egg share donors explain the nature of their conception to their children?

b) When and how is this information conveyed?

c) Do egg share donors seek support to assist in the sharing of this information? If they do, from where do they seek this support? Is it from other individuals who have experience of egg sharing, patient support groups, or professionals – via face-to-face, telephone or online?

d) What is the impact of egg sharing on their child/children? This is likely to be especially important for children whose mother's donation contributed to the existence of genetically-related half-sibling(s). The research should explore how children feel about this information and the impact that this might have had upon them, when they first found out and as they have grown up.

e) Do egg share donors update the information held by the HFEA about them? This might include current address or any new health issues that have emerged. What are their reasons for providing or not providing this information?

f) What happens to egg share donors, and their families if they are alerted to a request for donor information? How do they contend with this and what decisions do they make regarding possible future contact?

g) What is the impact of contact between donor-conceived people and their donors and the donor's family for all parties?

2) The study has highlighted the need for egg share donors to be asked about their perceptions of egg sharing. This should concentrate upon establishing how they view the donating of their eggs. Do they perceive it as a gift, or would they provide alternative descriptions? This should also explore how they feel about the recipient(s) subsidising their treatment. It was evident that even though financial considerations emerged as a theme in the study, it was not clear whether egg share donors equated subsidised treatment as payment for their eggs, since ascertaining this was not an aim in the study.

3) In the study it appeared that information leaflets and counselling enabled what I have described as dissociation from their eggs. This appeared to make the decision to become an egg share donor easier. Hence, it might be useful to explore egg sharing from the perspective of those working within fertility clinics and who provide information and counselling for egg share donors. This might include clinic counsellors (and egg donation co-ordinators if they are employed in a clinic). The research would provide an indication as to whether there is something discussed in counselling or information provision that influences decision-making.

4) It might prove beneficial to undertake a content analysis of the literature given out by clinics about egg sharing. This would provide an opportunity to determine the extent to which egg sharing is promoted. In particular, whether there is a discourse around the use of language that is used to describe egg sharing.

In conclusion, the work undertaken in the study has revealed what I have interpreted as unanticipated findings. These have led to the recommendations for future research that have been proposed. I would conclude that there is still more to be learned about the experiences of egg share donors. The current study contributes to the existing, but limited, evidence base, and has highlighted the need for this evidence base to be extended further. This should enable a better understanding of, support for, and the provision of information, that supports and informs the potential egg share donor, in the future.

## GLOSSARY

**Basal Body Temperature Checking:** Patients undergoing infertility investigations may be asked to record their temperature. They are given a chart that represents a cycle, this commences from the first day of a period (day 1 of the chart) and continues until the next period begins. They are asked to record their waking temperature this is then used to assess whether there are ovulation problems.

**Blastocyst transfer:** This process involves allowing an embryo to develop for five or six days following fertilisation before it is transferred to the womb. Embryo transfer is usually done after two or three days during a normal cycle of IVF.

**Clomid:** A drug used in stimulated DI and IUI cycles.

**Frozen embryo transfer (FET):** Embryos are thawed and returned to the uterus when the endometrium is at its most receptive.

**Gonadotrophins:** Drugs used to stimulate the ovaries.

**Human chorionic gonadotrophin injection** – is a protein hormone and its presence in maternal blood or urine indicates pregnancy. The hormone is secreted by the chronic villi of the placenta.

**Intra-uterine insemination (IUI):** The process whereby the best quality sperm is selected before being inserted into a woman's womb at her most fertile, around the time she ovulates, when an egg is released from the ovary.

**Intracytoplasmic sperm injection (ICSI):** Is a 'highly specialised variant of IVF' (Braude & Rowell, 2004, p.29). This treatment is used when the quality of the sperm is poor. The treatment involves the selection of the best quality sperm from a sample. A single sperm is then injected directly into the cytoplasm of the egg. It is only mature eggs that are suitable for use in ICSI.

**In vivo:** Fertilisation that is performed in the body.

**Luteinising hormone:** Is the hormone that is released by the pituitary gland. It is produced in response to the production of the Gonadotrophin Releasing Hormone (GnRH). This hormone is essential for the development of sperm and eggs.

**Ovarian hyperstimulation syndrome (OHSS):** OHSS is a potentially dangerous or fatal reaction to the fertility drugs used to stimulate the ovaries to produce more eggs.

**Polycystic Ovarian Syndrome (PCOS):** Polycystic literally means many cysts. It can lead to infertility because ovulation does not occur on a regular basis, without ovulation conception cannot take place. Instead small cysts develop on the ovary (one or both), a polycystic ovary is diagnosed if there are 12 or more cysts which are 2-9mm in size (Balen, Homburg & Franks, 2009). It is a serious condition which can arise from the use of gonadotrophins drugs used to stimulate the ovaries.

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## APPENDICES

## APPENDIX ONE

### Overview of relevant literature

AUTHOR(S) & DATE	SAMPLE	LOCATION	RESULTS
Ahuja, K. K., Simons, E. G., Fiamanya, W., Dalton, M., Annar, N., A, Kirkpatrick, P., Sharp, S., Arian-Schad, M., Seaton, A & Watters, A. J., (1996)	A sample of 55 women who had undergone 73 cycles of treatment that involved either fresh or frozen-thawed embryos were studied to assess donor motivation	UK	Success of egg-sharing is dependent upon shared interests. There also need to be a degree of altruism on behalf of the donors, recipients and treatment centre.
Ahuja K., Mostyn B., & Simons E. (1997)	Self-completion surveys were sent to 750 women who had either participated in egg sharing or were aware of it. Participants were both donors and recipients. A response rate of 227 was achieved, the returned surveys were analysed by the National Opinion Polls Research Group.	UK	The authors concluded that egg sharing is a dignified solution to a medical problem. They suggest that pragmatic altruism underlies egg sharing.
Ahuja K, Simons E, Mostyn B, Bowen-Simpkins P. (1998)	Self-completion surveys were sent to donors who had participated in an egg sharing scheme between 1993 and 1997. Analysis was undertaken on the 114 responses received.	UK	Of those responding to the survey 69% had not achieved a pregnancy, 31% had. They state that women who choose to become donors are well-informed and educated. The authors conclude that egg sharing is an evidence-based treatment that is practised worldwide and it is valued by patients and clinicians. They believe that egg sharing represents a dignified solution to the problems associated with the paucity of donor eggs in the UK.
Ahuja K, Simons E, Rimington M. R., Nair, S., Gill, A., Evbuomwan, I & Bowen-Simpkins, P	37 consecutive donors and 39 recipients who had achieved conception following a cycle of egg sharing. The author's used a	UK	The benefits to be had from the simultaneous treatment of donors and recipients should make it the preferred IVF choice for qualifying couples. Thus meagre NHS funds could be better focused.

(2000)	retrospective analysis of the outcome of egg sharing cycles that produced 103 consecutive births.		
Moomjy, M., Mangieri, R., Beltramone, F., Choist, I., Veeck, L. & Rosenwaks, Z. (2000)	A retrospective analysis of anonymous shared oocyte donation between 1990 and 1999. The authors analysed the 241 donor cycles that were eligible for shared oocyte donation.	USA	The study found that anonymous shared oocyte donation produced high pregnancy rates, rates unachievable when using non-shared donation. Thus they support oocyte sharing as the most efficient use of the precious resource that is the human oocyte.
Kolibianakis, E. M., Tournaye, H., Osmanagaoglu, K., Camus, M., Van Waesberghe, L., Van Steirteghem, A & Devroey, P. (2003)	One hundred and five donor-recipient pairs who had participated in an egg sharing program from 1998-2001 - the study assessed the efficacy of two different policy driven egg sharing programs.	Belgium	The findings demonstrated that decreasing the number of eggs required to proceed with egg sharing to 8 instead of 12 reduced the cycle cancellation rate. The authors surmised that this did not affect adversely, the probability of conception and delivery.
Blyth, E (2002)	Not applicable	UK	This paper provides a comprehensive analysis of the development of egg sharing in the UK. The paper covers all aspects of the legislative and regulatory frameworks. It considers the implications for donors, recipients and those born as a result of egg sharing.
Blyth, E (2004)	Retrospective semi-structured interviews with 20 women and 18 husband/partners who had either proceeded with egg sharing or who had chosen not to.	UK	Limited access to NHS treatment was a key feature of the treatment histories of participants. Several of whom cited financial aspects as the primary motivating factor. The author suggests that if NHS treatment provision were more readily available egg sharing would become less attractive to those seeking affordable treatment.
Rapport, F (2003)	The study used an opportunistic sample of 11 potential egg share donors. Open-ended interviews were conducted with participants to establish their beliefs and experiences regarding potentially	UK	The study revealed six distinct themes related to potentially becoming an egg sharer. These were: motherhood, context, doubt, coping, exchange and empathy. The findings suggested that there was a need for more empirical investigations to be undertaken by independent researchers to gain a clearer

	becoming egg share donors		understanding of women's responses to reproductive technologies.
Thum, M., Gafar A., Wren M., Faris, R., Ogunyemi, B., Korea, L., Scott, L & Abdalla, H. I. (2003)	This study undertook an evaluation of 192 egg sharers and 274 recipient cycles and 1098 cycles of non-egg sharing patients. The study was undertaken to assess the efficacy of egg sharing in terms of live birth rates in comparison to non egg sharing birth rates	UK	Egg sharing does not compromise the achievement of a pregnancy for either donor or recipient. There is no imbalance of egg allocation in evidence, nor is there a higher incidence of OHSS amongst egg sharers.
Simons, E. G. and Ahuja, K.K. (2005)	This paper provides a number of arguments regarding the efficacy of egg sharing.	UK	The authors believe that egg sharing is an evidence based solution that can overcome the paucity of donor eggs in the UK.

## **APPENDIX TWO**

### **Egg sharing for research**

A recent variant of egg sharing that has emerged in the UK is 'egg sharing for research'. A team of scientists at Newcastle University in North East England, who are members of the North East England Stem Cell Institute (NEESCI), were given the go-ahead by the HFEA in 2006 to promote the scheme (Newcastle University Press Office (NUPO), 2006). The scheme allows patients undergoing IVF to share their eggs with the team for research in exchange for subsidised treatment; the costs being offset by NEESCI. The team believes that women will benefit from the ability to access treatment which they might otherwise be unable to afford. They acknowledge the fact that it is essential that women are not coerced or influenced to share because of financial inducements. Thus the scientists in question are aware of the complex moral and ethical arguments surrounding egg sharing for subsidised IVF, yet they still sought a license for their scheme (NUPO, 2006). However, the notion of getting women to donate their 'spare' eggs for research may be a questionable practice. For example, it might be that these eggs would possibly not be spare if women could either afford to fund their own treatment, or if they chose to store them for future use (Roberts & Throsby, 2008).

### **Egg sharing for 'social' reasons**

Rates of delayed parenting have increased significantly over the last few years in the UK, resulting in a rise in the age at which women are becoming parents (HFEA, 2007). The Office for National Statistics (ONS) (2008a) reported the fastest increase in women giving birth aged 40 or over during the period 2005-2006 (ONS, 2008b). A theme reflected in women aged 35-39 (this group has also seen an almost systematic year on year increase in the number of births), and reflected in all Western European countries (Davies, 2006).

Crucially, as women age, their fertility declines naturally, thus reducing the chance of natural conception. Furthermore, as egg quality diminishes with age, a resultant factor may be that poorer egg quality may contribute to genetic disorders (Bongaarts, 1982; Craft, no date; Davies, 2006; Atalla, 2008). However, there is now a 'practical', but questionable, 'opt out' strategy available to women who choose to delay parenthood; they can opt to 'freeze and share'. The new scheme, available in the UK since October 2008, is marketed as an opportunity for women to have their eggs frozen for 'social' reasons, for free, if they agree to share their eggs with an unknown recipient (Davies, 2006; Taylor, 2007; Atalla, 2008; Templeton, 2008). This option could save women around £5000, the average cost of a five-year storage of frozen eggs (Atalla, 2008; Templeton, 2008).

The scheme was developed in an attempt to fulfil two major objectives; to redress the paucity of donor eggs in the UK which may not be achieved by 'traditional' egg sharing, and to offer women the opportunity to further delay parenting for 'medical, social and career-linked reasons' (Atalla, 2008, paragraph 14). Historically egg freezing had only been available to women being treated for cancer, who had reached an early menopause or those who on religious or ethical grounds would not permit the freezing of surplus embryos (Davies, 2006; Horsey, 2007).

The justification given for offering this option is that more women are delaying motherhood, largely because of the social structure of modern societies; women are either pursuing a career, or waiting longer to find a partner with whom to have children,

but their fertility is decreasing (Taylor, 2007; Atalla, 2008). However, in stark contrast to the UK, in the USA it has been stated that this form of treatment should not be offered to women for social reasons (Fritz, 2007 cited in Horsey, 2007, paragraph 2). Furthermore, allowing women to opt to delay parenting, by freezing their eggs, may lull them into a false sense of security about their ability to procreate.

Receiving free egg freezing might motivate women to pursue this option, an option they may not previously have considered. Pregnancy outcomes may also have a bearing on the arrangement, as no guarantee can be given that their eggs will be viable in the future. Additionally, the outcome for the potential children conceived through this arrangement merits consideration. It could transpire that the recipient of the eggs is successful – the result being the birth of child(ren) genetically-related to the donor. The donor, through no fault of her own, may end up childless. Presumably, the donor would be able to obtain information regarding the outcome of the recipient's treatment, however, if successful, the resultant information may cause psychological distress. There will also be the need to deal with the knowledge that a child, born as a direct result of this scheme, may choose to seek them out in years to come. As Parsons comments:

Vulnerable women as they approach their mid-30s are being encouraged to put their faith in a storage technique with as yet unproven efficacy in the hands of a clinic offering to exchange storage for eggs to donate to other women. These women may then delay childbearing, become infertile, not conceive with their own stored eggs and know that a woman or women conceived with the fresh eggs they donated some years previously.  
(Parsons, 2008, paragraph 4)

This scheme may well bring to the fore various other ethical issues regarding, for example, the welfare of the child but these aspects are not the focus of the current study. What such developments illustrate, however, is how rapid technological advancements continue to impact society and this area of study.

## **APPENDIX THREE**

### **Prompts for interviews**

#### STANDARD PROMPT TO BE USED AT THE END OF EACH STAGE

Before I move on I just want to check that you are okay with the process so far.

Do you have any questions for me before we move on to the next section?

#### ADDITIONAL PROMPTS

- Are you able to expand?
- Is there anything else that you would like to add?
- Why do you think that was the case?
- How did that make you feel?



## **APPENDIX FOUR**

### **E-interview protocols**

#### Interview Guidelines

Whilst undertaking the email interview please pay particular attention to the following guidelines:

- 1) You will be asked 25 main interview questions, which will be sent to you in five separate sections.
- 2) Depending on your answers, these questions may be followed up by me with some supplementary questions.
- 3) This process of question and answer will develop into an online dialogue until we have finished the interview.
- 4) Please reply to each question at the top of the screen. This will keep the questions and answers in sequence.
- 5) Please do not delete any of our email correspondence. It comprises our record of conversation to which we can refer back if necessary.
- 6) Wherever possible, please send your answers to my questions within three working days of receipt. I will try and reply within the same timescale.
- 7) If we work to this timescale the interview should normally be completed within five weeks. However more or less time may be needed. This is not a problem to me, as long as you are happy that the speed at which we are progressing meets with your approval
- 8) Once the email interview has been completed, I will ask you to authenticate your account.
- 9) I will contact you by email a week after we have finished the email interview to check how you are following our correspondence and whether you have any further questions about the interview.
- 10) I may contact you by email in the future to follow up your interview or to let you know of any publications that have been written as a result of your and others' participation in this project.

Having read these guidelines and the information sheet, if you are still willing to take part in this project, please complete the consent form and return it as an attachment with a reply to this email within 24 hours.

***Thank you***

## **Prompts for e-interviews**

### STANDARD PROMPT USED AT THE END OF EACH STAGE

Before I move on I just want to check that you are okay with the process so far.

Do you have any questions for me before we move on to the next section?

### ADDITIONAL PROMPTS

- If yes - What was their response?
- What impact do you think your decision has had on other family members?
- What were their views?
- Has this affected any family members?
  
- If no – How did you come to this decision?

## **APPENDIX FIVE**

### **Website information**

#### **Can women consent to share their eggs?**

Have you been an egg share donor at any time during the last five years? If the answer is yes then please read on - your help is needed.

My name is Berenice Golding and I am a PhD research student based at the University of Huddersfield. I am interested in finding out about women's experiences of being egg share donors. If you would be willing to share your experiences with me, then I would like to interview you.

The interview would be conducted by email correspondence and the process would last no longer than the time you need to answer the questions I would like to ask you about your experiences. All the information you share with me will remain confidential. If you are interested in finding out more about this project please contact me for further information at: [egg\\_share@hud.ac.uk](mailto:egg_share@hud.ac.uk)

## **APPENDIX SIX**

### **Study information**

Interview Schedule

#### **Project Introduction**

First of all I would like to thank you again for agreeing to take part in this project by allowing me to interview you by email.

Before we start the interview process I would just like to go through the details of this project.

My name is Berenice and I am a research student from the University of Huddersfield. The focus of my project is to look at the experiences of women who have donated eggs as part of an 'egg sharing' arrangement. The areas I want to explore focus upon you choosing to become an egg donor, the decision-making process and your understanding of informed consent.

To start with I will ask some general questions about you before moving on to find out in more detail about your experiences of 'egg sharing'.

At this point I want to remind you that your participation in this interview is entirely voluntary, you do not have to go ahead with the interview if you have changed your mind. If you still wish to participate can I remind you that you are free to withdraw from the project at any time. If you decide you want to withdraw from the study I would be grateful if you could inform me of your decision by email.

I also want to assure you that I am totally independent of the support group that you are a member of and that no information which you share with me will affect your membership of the support group.

As you are aware, you have agreed that this interview will be conducted by email. Can I again reassure you that all the information you share with me will remain confidential. Your anonymity will also be protected by the use of a pseudonym.

The data collected from all the email interviews will be used to help me complete my PhD thesis. The data may also be included in any journal articles or conference papers that are written as a direct result of this project. May I assure you again that no identifying information will be used in any of these documents.

The transcript from the email interview will be stored securely at the University of Huddersfield. This will be destroyed after a period of ten years has passed.

As the interview is being conducted by email you have a copy of our email conversation. If at any time during or after the interview has finished there is anything you want to add or change please let me know so that my copy is up to date.

I am also happy to send you copies of any journal articles that I write which include any of the information generated as a result of your being interviewed. If you would like me to do this please confirm this by email.

Last and by no means least, I am conscious of the fact that we are dealing with a time in your life which you may have found very emotional. If at any time you feel unable to answer a question or should you decide that you do not wish to provide any additional comments please stop me at that point. You are also free to stop the interview at any time should you choose not to continue.

After I have asked my questions you will have an opportunity to ask me any questions you may have.

Before I start is there anything you'd like to say or ask?

## **APPENDIX SEVEN**

### **Survey questions**

#### **Study Introduction**

First of all I would like to thank you for agreeing to take part in this study by taking the time to complete this questionnaire.

My name is Berenice Golding and I am a research student from the University of Huddersfield. The focus of my project is on the experiences of women who have donated eggs as part of an 'egg sharing' arrangement. The areas I want to explore focus upon your choosing to become an egg donor, the decision-making process you went through and your understanding of informed consent.

To start with I will ask some general questions about you before moving on to find out in more detail about your experiences of 'egg sharing'.

At this point I want to remind you that your participation in this interview is entirely voluntary, you do not have to go ahead with completing the questionnaire if you have changed your mind. However, if you still wish to participate, which I hope you do, please remember that you are free to withdraw from the project at any time.

No identifying information will be collected from you at any time, your anonymity is therefore ensured. However, anonymised quotations from your answers may be used in the writing up of my thesis and any publications that arise as a direct result of this project.

All data collected will remain confidential and will be used for research purposes only. This is in accordance with the regulations set out by the University of Huddersfield, details of which can be found at: [http://www.hud.ac.uk/sec/data\\_protection.html](http://www.hud.ac.uk/sec/data_protection.html)

Your consent to participate in the study will be assumed by your completing and submitting your responses to this questionnaire.

I would also like to assure you that I am totally independent of the support group of which you are a member and that no information which you share with me will affect your membership of the support group.

If you experience any problems completing the questionnaire electronically you may request a hard copy from me. I can be contacted via email at: [egg\\_share@hud.ac.uk](mailto:egg_share@hud.ac.uk)  
The questionnaire will take about twenty minutes to complete.

## SECTION ONE

This section is designed to find out about you and your fertility history. It will not ask you for any identifying information.

### About you:

1. How old are you?

---

2. How would you describe your ethnic background?

- |                        |                          |
|------------------------|--------------------------|
| White                  | <input type="checkbox"/> |
| African Caribbean      | <input type="checkbox"/> |
| Indian                 | <input type="checkbox"/> |
| South Asian            | <input type="checkbox"/> |
| Mixed Race             | <input type="checkbox"/> |
| Chinese                | <input type="checkbox"/> |
| Other (please specify) | <input type="checkbox"/> |
- 

3. What area are you from? e.g. London, Manchester, county

Please specify

---

4. Are you?

- |                            |                          |
|----------------------------|--------------------------|
| Single                     | <input type="checkbox"/> |
| Married                    | <input type="checkbox"/> |
| Divorced                   | <input type="checkbox"/> |
| Cohabiting                 | <input type="checkbox"/> |
| In a same sex relationship | <input type="checkbox"/> |

5. What is your highest level of qualification? e.g. GCE/CSE; A level; undergraduate degree etc

Please state

---

6. When did you first think that you might have fertility problems?

- |                       |                          |
|-----------------------|--------------------------|
| One year ago          | <input type="checkbox"/> |
| Two years ago         | <input type="checkbox"/> |
| Three years ago       | <input type="checkbox"/> |
| Four years ago        | <input type="checkbox"/> |
| More than 5 years ago | <input type="checkbox"/> |

If more than 5 years ago, please state the number of years

---

7. When did you start fertility treatment?

Yes

No

Other, please explain

## SECTION TWO

This section will ask you questions about the IVF treatment(s) you have had.

### About your treatment(s)

8. Did you receive National Health Service (NHS) treatment?

Yes

No

If no, please explain why

---

---

---

---

9. If you received NHS treatment how many cycles did you get?

One

Two

Three

Other, please explain

10. Which treatment(s) did you try before egg-sharing? Tick all that apply

In Vitro Fertilisation (IVF)

Intra-Cytoplasmic Sperm Injection (ICSI)

Intrauterine Insemination (IUI)

Pre-implantation genetic diagnosis (PGD)

Pre-implantation genetic screening (PGS)

Gamete Intra-Fallopian Transfer (GIFT)

Zygote Intra-Fallopian Transfer (ZIFT)

Donor insemination

Egg donation

Embryo donation

Surrogacy



Other, please state

---

### SECTION THREE

**This section focuses upon your decision to becoming an egg-share donor.**

#### **About your decision to become an egg-share donor**

11. How did you hear about egg-sharing? Tick all that apply

- NHS clinic
- Private clinic
- Magazine article
- Advertisement
- Internet search
- Friends
- Family
- Internet support group
- Leaflet
- Other, please explain

12. What were your initial feelings about egg-sharing? Please explain in as much detail as you like;

---

13. Can you tell me why you decided to become an egg-sharer? Tick all that apply

- It seemed like a good idea
- I (we) could no longer afford to fund own treatment
- I (we) wanted to be able to help someone in a similar position
- Other, please explain

---

14. What factor(s) helped you to make your decision? Tick all that apply

- Husband
- Partner
- Own decision
- Family
- Friends
- Counselling
- Clinic information
- Other, please explain

15. What information about egg-sharing do you remember getting?

- Leaflets
- Verbal information i.e. counselling
- Egg-share donor stories
- Other, please explain
- 

16. Did this help you to make your decision?

Yes

No

Please explain in as much detail as you like:

---

#### **SECTION FOUR**

**This section will focus on your personal experiences of egg-sharing as a donor.**

#### **Your experience(s) of egg-sharing**

17. How many times have you been an egg-sharer?

- One
- Two
- Three
- Other, please state
- 

18. Has your own treatment been successful?

- Yes
- No
- Other, please explain in as much detail as you like
- 

If you answered NO to this question please move on to question 21. If you answered YES please continue.

**19. Can you tell me in what year(s) your treatment was successful?**

---

20. Was your treatment successful on your first attempt?

Yes

No

If you answered NO please would you state on which attempt your treatment was successful.

---

21. Did you find out the recipient(s) results?

Yes

No

Still waiting to find out

Not ready to find out yet

Other, please explain in as much detail as you like

---

If you answered YES to this question please answer the next question. If you chose ANY other answer please move on to question 23.

22. Do you feel able to explain how this information made you feel?

---

## SECTION FIVE

**This is the final section of this study. It focuses upon the consent process and donor anonymity.**

### About the consent process

23. How was the consent process explained to you? Tick all that apply

In great detail

Not much detail

In very technical language

In a way that was easy to understand

Other, please explain

24. Who explained the consent process to you?

- Clinic counsellor
  - Fertility specialist/consultant
  - Egg-share co-ordinator
  - Fertility nurse
  - Other, please explain
- 

25. Did you fully understand what you were giving consent to?

- Yes
  - No
  - Not really but didn't want to admit it
  - Other, please explain
- 

26. Was donor anonymity discussed with you?

- Yes
  - No
  - Other, please explain
- 

27. Did having the consent process explained help/hinder your decision to become an egg-share donor?

- Helped a little
  - Helped a lot
  - No help at all
  - Hindered my decision
  - Don't know
  - Please explain your answer
- 

28. Did the discussion regarding donor anonymity help/hinder your decision?

- Helped a lot
  - No help at all
  - Hindered my decision
  - Other, please state
-

## **SECTION SIX**

### **End of study information**

Thank you for taking the time to be part of this study by allowing completing my survey, your responses are valued.

As mentioned at the beginning of the study, your responses will be used for research purposes only. No identifying data will be used. However, anonymised quotations from your responses may be used in the writing up of the research and any publications that arise as a direct result of this project.

I realise that the subject matter may have raised various emotions for you and again I would like to thank you for sharing your experiences with me.

Should you have any concerns following your involvement in this study and wish to speak to me, I can be contacted by email at: [egg\\_share@hud.ac.uk](mailto:egg_share@hud.ac.uk).

If, after completing my survey, you would be willing to be interviewed in more depth on the above issues, by telephone, e-mail or face-to-face, please email me at the above address or you can telephone me on 01484

Finally I would like to take this opportunity to thank you once more for taking the time to complete this survey. Your help is really appreciated.

## **APPENDIX EIGHT**

**Recruitment poster**

# Have you been an egg share donor at anytime during the last five years?

If the answer is YES, please read on - your help is needed

I am a PhD research student from the University of Huddersfield. I am interested in finding out about women's experiences of being an egg share donor.

Would you be willing to share your experiences with me?



If you would be willing to share your experiences with me, then I would like to hear from you.

If you are interested in finding out more about this project please contact Berenice for further information at: [egg\\_share@hud.ac.uk](mailto:egg_share@hud.ac.uk) or telephone me on: 01484 473845.

I also have a survey which you may prefer to complete. It can be found at the following link;

<http://www.survey.bris.ac.uk/hud/egg-sharing>

All the information you share with me will remain confidential

University of Huddersfield

## APPENDIX NINE

### Ethics application documentation

#### 9.1 Pro forma ethics application

**Aim / objectives:** This project is to be undertaken as part of an ESRC-funded PhD studentship. The overall aim of the proposed project is to investigate egg share donors' understanding of informed consent within the context of their decision to participate in an egg sharing arrangement. The project will investigate egg share donors' assessments of their ability to make an informed choice, their awareness and understanding of the constraints within which their decisions may be made, the factors that impact on their decision-making and the range of alternative options that may be available to them. More generally, the proposed project will contribute to the existing social science research base concerning egg sharing in the UK, which is limited to the work conducted by Blyth (2002, 2004) and Rapport (2003). The specific aims of this project are therefore to:

- Provide a narrative of the views and experiences of women who have become egg share donors as a way of resolving involuntary childlessness;
- Consider their understandings of egg sharing and the implications this may have for them and other members of their family;
- Investigate and comment upon the decision-making processes;
  - What factors contribute to participants' decisions to become egg share donors?
  - What are their perceptions and understandings of informed consent?

**Brief overview of research methodology:** A prospective study is planned. Qualitative data will be generated by means of semi-structured interviews with approximately 20 women who have agreed to participate in an egg sharing programme. It is envisaged that the principal method of enquiry will be qualitative in orientation, adopting a relational ontological position (Brown & Gilligan, 1992; Gilligan, 1982, 1988). Here there is an acceptance that women who make decisions with regard to egg sharing, are possibly involved in a complex web of social relations that are both intimate and also form part of their larger social interactions (Gilligan, 1982). Consequently, their decision-making has to be understood not only in terms of the individual and the internal psychological decision making processes, but also from within notions of being 'in relation' to and part of much wider mediating factors.

**Permissions for study:** Permission to access patients has been given by the medical director of one London Women's Clinic. This clinic pioneered egg sharing and is also one of the largest providers of egg sharing in the United Kingdom. It is the London Women's Clinic.

A letter detailing the intended project including the research proposal will be sent to the clinic. Formal written confirmation of the clinics agreement to allow me to recruit participants from patients at their clinic patients will be obtained.

**Access to participants:** Research participants will be recruited via the London Women's Clinic. The identification of those suitable for inclusion in this study will be



undertaken by distributing a leaflet at the clinic (see attached project information leaflet).

**Confidentiality:** Participants' right to confidentiality will be maintained throughout the project. All data collected as a result of this project will be treated with the strictest of confidence. All elements of the study will be conducted to ensure compliance with data protection legislation and the University of Huddersfield's requirements relating to secure data storage

Prior to data collection commencing participants will be reminded and reassured that all data collected as a result of their participation will be treated as confidential. They will also be informed that no identifying data including their name, address etc. will be shared with a third party.

Assurance will be given that the person employed to undertake the transcription of the data will adhere to the confidentiality and data protection regulations set out by the University. They will also be informed that the person who undertakes the transcription will be required to sign a further agreement related to confidentiality specifically for this project. A copy of this will be available to any participant wishing to see it.

Participants will be asked to sign a consent form prior to the interview. This makes explicit reference to arrangements for maintaining participants' confidentiality (please see attached consent form).

Interview tapes, transcriptions and consent forms will be stored in a locked cabinet on the University of Huddersfield premises in a location that has restricted access. All computerised data will be password protected.

All data generated will be assigned a pseudonym and a corresponding number will be assigned to the recorded material. All data and ensuing analysis will conform to the conditions set out by the 1998 Data Protection Act, the Data Protection Policy issued by the University of Huddersfield and also the guidance notes issued by the University of Huddersfield for researchers.

**Anonymity:** The researcher will have the names and contact details of the individuals who have agreed to take part in this project. These will be stored securely as outlined in "Confidentiality" above. However, no individual will be identifiable in any of the documentation that is written or published from this research. The anonymity of participants will be ensured in all matters relating to the study. This reference to the respect for anonymity will be incorporated into all documentation provided to prospective participants (see attached documentation – consent form, information leaflet).

**Psychological support for participants:** Ensuring the well-being of participants is a priority due to the sensitive nature of the proposed study. However, it is unlikely that the research interviews will explore issues with participants that have not already been covered during counselling sessions at the assisted conception unit and are not considered likely to generate further issues for participants.

Centres that provide fertility treatment have an obligation to make available counselling services and to continue to offer such services after treatment has been given (Human Fertilisation and Embryology Act 1990) relating to the provision of information for those undergoing assisted reproduction treatment.

Nevertheless, should it become apparent that additional sources of support are required the British Infertility Counselling Association offers a nationwide independent counselling service. In the event that participation in the project renders such counselling necessary, funding has been allocated to enable any independent counselling to be provided at no cost to the participant.

**Researcher safety/support:** Every effort will be made to ensure the safety of the researcher at all times, especially during the fieldwork phase of this project. The researcher has identified potential risks and the procedures that can be employed to minimise these risks.

**Conflicts of interest:** There are no conflicts of interest that need to be reported.

**Consent form:** Participants will be asked to read and sign a consent form when they agree to participate in this study. The researcher is aware that obtaining consent is not a one off event and that it may become necessary later in the project to check that participants still consent to the use of non-identifying data to be used in the writing of the thesis and any published work. It also lets participants know that they can have copies of the transcripts.

**Interview schedule:** This project is dealing with a sensitive and emotive issue: that of involuntary childlessness. The drafting of the interview has taken this fact into account so as not to cause unnecessary distress to participants. Participants will be reminded at the beginning of the interview that if there are any questions they feel unable to answer they have a right to decline to answer.

**Dissemination:** It is envisaged that the dissemination of the findings from this study will be undertaken in the following ways: 1 completed PhD, 1 international refereed conference paper, 2 papers for international peer reviewed journals, Conference Papers, Poster Presentations, University/School conferences for PhD student presentations. Papers will be made available to research participants.

**Other issues:** Transcription of the data by a third party. It is envisaged that a transcriber may be employed to transcribe the raw data generated from the interviews undertaken. This is necessary because the researcher has a condition which affects manual dexterity. Funding for this has been provided for this via the ESRC as part of the needs assessment undertaken through Disability Support Services at the University. In the event that this resource is to be used a member of University staff will be allocated after liaison with the university's Disability Support team. In keeping with the regulations of the University regarding confidentiality and data protection the person appointed as transcriber will be required to sign an additional confidentiality agreement which relates directly to the research project (please see attached confidentiality agreement).

## 9.2 Risk analysis form

THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT

ACTIVITY: PhD Research – Can women consent to share their eggs?			Name: Berenice Golding	
LOCATION: Various throughout the country			Date: Various	Review Date:
Hazard(s) Identified	Details of Risk(s)	People at Risk	Risk management measures	Other comments
<ul style="list-style-type: none"> <li>• Disclosure of whereabouts.</li> <li>• Visiting unfamiliar areas.</li> <li>• Visiting potentially problematic areas.</li> <li>• Unreliable public transport.</li> </ul>	<p>People not knowing where I am whilst undertaking fieldwork.</p> <ul style="list-style-type: none"> <li>• Getting lost.</li> </ul> <p>A potentially vulnerable female in an unfamiliar area alone.</p>	<p>Researcher</p> <p>Researcher</p> <p>Researcher &amp; Participants</p> <p>Researcher</p>	<ul style="list-style-type: none"> <li>• Telephone contact will be made with partner/supervisor which will confirm safe arrival and departure from the interview</li> <li>• Maps of the area being visited will be carried at all times.</li> <li>• Local taxi firm numbers will be stored in mobile phone and a hard copy will also be carried.</li> <li>• Arrange not to visit unfamiliar places in the evening wherever possible.</li> <li>• Use a chaperone if necessary but only to the outer vicinity of the address being visited.</li> <li>• Invest in a personal safety alarm</li> </ul>	<ul style="list-style-type: none"> <li>• The phone numbers of those people the researcher needs to contact will be stored in mobile phone memory. They will also be carried as hard copies.</li> <li>• Sufficient change will be carried in the event that there is a need to use a public telephone.</li> <li>• Will ensure that main routes to and from locations are used.</li> <li>• These will be used in the event that it is hard to locate the place that is being visited. Wherever possible ensure that prospective participants are happy to</li> </ul>

	<p>Missing connections home/failure in public transport to arrive.</p>		<p>Phone numbers of all alternative modes of transport in the area being visited will be carried on person and stored in mobile phone.</p>	<p>be interviewed during daylight hours or at weekends.</p> <ul style="list-style-type: none"><li>• If it is deemed necessary to use a chaperone participants will be informed.</li><li>• Ensure that the chaperone is aware that following the researcher is a serious breach of confidentiality and anonymity towards the participants.</li><li>• This will be carried at all times when undertaking fieldwork.</li><li>• Work out back up plans in advance of travel.</li><li>• Ensure sufficient money is being carried to cover any unanticipated travel costs.</li></ul>
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### 9.3 Letter seeking collaboration



Miss Berenice Golding  
School of Human and Health Sciences  
Central Services Building 14/04  
Queensgate  
Huddersfield  
HD1 3DH

01484 (47) 3845  
b.golding@hud.ac.uk  
2008

#### **Can women consent to share their eggs? A PhD Research Project**

Dear

My name is Berenice Golding and I am a PhD student based at the University of Huddersfield. I am currently undertaking a research project that is being funded by the Economic and Social Research Council. This project is being supervised by Prof. E Blyth, Dr. J Hargreaves and Dr. H Masson.

The project will seek to elicit the views of women who have been involved in 'egg sharing' as a donor. The main aims of the project are to explore and report on the views of women in relation to the decision-making process, their motivations to become an egg donor and their understanding of informed consent. I enclose a copy of the research proposal which outlines all the stages of the project.

The reason for writing to you today is to ask for your assistance with this project.

As a leading clinic offering 'egg sharing' it is hoped that you would be willing to collaborate in this project by facilitating the recruitment of potential participants who have chosen to become an 'egg share' donor via your clinic. This access to potential participants would in no way impact on the services you offer, nor will it require access to any confidential patient information held by you.

What I am proposing as a means of recruiting participants is for leaflets detailing the project to be forwarded to patients who you consider may be eligible for inclusion in the project. The leaflet asks for prospective volunteers for the project to make contact with me. It also explains in detail the aims of the project and how it will be conducted. This means that potential participants would need to be told in clinic that you are collaborating with this project. It would then also be necessary for information about the project to be forwarded to them at later date. The information for potential participants includes a letter of invitation, a leaflet explaining the project, a reply slip and a pre-paid self-addressed envelope. This will all be provided to you in pre-paid

envelopes which can then be forwarded to potential participants. They would also need to be assured that at this stage that I do not know their identity and that it is entirely up to them whether they wish to make contact with me in the future.

I am more than willing to discuss the project in greater detail with you should you request it. I am also happy for you to see in advance copies of all the information I referred to earlier.

I await your correspondence on this matter in the hope that you are able to assist with the recruitment of potential participants.

Yours sincerely

Berenice Golding BSc (Hons) PGCE MSc  
Enc.

## 9.4 Research proposal for clinics

### Background

Fertility problems affect many couples nationally in the United Kingdom and it is estimated that these affect about “one in seven couples” (HFEA, 2006a). In some cases there may be no obvious cause, however, for others, the cause of the problems may be established through investigation. Nevertheless, whether or not there is a definitive diagnosis, for the many couples who find themselves in this situation they face the prospect of remaining childless. There is, however, an option, the use of reproductive technologies that have been made possible due to technological advancements. Nowadays, access to third party assisted conception treatments (Blyth & Landau, 2004) is also an option. These types of treatments involve the use of donated sperm, eggs or embryos.

The Human and Fertilisation and Embryology Authority (HFEA, 2006b, p.1) suggests that “the donation of sperm, eggs or embryos to help a couple have a child is one of the most generous gifts anyone can give”. The focus of this project is to examine one particular form of third party assisted conception treatments which is known as “egg sharing”, which is when a woman who is herself undergoing assisted conception procedures “shares” her eggs with one or more recipients requiring donor eggs, primarily in exchange for receipt of lower-cost treatment that is subsidized by the recipient. It also allows treatment to be accessed more expeditiously. It was developed and promoted in the early 1990s by Simons and Ahuja (2005) primarily, due to the fact that “payment in kind” to donors is not prohibited in the United Kingdom.

Egg sharing is offered by an increasing number of centres in the UK; by 2005, 43 UK licensed treatment centres were offering egg sharing (HFEA, 2005a). This figure had risen to 47 by 2007 (HFEA, 2007). It is estimated that over 2,000 children have been born to both donors and recipients in the UK as a direct result of egg sharing (Simons and Ahuja, 2005). Furthermore, egg sharing provides the biggest source of donor eggs in the UK – approximately two thirds of the UK total (HFEA, 2005b).

The attraction of egg sharing for the potential donor who is eligible for National Health Service (NHS) treatment is that lengthy NHS waiting lists can be avoided, while the attraction for the potential donor who is not eligible for NHS treatment is that treatment can be accessed much more cheaply. While much of the debate on egg sharing has focused on financial incentives, the fact that women are able to access treatment more expeditiously, given that female fertility declines markedly from the mid-30s (Bongaarts, 1982) and then more rapidly after the age of 40 (Craft, no date) may also be a significant motivating factor.

With regard to donor eggs it is widely recognised that the demand for them from women with fertility impairments far exceeds the supply (Groskop, 2007). This imbalance has been especially acute in countries, such as the UK, where overt payment to donors is prohibited, and is considered by many to have been exacerbated – at least in the short term – by the requirement that donors recruited after April 2005 must be willing to disclose their identity to any child conceived using their eggs who has reached the age of 18. This legislative change means that any child conceived using donated eggs, sperm or embryos has the right to access greater personal information about the donor including their home address (HFEA, 2004). It was believed by some that the abolition of donor anonymity would lead to a dramatic decrease in the number of donors (Pennings, 2005). In terms of egg sharing it was predicted that this effect would lead to a breakdown of egg sharing programmes (Serhal cited in Henderson, 2004). However, as yet there is no conclusive evidence to suggest that this is the case (Blyth & Frith, 2008).

Nevertheless, while advocates champion egg sharing as a “win-win” arrangement, in which both the egg share donor and the recipient are able to access fertility treatment that they would otherwise be unlikely to receive, the practice has not been accepted without question. In particular, concerns regarding the ability of prospective egg share donors to give informed consent if their only other option is no treatment at all due to financial pressures has been noted (Blyth, 2002; English, 2005; Johnson, 1999; Lieberman, 2005).

Informed consent for the purpose of this project is defined as “an autonomous authorization of a medical intervention” (Beauchamp & Childress, 2001, p.78) that is made once the individual(s) “have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision...” (World Medical Organisation, 1996).

In relation to egg sharing some critics consider that it is an unethical type of treatment because they do not believe it is possible for women to give informed consent (English, 2005; Johnson, 1999; Lieberman, 2005). This view is discussed by English (2005) who believes that the validity of a woman’s consent is questionable in instances where a woman who is childless may feel induced to donate eggs if she is financially restricted and therefore cannot afford treatment. This in turn may affect the capacity to give consent voluntarily without any pressure, which potentially affects the validity of the consent obtained. The notions being posited by these critics is that consent and the ability to give it freely may be affected because elements of implicit coercion may exist. In this instance it is thought that subsidised and speedier access to treatment may factor into the decision-making process.

In contrast, however, supporters of women’s ability to consent believe that “access to counselling and informed consent are pivotal, and provided these are available, it cannot be argued that women of reproductive age and their partners are incapable of making rational and informed decisions” (Ahuja et al., 1996, p. 1127). This view is discussed later by Simons & Ahuja who state that criticisms of egg-sharing are not supported by evidence. They go on to state that “the suspected dilution of women’s consent due to subsidized or free IVF has been vigorously examined” (Simons & Ahuja, 2005, p.113). These views suggest that the negative and ethical debate surrounding the ability to give informed consent is not warranted. This is why this area merits more detailed examination, in particular, through ascertaining the views and experiences of egg share donors themselves about informed consent, the focus of this proposed study.

Obtaining consent is a requirement stipulated by the Human Fertilisation and Embryology Authority who say that this must be obtained before proceeding with the egg sharing arrangement (HFEA, 2000) but the ability to give consent in general is complex. It has been mooted that “the complexity of informed consent hangs on the fact that it can go wrong either in the informing or in the consenting” (Gorovitz cited in Bromham, 1988 p.230) though, in this instance and because of the HFEA’s guidelines, it is evident that they do not consider the obtaining of consent from an egg share donor to be unachievable. However, without seeking the views of egg share donors the debate will continue as to the questionable nature of egg sharing. Is it really a questionable practice or is it a treatment option that gives donors hope of overcoming childlessness whilst altruistically helping another childless couple? These questions cannot be answered without seeking to find out the experiences of egg share donors. This will allow the ‘real voices’ of those involved in ‘egg sharing’, the donors’ voices, to be heard. This should then contribute positively to the debate through the presentation of findings that are based on the lived experiences of women involved in ‘egg sharing’.



It should then also help to assuage some of the debates regarding the giving of informed consent within the context of an egg sharing arrangement.

**Research Questions:** The project will investigate egg share donors' assessments of their ability to make an informed choice, their awareness and understanding of the constraints within which their decisions may be made, the factors that impact on their decision-making and the range of alternative options that may be available to them. More generally the proposed project will contribute to the existing social science research base concerning egg sharing in the UK, which is limited to the work by Blyth (2002; 2004) and Rapport (2003). Taking all these factors into account this project aims to answer the following questions:

What are the views and experiences of women who have become egg share donors towards involuntary childlessness?

Did they consider all the available options before deciding to become an egg share donor?

What is their understanding of egg sharing and the implications for them?

What implications has their decision had on other members of their family?

Why did they decide to become an egg share donor?

What are their perceptions and understanding of informed consent?

**Methods:** A prospective study is planned. Qualitative data will be generated by means of semi-structured interviews with approximately 20 women who have agreed to participate in an egg sharing programme. Only one interview per participant will be conducted and this will last for approximately one hour. Research participants will be recruited via an assisted conception unit offering an egg sharing programme.

It is envisaged that the principal method of enquiry will be qualitative in orientation adopting a relational ontological position (see for example Brown & Gilligan, 1992; Gilligan, 1982, Gilligan, 1988; Mauthner & Doucet, 2003). Thus there is an acceptance that women who make decisions with regard to egg sharing will be involved in a complex web of social relations that are both intimate and also form part of their wider social interactions (Gilligan, 1982). Consequently, their decision-making has to be understood not only in terms of the individual and the internal psychological decision making processes, but also from within notions of them being 'in relation' (Mauthner & Doucet, 2003, p.422) to and part of much wider mediating factors.

The emphasis of the interviews would be on enabling the women to take time to convey their experiences of egg-sharing and what this might mean for them, and their families, both currently and in relation to anticipated futures. It will also investigate whether they have shared their decision to become an egg donor with other family members and what effects, if any, their decision to become an egg share donor has had on other family members.

**Data Analysis:** A narrative approach to data analysis will be undertaken. The underpinning rationale behind using this approach is that it can be used as a way of "opening a window on the mind" (Cortazzi, 1993, p.2). For the purpose of this project this approach is being utilized to analyse the views of a group of people and it will be used to open "a window on their culture" (Cortazzi, 1993, p.2). In this instance the shared culture that they represent is that of women who have agreed to donate some of their eggs as part of an egg sharing programme.

The analysis itself will be conducted using a thematic approach. This will incorporate template analysis strategies that allow the location of meaning within the data to become apparent. King (2006) states that "template analysis involves the development

of a coding "template", which summarises themes identified by the researcher". The emphasis of the analysis will focus on what is being said by the participants rather than how it was said (Bryman, 2004).

A voice-centred relational method (Brown & Gilligan, 1992; Mauthner & Doucet, 1998 cited in Elliott, 2005, p.158) will also be adopted as a way of enabling the lived experiences of the participants to be heard. This approach also allows for researcher reflexivity to become an integral feature of the analysis.

**Ethical Issues:** The proposed project deals with a sensitive topic, infertility. Fertility treatment is also known to be a highly stressful and potentially distressing experience. Therefore, in addition to 'standard' ethical issues such as informed consent, participant anonymity and confidentiality, the need to ensure the well-being of participants will be a priority. While it is unlikely that the research interviews will explore issues with participants that have not already been covered during counselling sessions at the assisted conception unit, participants may welcome the opportunity of subsequent specialist support. Centres that provide fertility treatment have an obligation to make available counselling services and to continue to offer such services after treatment has been given.

The ethical guidelines laid out by the British Psychological Society state that researchers should "consider all research from the standpoint of research participants, for the purpose of eliminating potential risks to psychological well-being, physical health, personal values, or dignity" (BPS, 2006, p.18). This factor plays an integral part of this study due to its sensitive and emotive nature. The current research will adopt the principles defined by the British Psychological Society (BPS, 2006) the Data Protection Act (1998) and the guidelines set out by the University.

Talking to women about their experiences of 'egg sharing' brings with it some ethical issues which need to be addressed. These focus upon anonymity, confidentiality, psychological well-being and consent. The safety of the researcher is also an important consideration.

**Anonymity:** Anonymity of participants will be ensured in all matters relating to the study. The researcher will have the names and contact details of the individuals who have agreed to take part in this project. These will be stored securely as outlined in the "Confidentiality" section below. No individual will be identifiable in any of the documentation that is written or published from this research. The anonymity of participants will be ensured in all matters relating to the study. This will be incorporated into all documentation provided to prospective participants (See consent form).

This will also be reiterated verbally to participants at the outset of inclusion in the project and in the debriefing at the end of the proposed interviews.

The researcher will ensure that any potentially identifying data will be stored securely in a location away from any data collected. A pseudonym will be assigned to all participants to protect their anonymity. This pseudonym will be used in the write up of the thesis and any ensuing publications that arise as a direct result of this project.

**Confidentiality:** Participants' right to confidentiality will be maintained throughout the project. Subsequently all data collected as a result of this project will be treated with the strictest of confidence.

Prior to data collection commencing participants will be reminded and reassured that all data collected as a result of their participation will be treated as confidential. They will

also be informed that no identifying data including their name, address etc. will be shared with a third party.

Assurance will be given that the person employed to undertake the transcription of the data will adhere to the confidentiality and data protection regulations set out by the University. They will also be informed that the person who undertakes the transcription will be asked to sign a further agreement related to confidentiality specifically for this project, a copy of which will be shown to them should they wish to see it.

Participants will be asked to sign a consent form prior to the recording of the interview. On the consent form it makes explicit reference to how the participants' confidentiality will be maintained (please see attached consent form).

Interview tapes, transcriptions and consent forms will be stored in a locked cabinet on the University of Huddersfield premises in a location that has restricted access. Any computerised data will be password protected.

All data generated will be assigned a pseudonym and a corresponding number will be assigned to the recorded material.

Data generated as a result of this project will be stored in this way for ten years after the completion of this project. After this time all data will be destroyed.

All data and ensuing analysis will conform to the conditions set out by the 1998 Data Protection Act, the Data Protection Policy issued by the University of Huddersfield and also the guidance notes issued by the University of Huddersfield for researchers.

**Ensuring the well-being of participants:** Should it become apparent that additional sources of support are required the British Infertility Counselling Association offers a nationwide independent counselling service. In the event that participation in the project renders such counselling necessary, funding has been allocated to enable any independent counselling to be provided at no cost to the participant.

**Researcher Safety:** A fundamental and underlying principle associated with conducting research in the 'real world' is the need to ensure the safety of the researcher. The British Sociological Association's guidelines for conducting ethical research state that "social researchers face a range of potential risks to their safety. Safety issues need to be considered in the design and conduct of social research projects and procedures should be adopted to reduce the risk to researchers" (BSA, 2002, p.2). In this instance a thorough investigation of the issues that may arise as a direct result of this project has been undertaken (please see risk analysis document).

**Dissemination of the Research:** It is anticipated that the findings from the proposed project will be disseminated in the following ways:

- 1 completed PhD
- 1 international refereed conference paper
- 2 papers for international peer reviewed journals
- Conference Papers
- Poster Presentations
- University/School conferences for PhD student presentations

Participants will be made aware of how results will be disseminated (see information leaflet). They will also be advised that copies of any papers published will be available to them.

## 9.5 Participant information leaflet

### **Confidentiality**

Your right to confidentiality will be maintained throughout the project. This means that all data collected as a result of your participation in this project will be treated with the strictest of confidence.

All data will be stored securely in a location at the University of Huddersfield.

It will be stored in this way for a period of ten years. After this time all data will be destroyed.

### **Anonymity**

If you agree to take part in this project please be assured that your anonymity will be protected. This will be done by using a pseudonym.

This means that none of the information you provide will be used in a way that would identify you as a participant. This includes the use of your information in any publication that may arise as a direct result of your participation in this project.

### **Expressing an Interest**

If you are interested in taking part in this project or would like any further information please contact me using the details at the bottom of this page. Alternatively, complete the enclosed reply slip and post it back to me in the pre-paid envelope.

Please be assured that expressing an interest does not mean that you have agreed or committed to taking part.

**Contact:** Miss Berenice Golding  
School of Human and Health Sciences  
Human & Health Sciences Research  
Building g/04  
Queensgate  
Huddersfield  
HD1 3DH  
**Phone:** 01484 (47) 3845  
**Email:** b.golding@hud.ac.uk




University of  
**HUDDERSFIELD**

**Can women consent  
to share their eggs?**



**Can you help?**



### ***Volunteers Needed***

My name is Berenice Golding and I am a PhD Research Student from the University of Huddersfield.



I am undertaking a research project which is funded by the Economic and Social Research Council.

The project is seeking to explore the views of egg donors who have been involved in an 'egg sharing' programme.

### ***Reasons for the Project***

At present there is very little research available that focuses upon the experiences of women who donate eggs as part of an 'egg sharing' arrangement.

### ***Aims of the Project***

The main aims of this project are to explore the experiences of women who agree to donate eggs as part of an 'egg sharing' arrangement. This will be done by conducting interviews with women who agree to be involved in this project.

The questions I am trying to answer are related to:

- Finding out why you agreed to become a donor and how you reached your decision;
- To explore your understanding of informed consent;
- To explore your understanding of egg sharing and the implications this may have for you and other members of your family.

The outcomes of the interview will allow me to provide an account of the views and experiences of women who have agreed to become egg share donors.

### ***The Interview Process***

If you agree to take part in this project I would like to interview you on one occasion.

The interview itself should not last any longer than an hour and will be conducted in a mutually convenient place where you feel comfortable. This could be in your own home.

The interview will be informal and will focus on your personal experiences of being involved in egg sharing as a donor.

It would also be helpful if I could record your interview so that I do not forget anything.

### ***What happens to the information I share?***

The information you share with me will be used for this project. It may also be used in any publications or conference presentations that are undertaken as part of this project.

Your anonymity will be protected at all times by the use of a pseudonym.

The tape will be numbered which will ensure that the information you provide remains anonymous.

## 9.6 Participant reply slip

# Reply Slip



Dear Berenice

I am interested in finding out more about the project	<input type="checkbox"/>
I wish to take part in the project but would like to speak to you first	<input type="checkbox"/>
I wish to take part in the project	<input type="checkbox"/>

<b>From:</b>
<b>Name</b> .....
<b>Address</b> .....
.....
<b>Tel no</b> .....
<b>Email</b> .....
<b>Convenient contact time</b> .....



## 9.7 Interview Schedule

**Project Introduction:** First of all I would like to thank you for agreeing to take part in this project by allowing me to interview you.

Before we start the interview I would just like to go through with you again the details of this project.

My name is Berenice Golding and I am a research student from the University of Huddersfield. The focus of my project is to look at the experiences of women who have decided to donate eggs as part of an 'egg sharing' arrangement. The areas I want to explore focus upon your choosing to become an egg donor, the decision-making process and your understanding of informed consent.

To start with I will be asking some general questions about you before moving on to find out in more detail about your experiences of 'egg sharing'.

At this point I want to remind you that your participation in this interview is entirely voluntary, you do not have to go ahead with the interview if you have changed your mind. If you still wish to participate can I remind you that you are free to withdraw from the project at any time. I also want to assure you that I am totally independent of the clinic where you have had treatment. This means that your participation/non-participation will have no effect on the care/treatment you are receiving at the clinic.

As you are aware, you have agreed that this interview can be tape recorded. Can I again reassure you that all the information you share with me will remain confidential. Your anonymity will also be protected by the use of a pseudonym.

The data collected from all the interviews I conduct will be used to help me complete my thesis. The data may also be used to support any journal articles or conference papers that are written as a direct result of this project. May I assure you again that no identifying information will be used in any of these documents.

The tape and resulting transcript will be stored securely at the University of Huddersfield in a location that only I will be able to access. This will be destroyed after a period of ten years has passed.

I am happy to send you a copy of the tape/transcript for your comments should you wish me to do so. I am also happy to send you copies of any journal articles that I write which include any of the information generated as a result of your being interviewed today.

Last and by no means least, I am conscious of the fact that we are dealing with a time in your life which you may have found very emotional. If at any time you feel unable to answer a question or should you decide that you do not wish to provide any additional comments please stop me at that point. You are also free to stop the interview at any time should you choose not to continue.

After I have asked my questions you will have an opportunity to ask me anything. Before I start is there anything you'd like to say or ask?

## **Interview Schedule**

### **First of all I would like to find out a little bit about your fertility problems.**

Can you explain what your fertility problems are?

When did you realise that you had fertility problems?

What did you do when you realised that you had fertility problems?

Can you take me through what happened before you decided to participate in the egg sharing programme?

### **Now I would like to concentrate on 'egg sharing'?**

How did you hear about the 'egg sharing' programme?

What were your initial feelings about 'egg sharing'?

### **I would now like to move on to find out how you decided to join the egg sharing programme**

What made you decide to become an egg donor?

Did you consider other forms of treatment?

Was your partner involved in making your decision?

What things did you need to know before you decided to become an egg donor?

What were the advantages of egg sharing for you?

Were there any disadvantages of egg sharing that you considered?

What is your understanding of 'informed consent'?

Explore in more detail following initial response?

How was this issue dealt with at consultation?

Did you fully understand why you were giving consent?

Did this help/hinder you when you came to making your decision?

### **Now I would like to move on to find out about your experiences of 'egg sharing'**

What were your experiences of 'egg sharing'?

How do you feel now about 'egg sharing'?

Did you tell anyone else about your decision to become an egg donor?

**If yes - What was their response?**

**What impact do you think your decision has had on other family members?**

**What were their views?**

**Has this affected any family members?**

**If no – How did you come to this decision?**

**We are now coming to the end of the interview so I would just like to ask you one final question**

Is there anything else you would like to add based on your experience so far that you think is relevant and that I have not asked you about?

**Before I conclude the interview are there any questions you would like to ask me?**

**Participant Debrief**

Thank you for taking the time to be part of this study by allowing me to interview you, your responses are valued.

As mentioned at the beginning of the study, your responses will be used for research purposes only. No identifying data will be used. However anonymised quotations from your responses may be used in the writing up of the research and any publications that arise as a direct result of this project.

I realise that the subject matter may have been rather emotive and again I would like to thank you for sharing your experiences with me.

I will telephone in about a week to check that you are okay. This will also give you a chance to discuss anything else you think might be relevant to the project.

I would also like to say that you can contact me at any time in the future should you have any further questions or concerns arising from your participation in this project. My contact details can be found on the information leaflet I gave to you and also on my card.

Once again I would like to thank you for taking the time to be interviewed.

## 9.8 Participant consent form



### *Can women consent to share their eggs?*

#### **Participant Consent Form**

Please read this form carefully before completing

Researcher seeking consent: **Berenice Golding** Organisation: **University of Huddersfield**

The completion of this form is necessary for my records to confirm that you give consent to be interviewed for this project. If you feel unable to answer any of the questions please do not hesitate to speak to the researcher. She is also happy to discuss any other questions that you may have.

	<b>Yes</b>	<b>No</b>
Having been provided with a leaflet about this project I have read and understood it. I have also had the project explained to me fully by the researcher.	<input type="checkbox"/>	<input type="checkbox"/>
I have been given an opportunity to ask questions about the project.	<input type="checkbox"/>	<input type="checkbox"/>
I have been informed that no identifying information that I tell the researcher will be shared with anyone. I also understand that no identifying information will be included in any report, publication or presentation which results from this project. I understand that this is in keeping with the data protection regulations set out by the University of Huddersfield.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that the interview will be conducted in a location that is convenient for me and that it will take about an hour of my time.	<input type="checkbox"/>	<input type="checkbox"/>
I have been made aware that someone other than the researcher may transcribe my interview. I have been assured that no identifying information will be given to the person who transcribes the interview. I have also been made aware that any potentially identifying information that may be in the recording will be erased before it is transcribed by a third party.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can request a copy of the interview recording to listen to before it is transcribed by a third party. I have also been made aware that the person who may transcribe my interview is employed by the University of Huddersfield.	<input type="checkbox"/>	<input type="checkbox"/>

I have been informed that my involvement in the study is voluntary and that I have the right to withdraw at any time.

I understand that I can request to see transcripts of the interview at any time and that I should contact Berenice Golding for them. I am also aware that I can contact her should I have any questions or concerns about being a participant in this study.

## 9.9 Transcriber consent form



### Confidentiality Agreement

I \_\_\_\_\_ do hereby agree to undertake the transcription of the interview conducted by Berenice Golding. I am aware that the aforementioned person is a PhD student based at the University of Huddersfield.

I agree to abide by the rules and regulations set out by the University with regards to confidentiality and data protection.

I also agree that for the purpose of this project the data that are transcribed by me will be treated in the strictest of confidence.

I also agree not to retain copy of the data once the transcription has been completed.

**Signed** \_\_\_\_\_

**Date** \_\_\_\_\_

## APPENDIX TEN

### Revised ethics application and risk analysis form

**Aim / objectives:** This project is to be undertaken as part of an ESRC-funded PhD studentship. The overall aim of the proposed project is to investigate egg share donors' understanding of informed consent within the context of their decision to participate in an egg sharing arrangement. The project will investigate egg share donors' assessments of their ability to make an informed choice, their awareness and understanding of the constraints within which their decisions may be made, the factors that impact on their decision-making and the range of alternative options that may be available to them. More generally, the proposed project will contribute to the existing social science research base concerning egg sharing in the UK, which is limited to the work conducted by Blyth (2002, 2004) and Rapport (2003). The specific aims of this project are therefore to:

- Provide a narrative of the views and experiences of women who have become egg share donors as a way of resolving involuntary childlessness;
- Consider their understandings of egg sharing and the implications this may have for them and other members of their family;
- Investigate and comment upon the decision-making processes;
  - What factors contribute to participants' decisions to become egg share donors?
  - What are their perceptions and understandings of informed consent?

Brief overview of research methodology: A retrospective project is planned.

Qualitative data will be generated by means of semi-structured email interviews with approximately 20 women who have participated in an egg sharing programme as a donor. The sample will include women who have been an egg share donor within the last five years.

It is envisaged that the principal method of enquiry will be qualitative in orientation, adopting a relational ontological position (Brown & Gilligan, 1992; Gilligan, 1982, 1988). Here there is an acceptance that women who make decisions with regard to egg sharing, are possibly involved in a complex web of social relations that are both intimate and also form part of their larger social interactions (Gilligan, 1982). Consequently, their decision-making has to be understood not only in terms of the individual and the internal psychological decision making processes, but also from within notions of being 'in relation' to and part of much wider mediating factors. The method that will be employed to conduct the interviews will be data collection using computer mediated communication (CMCs) techniques (Mann & Stewart, 2000).

The rationale behind the choice of recruitment method is echoed in the words of Hamilton & Bowers (2006, p. 821) who state that "the reach and accessibility of the Internet has vastly expanded the potential pool of participants for health research". This benefit that can be ascribed to the Internet as a research tool will be exercised through this project.

The proposed interviews will be conducted by email asynchronously as opposed to synchronously (Illingworth, 2001; McAuliffe, 2003; McCoyd & Kerson, 2006). Asynchronous techniques involve conducting in-depth, semi-structured interviews over a period of time, rather than at a single point in time or in 'real time', a method that is employed when conducting synchronous interviews (Mann & Stewart, 2000; Illingworth, 2001; McAuliffe, 2003; McCoyd & Kerson, 2006). The distinction between the two methods is that asynchronous methods are not time limited; they take place over a

period of time that is defined at the start of the data collection period. Synchronous techniques apply to a method of data collection that involves the researcher and the participant being online at the same time, communicating in the virtual realm, within a clearly defined period of time such as that which is used with 'instant messaging' (Mann & Stewart, 2000). The project will adhere to the ethical guidelines set out by the British Psychological Society (BPS, 2007) and the Association for Internet Researchers (Ess & AOiR, 2002).

**Permissions for study:** Permission to recruit respondents via their websites has been granted by three online support networks. These are: National Gamete Donation Trust, Fertility Friends and Infertility Network UK. Each of the three organisations has agreed to post a brief introduction to the project on their website.

**Access to participants:** Research participants will be recruited via the aforementioned UK support network websites. Research participants will be recruited via invitations placed on the support network websites. Women will be asked to email for further information about the project if they are interested in possibly taking part. A process of self-selection for possible inclusion in the project will take place.

**Confidentiality:** Participants' right to confidentiality will be maintained throughout the project. All data collected as a result of this project will be treated with the strictest of confidence. All elements of the project will be conducted to ensure compliance with data protection legislation and the University of Huddersfield's requirements relating to secure data storage.

Prior to data collection commencing participants will be reminded and reassured that all data collected as a result of their participation will be treated as confidential. They will also be informed that no identifying data including their name, address etc. will be shared with a third party. Participants will be asked to complete a consent form prior to the interview. This makes explicit reference to arrangements for maintaining participants' confidentiality. Consent forms will be stored in a locked cabinet on the University of Huddersfield premises in a location that has restricted access (See Consent Form Section) for a more detailed discussion of the procedures related to the obtaining of consent. All data generated will be assigned a pseudonym and a corresponding number will be assigned to the recorded material. As the data are being generated using CMC the following criteria will also be used for confidentiality purposes. The email account used by the researcher will be a new institutional account which will be set up specifically for this project, it will be password protected. The password will be changed regularly.

A hard copy of the emails will be printed once all identifying information has been erased and a unique reference number and pseudonym have been assigned to it. These will be stored in a locked filing cabinet. Additionally, once all identifying information has been removed the content of the email will be copied and pasted into a word document. This document will then be saved using its unique reference number in a password protected, encrypted folder. This document will be used for the ensuing analysis. The data will be stored on the hard drive of the researcher's personal computer, which will be encrypted and password protected, on an external storage device and on the university's network storage facility. Data will be password protected on each of the storage devices. The original email will be deleted and then re-deleted from the file containing deleted emails once the interview process has been concluded. Participants will be reminded that their communications with me via email may need to be password protected on their own computer. All data and ensuing analysis will conform to the conditions set out by the 1998 Data Protection Act, the Data Protection



Policy issued by the University of Huddersfield and also the guidance notes issued by the University of Huddersfield for researchers.

**Anonymity:** The researcher will have email contact details and names of the individuals who have agreed to take part in this project. These will be stored securely as outlined in “Confidentiality” above. No individual will be identifiable in any of the documentation that is written or published from this research. The anonymity of participants will be ensured in all matters relating to the project.

As participants are being recruited from an online forum they may already be interacting in the ‘virtual’ world using a pseudonym. It will therefore be necessary to give them a dedicated pseudonym for the project that will further protect their identity. This is necessary as some studies suggest that people in online communities using pseudonyms actually care about the reputation of their pseudonym and treat it with the same regard that they have for their real names (Donath, 1999; Bruckman, 2002). Furthermore, the pseudonyms they use online may identify them if they were to be used in any documentation arising as a direct result of their participation in this project. This reference to the respect for anonymity will be incorporated into all documentation provided to prospective participants (see previously submitted documentation).

**Psychological support for participants:** Ensuring the well-being of participants is a priority due to the sensitive nature of the proposed project. However, it is unlikely that the research interviews will explore issues with participants that have not already been covered during counselling sessions at the assisted conception units when they became donors and are not considered likely to generate further issues for participants. Nevertheless, should it become apparent that additional sources of support are required the British Infertility Counselling Association offers a nationwide independent counselling service. In the event that participation in the project renders such counselling necessary, funding has been allocated to enable any independent counselling to be provided at no cost to the participant.

**Researcher safety/support:** Every effort will be made to ensure the safety of the researcher at all times, especially during the fieldwork phase of this project. The researcher has identified potential risks and the procedures that can be employed to minimise these risks.

**Conflicts of interest:** None to be reported.

**Consent form:** The researcher is aware that obtaining consent is not a one off event and that it may become necessary later in the project to check that participants still consent to the use of non-identifying data to be used in the writing of the thesis and any published work.

The consent form will be sent as an attachment to be opened and completed by the respondents. It will ask them to indicate (using a tick box) their agreement to the conditions for the use of their data, details about why the project is being undertaken, issues relating to confidentiality and anonymity. It also includes the methods that will be used to store data generated from the email interviews.

Respondents will be asked to check the boxes to show that they have read, understood and agree with the statements on the consent form. At the end of the form they will be asked to write a short sentence stating that “they have read the consent form, that they have had the opportunity to ask questions and that they understand that they have the right to withdraw from the project at any time with no consequences for themselves” (Adapted from McCoyd & Kerson, 2006, p. 394). They will be asked for their password

in order to authenticate their identity. They will then be asked to return the form by email.

Should respondents encounter any problems opening/downloading the attachment this will be dealt with in the following way; the content of the consent form will be copied and pasted into the email and forwarded back to respondents for completion. This should reduce any issues related to how comfortable the respondents are with computer technology and its uses.

I am aware that a traditional way of obtaining informed consent is to get a signature at the bottom of a consent form. This is a practical method that is best used in a face-to-face interaction. As there is no face-to-face interaction in this project there is the realization that obtaining consent is not straightforward. A consent form could be sent through the post but there is no assurance that the signature on the returned form belongs to that of the participant (Bennett, 1999 cited in Mann & Stewart, 2000). However, by using an email attachment certain strategies can be put in place to ensure that consent is being obtained from the right source. Once consent has been obtained it will be assigned its unique reference number before being stored in a separate password protected, encrypted folder. A hard copy of the form will be printed and stored in a secure location at the University.

**Interview schedule:** This project is dealing with a sensitive and emotive issue: that of involuntary childlessness. The drafting of the interview schedule has taken this fact into account so as not to cause unnecessary distress to participants. Participants will be reminded at the beginning of the interview process that if there are any questions they feel unable or do not wish to answer they have a right to decline to answer.

**Other issues:** Conducting interviews using computer mediated communication – email: As with any type of social research the positive and negative effects related to the chosen methodology have to be considered. Email interviewing is a relatively new method of carrying out social research which brings with it a variety of areas that need to be considered. The potential problems associated with this research method will be discussed in the first instance.

**THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT**

<b>ACTIVITY:</b> PhD Research – Can women consent to share their eggs?			Name: Berenice Golding	
<b>LOCATION:</b> Huddersfield via email			Date: Various	Review Date:
<b>Hazard(s)</b>	<b>Details of Risk(s)</b>	<b>People at Risk</b>	<b>Risk management measures</b>	<b>Other comments</b>
<b>Identified</b> Email security	Preventing internet spam hackers	Researcher	The email account used by the researcher will be a new institutional account which will be set up specifically for this project. It will be set up using the project title as the email address rather than any information that identifies the researcher. Logging into the email account via a webpage rather than through SHUM will further minimize communications being traced back to the researcher.	
Online safety	Internet stalkers - the recruitment of participants through an online support forum brings with it the risk of unwanted attention/participants who claim to be someone they are not.	Researcher		

## APPENDIX ELEVEN

### Online consent form

UNIVERSITY OF HUDDERSFIELD

#### Can women consent to share their eggs?

Email Interview Consent Form

I have been fully informed of the nature and aims of this research and consent to taking part in it.

I understand that I have the right to withdraw from the email interview process at any time without giving a reason.

I understand that I have a right to withdraw my data if I wish

I give permission to be quoted (by use of pseudonym).

I understand that the email interview will be copied and pasted into a word document that will be printed and kept in a secure location at the University of Huddersfield.

I understand that my identity will be protected by the use of a pseudonym and that no information that could lead to me being identified will be included in any report or publication that results from this research.

## **APPENDIX TWELVE**

### **Pseudonym list**

This is a list of the names that I will use to protect your identity. The names I have chosen are names of British women who have made great contributions to the country. Please choose the name you would like me to use to protect your identity – send me your answer by email.

Thanks

*Berenice*

Emmeline

Josephine

Elizabeth

Emily

Catherine

Diana

Florence

Victoria

Margaret

Anne

Mary

Beatrix

Charlotte

Diane

Anna

Jayne

Sarah

Millicent

## APPENDIX THIRTEEN

### Analysis: brief sample of some of my responses to reading one

<p>I Can you tell me how old you are?  R Yes, I'm 24, (was 22 when I did Egg Share)  I Can you explain what fertility problems you experienced?  I When did you realise that you had fertility problems?  R As we needed treatment anyway due to my husband, I didn't realise about me until I started going for scans and tests to start IVF.  I What did you do when you realised that you had fertility problems?   R Looked it up on the Internet! I'm was quite shocked, but don't think it affected me too much as we're were having IVF anyway.  I Can you take me through what happened before you decided to participate in the egg sharing programme?   R We were advised so we started to look around at which hospital's near us. We attended an opening evening, and they explained the cost of IVF and also told me about Egg Share. Up until this I didn't really know about it. We we're given information to take home and read, and that's when we decided to Egg Share. When we were ready to start treatment, I explained that we wanted to egg share and they went though the legal side of it, made sure I was mentally ready for it, had to have counselling, andthe hospital made sure I understood everything about it.  I How did this make you feel?  R In a way, I thought it would have been nice to know a bit of the recipients back ground or even just her first name. Then at least I would have a tiny bit of knowledge of her, instead of nothing. But as far as I am aware, that is the Law so I couldn't do anything about that.   Without sounding selfish, egg share was really the only option for us. We were desperate for a baby and could not afford the full price of IVF. I looked at it two ways, one way was I was giving another couple the chance of been parents and also give us a chance. But having said that, I looked at it as though I wasn't giving anything of mine away. The egg's hadn't been fertilized so it wasn't like I was giving my child away, and it wasn't like giving part of me away .I kept remember something id seen on a leaflet saying 'you flush egg's</p>	<p>I was surprised at how young this participant was to be going through with egg sharing</p> <p>Internet is a wealth of information</p> <p>It is interesting how the open evening is a factor cited in the decision to ES</p> <p>It wasn't until they went to the clinic that they heard about egg sharing – interesting, does that mean that it is 'sold' as a treatment option?</p> <p>The reference to eggs here is rather disconcerting – just eggs – I don't get it, surely these eggs have the potential to become life so should be more valuable</p> <p>It would help to know who the eggs have gone to -</p> <p>Financial pressures influence the decision to ES – without this treatment other treatments cannot be afforded. Means to an end?</p> <p>Altruism comes into effect here though I feel as though the participant has been told that this is what she is doing – not really her choice</p> <p>Language and the information provided change a woman's perspective in relation to their eggs – something that is lost – natural cycle – going to waste – as if!! I find this whole notion quite ludicrous really – yes eggs are flushed away per se but is that not part of our physiologically functioning? It is almost as if the coercive nature of ES begins with the information clinics provide – of course they</p>
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<p>away every month during your cycle' so instead of mine going to waste, I gave them another couple.</p> <p>I never let it register in my head that if the other couple did go on to have a child with my egg's, that the child would have biologically come from me. my thoughts were, the lady has grown this child, given birth to it so how can it possibly be connected to me via the same DNA. I did want the treatment to work for the others who had received my egg's, and I didn't allow my self to think too much into things.</p> <p>Sorry this might not be making sense, its just so hard to put it into words. I don't mind telling you as much as you want to know, so if you need me to elaborate on anything, just say</p> <p>R Before my eggs were removed, I did think, what if they wasn't enough, id have to decide weather to keep them for myself, or give them all to the recipients. But I decided I would cross that bridge if/when it came to it. And luckily I didn't have to. And I wasn't sure about how I felt, that the potential child could contact me in 18 years time. And to be honest I still don't know how I feel about that now, which goes onto the other disadvantage (this relates to after the treatment, not sure if that's what the question just means before, Feel free to cut if this question arises later!) and that its wondering. It is since my own son was born, but I constantly think of the eggs I donated, if treatment worked for them, 'have they had boy or girl', 'have they frozen any embryos' 'what is he/she like' and mainly I wonder if he/she looked like me at all. My little boy is double of his dad, so I think, if we had a girl, maybe she'd be double of me, and that then gets me thinking about if the children born from my eggs would resemble me. And the sorry part is, if im out shopping say, and I look at babies, there's always the thought there is my head, I know realistically the chance of that is impossible but the thoughts always there. And just recently I've wrote to the HFEA to find out the outcome of the egg sharing, the information I can be told is, whether a child was born, girl or boy and the year in which he/she was born. I think then at least I will know, and just maybe stop these questions in my head. Or it could have the reverse affect !!</p>	<p>want women to believe that their eggs are going to waste – that way they see it as a less wasteful process? I feel quite angry that the way information is relayed to women changes their perceptions of their eggs</p> <p>Distancing herself from what might possibly happen – if she does not think about it then she is in a safe place</p> <p>Pressure to produce enough eggs</p> <p>Potential future implications cause ES donors to think of future children – this must be incredibly difficult to cope with What is interesting here is that the concept of the eggs changes – something that is a waste product is not potentially a life where before the eggs were merely eggs</p> <p>The need to know the outcome becomes an important matter – it is quite worrying that it is only after the birth of her child that she recognises that the eggs which she shared may also now be children.</p>
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## APPENDIX FOURTEEN

### Complete 'I' poems

#### **I poem - Charlotte**

*I went back to my GP,  
i am sure you are aware IVF isn't cheap,  
i searched on the internet for cheaper  
treatment*

*I think,  
I am in touch with,  
I think I am lucky,  
I have felt,  
I have had to push each stage a long  
[sic],  
I would say,  
I have been in touch with,  
I am enjoying answering them,  
I am finding it all quite therapeutic.*

*I rang/emailed several clinics,  
I wasn't able to egg share,  
I had PCOS,  
I rang (clinic anonymised),  
I had received treatment for my PCOS,  
I make an appointment to see,  
(they went through and reviewed all of  
my bloods and treatments that) I had  
previously had,  
I should finish my current treatment,  
I was in the middle of six months of  
clomid,  
I could either go for IUI or IVF,  
I would be suitable,  
I would need to produce at least 8 eggs,  
I spent a lot of time looking on fertility  
websites.*

*I haven't been told anything about the  
recipient,  
I never expected to be told,  
I knew from the start,  
I am curious,  
I know,  
I am also very grateful to her .*

*I was able to egg share,  
I had been matched,  
I was over the moon,  
I need to try <sup>20</sup> lose some more weight,  
I would continue to try,  
I lost a further,*

*Could I get to the clinic as the recipient  
was ready,  
I went to the clinic. they gave me the  
drugs,  
What I need to take,  
I am a nurse so had a rough idea,  
I had a couple more scans,  
I am now on the dreaded 2 week wait!!  
Only 6 days until I can test.*

*I have always liked,  
I am helping another couple,  
If I didn't produce enough,  
I didn't want to let the other couple down,  
I also had a few questions.*

*I guess,  
I have to give,  
I am donating half my eggs.*

*I have to say that most people thought it  
was a really lovely thing to do,  
(a couple of people have found it strange  
that) I would want to give my eggs away,  
I could end up having children genetically  
linked to me,  
I will never know.*

---

<sup>20</sup> Typo in original.



## **I poem - Florence**

*I had been to the GP,  
I had a lap and dye.*

*I crumbled,  
I couldn't believe,  
I did it hit me,  
I was only 29,  
I am now 33.*

*I was desperate,  
I found out about,  
I knew this was our opportunity,  
I also felt.*

*I found out,  
I suffered,  
I had to leave,  
I would turn up,  
I couldn't think about anything else,  
I had,  
I said,  
I narrowly escaped,  
I was going,  
I used.*

*I have previously,  
I had,  
I was keen to donate,  
I was quite ill,  
I needed to produce enough,  
If I qualified.*

*I would do,  
If I were,  
I was doing,  
I would do,  
I also felt,  
I would go through,  
I wanted her to know,  
I wouldn't let her down.*

*I qualified,  
If I need to talk.  
I don't know,  
I was asked,  
I know nothing,  
I think about alot,  
I have a feeling,  
I had,  
I guess,  
I was giving,  
I was offering,*

*I was helping,  
I don't have,  
I don't know,  
I am trying,  
I did,  
I lost,  
I was.*

*I will,  
I want,  
I did,  
I couldn't,  
I feel able.*

*I think,  
I could write,  
I could go,  
I have experienced,  
I have almost,  
I know,  
I wouldn't have,  
I hadn't,  
I feel,  
I was meant,  
I now feel.*

*I got my answer today to the call,  
I made,  
I am experiencing now all those feelings,  
I talked about,  
Happy that I helped another couple,  
I do,  
I spoke to the clinic director,  
I gave them this gift,  
I did this for the right reason,  
I keep telling myself,  
I wouldn't have the embryo's,  
I'm sure,  
I will think about this alot,  
Now I know.  
I wanted to find out,  
I told the director,  
I am helping you.*

*I was depressed and needed to get  
going,  
I had had a bad experience,  
I wanted to move on,  
And I guess more gutsy,  
More aggressivel suppose.*

*I made,*

*I did,  
I discussed it with the clinic,  
I made the decision to do it,  
It's highly personal,  
I was asked to have certain tests.*

*I wanted to know,  
I am one,  
I wanted to know how much information,  
I wanted to know how I accessed  
information,  
I have to put that into action.*

*I helped another couple (possibly),  
Now I know for definite that I did.  
I lost a baby,  
I would have to endure,  
I would have had had go through,  
I will always be wondering.*

*I could,  
I read my mum the paperwork,  
I have a very close relationship with my  
mum,  
I was to get going with treatment,  
I was very knowledgeable,  
I was happy,  
I had all the information,  
I needed,  
I was receiving counselling.*

*Shocked that I could even contemplate,  
I explained our predicament,  
I have had to spell out,  
I reacted sometimes as,  
I did.  
I couldn't see them though,  
I think,  
I met,  
I felt it was my decision,  
I attempted,  
I was going to do it,  
I had a huge support base,  
I return that support.*

*I understood,  
I was agreeing,  
I would be informed,*

*I was required,  
I understood,  
I was encouraged to ask,  
If I was in doubt,  
I would donate,  
If I produced 8,  
If I didn't.  
I only spoke,  
I was treated,  
I knew,  
I didn't,  
I'm sure,  
I was told,  
I achieved 20.  
I would have no contact,  
I terminated all rights,  
I also consented,  
I needed to have,  
I was fully aware,  
I was agreeing.  
I needed to secure treatment,  
I was able to help,  
I did something special.*

*I thought,  
I couldn't get any lower,  
I was prior to treatment,  
I've ever felt in my life.  
I lost mine,  
I didn't have the knowledge,  
I am able to,  
I will always wonder,  
What if I had kept all those eggs?  
I suppose,  
If I hadn't been successful.*

## I poem - Jayne

*I didn't realise,  
I started going,  
I didn't really know,  
I explained,  
I was mentally ready for it,  
I understood everything,  
I didn't see it as though,  
I was giving,  
I was given,  
I wasn't allowed,  
I thought it would have,  
I would have,  
I am aware,  
I couldn't do anything.*

*I looked at it two ways  
I was giving,  
I looked at it as though,  
I wasn't giving,  
I was giving  
I kept remember<sup>21</sup> something I'd seen,  
I gave them another couple*

*I never let it register,  
I did want,  
I didn't allow,  
I don't mind telling you.*

*I would be helping,  
I did feel proud of,  
I do believe,  
I thought about,  
I had an idea of how,  
I could possibly help,  
I was doing something 'good'*

*I wanted to know,  
Could I ever,  
I didn't have,*

*I could possibly have helped,  
I remember thinking,  
I knew about IVF,  
I've at least given them,  
I did think what if,  
I decided,  
I would cross that bridge,  
I didn't have to,  
I wasn't sure about how,*

*I felt  
I still don't know how,  
I feel about that now.*

*I constantly think,  
I donated,  
I wonder if,  
I think,  
I look,  
I know,  
I've wrote,  
I can be told,  
I think then at least,  
I will know.*

*I was told then,  
If I wanted to know,  
I decided to write,  
I feel,  
I need to know,  
I need the answer.*

*I explained it,  
I told her,  
I don't think,  
I felt they didn't understand,  
I didn't care,  
I felt they didn't want to know,  
I don't think.*

*I do think,  
I have tried,  
I feel there,  
I would have,  
I wouldn't have,  
I needed,  
I got that,  
I wasn't going.*

*I would be agreeing,  
I needed to fill in,  
I was signing.  
I did understand,  
What I was signing.  
I would share my eggs,  
I wasn't legally connected.  
I can't remember,  
I had to sign.*

*I can not [sic] know the recipient,  
I need to send,  
Im [sic] going,*

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<sup>21</sup> Typo in original.

*I will be sending,  
I come back,  
I will let you know.*

*I did egg share twice,  
I do feel,  
I am 100% grateful!  
I've gave 2 couples.*

*I don't really see it as negative,  
I've got to learn,  
I'm never going to know,  
I'm never going to know,  
I could,  
I feel,*

*I did,  
I've just got to learn.*

*I'm glad,  
I did it,  
I've never wished,  
I hadn't,  
I could do it again.  
I admire,  
I don't think,  
I think differently now,  
I did,  
I didn't really think.  
I have my child,  
I think about it quite often.*

## I poem - Emmeline

*I have always thought,  
I would have,  
I thought,  
I felt,  
I had been trying,  
I went to see my GP,  
I told her,  
I had been trying,  
I wanted,  
I still wanted.*

*I saw a fertility specialist,  
If I recall correctly,  
I do ovulate,  
I was lead to believe,  
I was told,  
I had clear tubes,  
I went back,  
I took the clomid,  
I was told,  
I had 'unexplained' infertility,  
I would not be eligible,  
Until I had been trying,  
If I wanted a baby,  
I had to go private.*

*I was not eligible until,  
I had been TTC for two years,  
I began,  
I found,  
I researched,  
I have,  
I knew,  
I came across the concept of egg share.  
I have,  
I was,  
I from the,  
I always felt,  
I have no doubt,  
I should do something.*

*Before I was TTC,  
I researched,  
I found out,  
I felt,  
I would not be able,  
I found out,  
I could donate,  
I couldn't believe my luck,  
I looked into,  
I thought,  
I found,*

*I just wanted,  
I thought,  
I felt,  
I was excited,  
I hadn't thought,  
I thought,  
I found,  
I found,  
I was worrying,  
I would feel if the other,  
I didn't,  
I found,  
I started,  
I would often think,  
I would be sharing,  
I told most,  
I got positive responses,  
I think.*

*I was hoping,  
I have family there,  
I could stay.*

*I was trawling the internet,  
I stumbled upon,  
I knew of egg donation,  
I phoned,  
I thought,  
I could not believe.  
I first decided,  
I did,  
I had talked,  
I had a thought,  
I feel,  
I would be able,  
I had been told,  
I was not eligible,  
I remember,  
I had to produce,  
I would have to choose,  
I wanted,  
I recall knowing,  
I could change my mind,  
I knew,  
I would not,  
I imagine,  
I knew,  
I could,  
I was told,  
I thought,  
I recall.  
I wasn't told,  
I would be,*

*I celebrated,  
I got,  
I knew,  
I know,  
I thought,  
I decided,  
I didn't want,  
I asked,  
I would be eligible,  
I nodded,  
I know,  
I took this confirmation,  
I wanted to know,  
I would feel,  
I wasn't.*

*I think,  
I said before,  
I didn't know,  
I cried,  
I had been afraid,  
I would feel,  
I called,  
I am a little fearful,  
I will feel,  
I almost felt,  
I hope,  
I wonder,  
I can feel,  
I wanted to know,  
I would have liked to.*

*I know that,  
I did find,  
I often wondered,  
I don't really know,  
I would have wanted,  
I suppose.  
I don't think,  
I won't have,  
I think,  
I was so,  
I fear,  
I have had,  
I want to feel,  
I know,  
I will be ok,  
I am now greedy,  
I think,  
I know,  
I have a new recipient,  
I start.*

*I wanted to be an egg donor some years  
ago,  
It wasn't something I had thought about  
recently,  
I saw it,  
I jumped at the chance.  
I am pleased,  
I had the chance,  
I would probably chose to not be,  
I am very pleased,  
I have done it,  
I think.*

*I wanted to know,  
I would produce,  
I wanted to know,  
I would want,  
If I was in her shoes,  
I now know,  
If my... I would happily share.*

*The fear I had,  
I would feel if the recipient fell pregnant,  
I didn't. The worry,  
I would feel,  
I thought a lot.  
I felt quite a lot of pressure,  
I also worried,  
I had produced 8 eggs,  
I would only have 4.  
I feel my OHSS,  
I think,  
If I had just,  
I wouldn't have overstimulated,  
I don't think it is the norm/*

*I constantly,  
I sometimes feel,  
If I hadn't egg shared.  
I think we have been,  
I am happy,  
I am not in the mood to talk,  
I have just asked,  
I forgot,  
I ended up,  
I was quite highly strung,  
I imagine,  
I know,  
I felt.*

*I tried desperately to hide,  
How sick I was,  
I just couldn't,  
I was,*

*I think,  
I was,  
I didn't want,  
I felt quite vulnerable,  
I understood.  
I explained,  
I had frozen embryo's,  
I wouldn't need,  
I don't think,  
I do IVF again.*

*I chose,  
I think,  
I suppose,  
I said,  
I don't,  
I would,  
If I wasn't,  
I shared the 29,  
I kept 15,  
I forgot,  
I really like.*

*I don't seem to remember,  
I know,  
I was given,  
I don't recall,  
I did get,  
I remember my initial consultation,  
I went over the consent,  
I assume,  
I can't be sure,  
I think,  
I may have been more fixated,  
When can I start.*

*I went,  
I didn't understand,  
I got sticky labels,  
I wasn't sure about,  
I wrote out,  
I thought,  
I could discuss,  
I assumed,  
So I asked,  
I went through,  
I had,  
I was happy,  
I signed,  
I am not sure,  
Had I not asked,  
I had,  
I signed,  
I don't know,*

*I gave consent,  
I remember thinking it was strange,  
I had to consent to the storage,  
I recall,  
I wasnted<sup>22</sup>,  
I didn't feel,  
I should have,  
I did feel,  
I would not have been happy.*

*I believe,  
I did fully understand,  
I was giving consent to,  
I do believe,  
If I hadn't been assertive,  
I also hadn't thought,  
I felt quite strongly,  
I only wanted them to go to one family.*

*I think you will be pleased,  
I have,  
I am now preggies,  
I think,  
I am starting to settle a little now.*

*I know,  
I didn't feel comfortable,  
I think,  
I felt a bond,  
I shared my eggs,  
I would feel.  
I first found out,  
I knew it was right,  
I knew,  
I would be proud,  
I regularly thought,  
I think this gave me.  
I think  
I think,  
I would,  
I think,  
I had had to wait,  
I would have found,  
I was in hospital,  
I found comfort,  
I walked through,  
I calculated,  
I was conscious,  
I felt,  
I am now 3 months.*

---

<sup>22</sup> Typo in original.

*I still believe,  
I wouldn't have had,  
I had plenty,  
I wasn't in,  
I think,  
I may still be,  
I also found,  
I worried,  
I can't explain,  
I had no plan,  
I was pregnant.  
I think it has been a fantastic opportunity,  
I think I benefitted,  
I have absolutely no regrets,  
I was now in a position,  
I think,  
I would find it harder,  
I often chatted,*

*I think,  
I said before,  
I am pleased I did it,  
I think,  
I would have found,  
I would perhaps have tried to pay.*

*I feel,  
I have been extremely lucky,  
I will be celebrating,  
I also know,  
I will ask,  
I am allowed,  
I mainly want,  
I also look forward to the day,  
I get a knock on the door,  
I would say.*



