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MAJOR RESEARCH PROJECT

NICOLA SHORTEN BSc Hons

Section A: Legal and ethical rights to awareness of genetic origins in the context of donor conception: A review of historical and current legislation, theoretical understanding and research findings.

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Section B: An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.

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This project is dedicated to my sister,

Emma

My sister by chance, my friend by choice

Summary of portfolio

Section A provides a critical review of the research literature relating to the legal and ethical rights to awareness of genetic origins in the context of donor conception. Definitions and a historical context of the pertinent issues are provided, followed by a discussion of understanding drawn from theoretical literature and a systematic review of research related to openness in donor conception. Potential gaps and requirements of future research are highlighted.

Section B presents the findings of a grounded theory study which aimed to explore the experience of openness in donor conception families, in relation to the social and emotional experience of young people. A constructed model pertaining to the process involved in achieving positive outcomes for children and families in a context of openness is provided. The model is discussed in relation to existing theory and research. Methodological limitations and clinical and research implications are highlighted.

Section C provides a critical appraisal of the research methodology and findings, as well as clinical implications and suggestions for future research.

Section D contains appended supporting material.

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SALOMONS
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Section A: Legal and ethical rights to awareness of genetic origins in the context of donor conception: A review of historical and current legislation, theoretical understanding and research findings.

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Abstract

The current review evaluates the extant literature regarding individuals' legal and ethical rights to awareness of their genetic origins in the context of donor conception. Definitions are provided and the historical and cultural context of donor conception is outlined, including a description of relevant legislation regarding knowledge of genetic origins. The review briefly evaluates knowledge from theoretical understandings which can inform the topic area as well as an overview of research areas related to the subject. Literature from a systematic search related to experiences of parents and offspring regarding openness in donor conception is then reviewed. The literature reviewed includes studies of parent's disclosure decisions, methods of disclosure and responses of offspring to the information. It is concluded that whilst research has begun to explore the experience of openness for individuals and their parents, there is still much to know about the complexities involved in openness and the implications for therapeutic work with donor conceived individuals and their families.

Introduction

Our societal context places increasing value on a knowledge of genetic origins, with the growing availability of online access to family ancestry, the mapping of the human genome and the growing emphasis on genetics in medical care and illness prevention. Most commonly, stories of secrecy regarding genetic origins are found in contexts such as, illegitimacy, adoption, step-families and, more recently, that of assisted reproduction technologies (ART). Research conducted with individuals who discovered that their genetic origins had been concealed reported the negative impact of this on the individuals involved (Pettle, 2002; Turner & Coyle, 2000). In light of such findings, is it reasonable to suggest that a child has a right to know their genetic origins?

This review provides an overview of the debate around a child's legal and ethical right to knowledge of their genetic origins. The historical context related to donor conception shows a cultural shift encouraging greater openness. The implications of this for donor conceived individuals and their families are considered in the light of theoretical understandings and the expanding research base within this area. The need for further research regarding psychological implications of openness in donor conception is also highlighted.

Donor conception: definitions

'Donor conception' denotes a pregnancy using donated gametes: sperm and/or oocytes (eggs) or embryos. It may be used by infertile heterosexual couples, lesbian couples or single mother by choice families. Historically, gametes used have been mostly, but not always, from anonymous donors.

A child created is born into a family, in which either one or both parents are not genetically related to him/her. Historically, donor conception has been associated with secrecy (Murray, 2003), and many offspring have never been informed of the fact they were donor conceived; growing up believing that both their parents were their genetic relations. There has been much debate about children who are donor conceived having access to information about the donor(s). In recent decades changes in legislation reflect a growing emphasis on the rights of children created this way.

Legislation in donor conception

Awareness of the importance of social, psychological and ethical implications of scientific advancement is reflected in attempts to develop regulations to guide the implementation of ART (Blyth, Martin & Potter, 2003). In the 1980s the British Association of Social Workers set up the project group (PROGAR), in order to provide a social work perspective in relation to issues of infertility and assisted reproduction (BASW, 2012). In 1982 the Department for Health and Social Security (DHSS) appointed the Warnock Committee to report on the implications of developments in human fertilisation and embryology. The Warnock report (DHSS, 1984) recommended a regulatory framework, which led to the Human Fertilisation and Embryology Act 1990, which established the first regulatory body for services providing ART, the Human Fertilisation and Embryology Authority (HFEA).

One of the requirements is that treatment should not be given without consideration to the welfare of any child born as a result (HFEA, 1993). It has been suggested, however, that this recommendation lacks consideration of the welfare of individuals beyond childhood. The 'right to know' debate (Blyth, Martin & Potter, 2003) has involved discussions regarding the rights of donor conceived children to be informed of their genetic origins, and to have

access to identifying information regarding the donor. It has been argued that withholding this information is in contradiction of the child's human rights, as laid out in the United Nations Convention of the Rights of the Child (2002).

Changes in legislation were implemented (HFEA, 2004) so that from April 2005 onwards, all children conceived with donated gametes will be allowed access to identifying information about their donor. The HFEA also advised clinics providing treatment to encourage parents to disclose donor conceived origins to potential children and prepare future parents on how to go about this (HFEA, 2005a, 2005b, 2007).

Although the HFEA currently encourages openness, there remains no legal obligation for parents to disclose. Sharing of the information is therefore a parenting choice. Research suggests that many families continue to be secretive about their use of donor conception (Freeman & Golombok, 2012; Golombok *et al.*, 1996; 2002a) whilst an increase in engagement with support networks advocating openness (in the UK, chiefly the Donor Conception Network [DCN]) suggests many families are choosing to share this information. It is unclear what factors facilitate openness for some families and hinder it for others.

It has been argued that ART can be viewed in two ways, 1) as treatment for infertility and associated clinical issues or 2) as a family building approach (Daniels & Thorn, 2001). The latter perspective allows for the implications to be considered far beyond the creation of a baby. It also further supports the need for adequate services and support for families, prior to, during and post treatment, and research to inform this.

The following section identifies how understanding drawn from psychological theory can inform issues related to openness in donor conception and provide a framework for future research.

Theoretical perspectives

Social constructionism.

Social constructionist theory assumes that knowledge is shaped by historical, cultural and social processes (Burr, 1995). Thus, approaches taken to secrecy and openness will be influenced by changing historical, cultural and social discourses. Changing social attitudes towards illegitimacy and infertility are reflected in the prevalence of more discussion in the media; television documentaries; radio features; novels (Elton, 2000) and films. This has almost inevitably impacted on the move towards greater openness within donor conception (Blyth, Langridge & Harris, 2010; Crawshaw, 2008).

It is suggested that construction of the self is rooted within a relational context (Gergen, 1991). Thus, the construction of ourselves, our sense of identity, is built through our communications, interactions and relationships with others. Narrative approaches suggest that through these relational interactions we construct narratives which give shape to our lives and identity (Pettle, 2003). Smart (2011) discussed the importance of shared family narratives in the form of memories, which are carried across generations to form a coherent sense of family identity. Where donor conception has been concealed an alternative narrative is created, in which the true story remains unknown to the individual. When the information is disclosed, this may conflict with the individual's narrative identity, leading to a rupture in the sense of self (Pettle, 2002; Turner & Coyle, 2000).

In a changing context, in which non-biological parentage is more widely accepted, and the potential impact of unplanned or late revelation more understood, openness may be seen as the more protective and ethical option.

Systemic theory.

Theoretical understanding of the effects of secrets in families informs our knowledge of the potential consequences in donor conception. Secrecy involves the withholding or sharing of information between individuals and is embedded in a relational context (Karpel, 1980).

Karpel (1980) refers to the type of secret involved in non-revelation of donor conception as an 'internal family secret', and suggests that such secrets create anxiety, and a power imbalance within the family. Karpel also discusses the ethical-existential dilemmas created by family secrets, in considering that the concept of trust, where a secret is held, is not necessarily afforded by trustworthiness, creating a dilemma in which the unaware is made to "live a lie", even though he/she is not aware of the lie (Karpel, 1980). Imber-Black (1998) discusses the implications for the creation of anxiety, she comments on the experience of adult offspring who speak of "sensing secrets all of their lives" (p.91), thus adding to the impression that secrets can impact on the emotional functioning of families before being disclosed. Through the retrospective understanding of non-disclosure systemic theory sheds light on the potential for openness within families to avoid these negative implications, and to facilitate trust and communication.

Developmental theory.

Piaget's theory of cognitive development (1955) described children's ability for logical and abstract reasoning developing over time. At a pre-school age the child is functioning at a level of pre-operational reasoning, and has a limited understanding of abstract concepts. It has been suggested that understanding of information relating to donor conception would need to wait until the child reaches the next stage (concrete operations), and has the ability for abstract thought. This has been supported by research suggesting children under 7 cannot fully understand concepts of biological inheritance (Solomon, Johnson, Zaitchik & Carey, 1996).

It is however, important to consider the influence of experience on understanding. Children who are terminally ill have an increased ability to understand death and dying, in contrast to other children (Spinetta, 1974; Speece & Brent, 1984). If direct experience increases potential for understanding then it can be assumed that donor conceived children can be supported to understand information regarding some aspects of their genetic origins from a young age.

Another important factor from developmental theory is that of identity development. Erikson (1959) put forward a stage model of identity in which particular developmental tasks are confronted at different stages of the life cycle. The first task of 'basic trust versus mistrust', when considered in the context of systemic theory of family secrets, suggests that basic trust may be undermined through the withholding of information by parents. This also links with attachment theory (Bowlby, 1969) and the development of a secure base for relationships.

Kroger (2004) discusses the significance of adolescence in the formation of identity in relation to five developmental models (Blos, 1962; Erikson, 1959; Kegan, 1979; Kohlberg,

1969; Loevinger, 1976). Each model suggests a process of intrapsychic differentiation of self from external others during adolescence, together with a rebalancing of relationships. The sudden revelation of donor conception in adolescence is likely to disrupt formation of ideas of self, potentially contributing to difficulties such as role-confusion (Breakwell, 1986; Erikson, 1959). Such possibilities are reinforced by adult donor conceived offspring's reports of difficulties in relation to self-identity following late disclosure of their conception (Pettle, 2002; Turner & Coyle, 2000).

The current position of donor conception research

Previous research has explored the implications of donor conception for child development and family functioning (Brewaeys, 2001; Golombok *et al.*, 1996; Golombok *et al.*, 2002a; Golombok, MacCallum, Goodman & Rutter, 2002b; Golombok *et al.*, 2004). Such research has reported no significant difference in parent-child relationships or child development in donor conceived families when compared with natural conception or in-vitro fertilisation (IVF) families, on a number of measures. The history of secrecy, however, has meant that this research has involved families who have not disclosed the information to offspring, limiting its value in understanding implications for families being open about donor conception.

Another influence towards openness has been adoption research. It has been suggested that donor conceived families face similar issues to families choosing adoption in terms of decisions of whether or not to disclose information regarding genetic relationships (Feast, 2003a). It is now widely accepted that openness about biological heritage is beneficial to adopted children, and it has been suggested that such findings are applicable to donor conception families (Blyth, Crawshaw, Hasse & Speirs, 2001; Crawshaw, 2002; Feast, 2003b;

Haimes, 1998). It must be noted, however, that such conclusions have not been uncontested. Caution must be used in drawing direct comparisons with adoption, as donor conceived offspring often have a genetic relationship with one parent and gestation and birth have occurred within the family (Feast, 2003a).

These factors: adoption research; theoretical literature and greater cultural acceptance, have led to a change in discourse and, with the changes in legislation, prompt a greater focus for research on the process and implications of openness in donor conception.

The following sections provide an overview of research findings identified from a systematic search of available research evidence (details of search strategy are provided in Appendix 1). Articles reviewed explored the experiences of parents and offspring regarding openness in donor conception.

Parents' experiences of openness

Research exploring the experiences of parents has included heterosexual couples, lesbian couples and single mothers. The findings from these studies focus on two key areas; including,

1. Reasons for disclosure/non-disclosure
2. The process of disclosure

Reasons for disclosure/non-disclosure.

A number of studies have explored parents' choices about sharing information about origins with their child/children. The findings across studies indicate the main reasons for disclosure are a desire for openness and honesty within the family, a wish to avoid

accidental disclosure and a belief that the child has 'a right to know'. Parents not wanting to disclose have stated their belief that disclosure is unnecessary, a desire to protect their child from potential negative responses, and a lack of confidence or knowledge of how to tell.

The studies retrieved were conducted across a variety of countries, allowing for generalisation of findings. Caution in generalising the results must be taken, however, due to differences in legislation regarding access to donor information across different countries, which may impact on parental disclosure decisions, as is discussed in the findings of the cited studies.

Studies in the USA using self-administered questionnaires asked parents to comment on their opinions and/or concerns about their disclosure decision (Nachtigall, Becker, Szkupinski-Quigora, & Tschann, 1998) and the impact of stigma on disclosure (Nachtigall, Pitcher, Tschann, Becker & Szkupinski-Quiroga, (1997). Findings indicated that parental beliefs regarding disclosure related to views of either honesty or confidentiality, with those holding beliefs of honesty disclosing and those holding beliefs related to confidentiality not disclosing. A positive correlation was found between disclosure and younger age of parents and lower scores for experience of stigma. This correlation further supports the relevance of social constructionist views regarding the impact of changes in discourse.

In the USA a proportion of centres providing donor conception treatment offer the option of use of donors who are willing to provide identifying information to the child when they reach age 18, commonly referred to across the literature as 'open-identity' donors. A further USA questionnaire study (Scheib, Riordan & Rubin, 2003) found that almost all parents choosing 'open identity' donors had shared the information with their child, suggesting that the decision to use this type of donor correlates with disclosure. The use of

self-report questionnaires allows for increased sample sizes but limits the capacity for in depth responses. The full complexity of the issues involved in decisions to tell may therefore not be accurately captured in the findings.

Shehab *et al.* (2008) conducted semi-structured interviews with heterosexual couples in the USA regarding disclosure decisions. Thematic analysis of 141 interviews showed that factors influencing disclosure decisions included local socio-political environment, professional opinion, counselling, religious and cultural background, family relationships, and individual personal, psychological, and ethical beliefs. Such findings highlight the need for research exploring the ways in which such factors impact on families and how those providing treatment, and associated counselling, can support families with this. Further research is also required to improve generalisability as both the 2003 and 2008 USA studies recruited from the same Californian sperm bank, which was one of the first offering 'open-identity' donor treatments, and hence may be more likely to support families to disclose.

In Sweden, legislation has given donor conceived offspring the right to identifying information about the donor, when reaching a 'sufficiently mature' age, since 1985. A Swedish questionnaire study found that only a small percentage of parents had disclosed (11%), or intended to disclose (41%), (Gottlieb, Lalos & Lindbald, 2000; Lindbald, Gottlieb & Lalos, 2000). A follow up study (Lalos, Gottlieb & Lalos, 2007) with 73% of the original study participants (n=36), found an increase in number of parents who had disclosed (61%), suggesting an increasing trend towards disclosure. An interesting finding was that, despite legislation to encourage openness, 20 participants felt they had not been encouraged by staff involved in their treatment to disclose information to their child. The majority of the

remaining participants, who felt they had been partly (n=10) or directly (n=6) encouraged to disclose, had done so, highlighting the role of health care staff in influencing attitudes.

A recent Swedish questionnaire study (Isaksson *et al.*, 2011) with 179 heterosexual couples, found further evidence of an increasing trend towards openness among Swedish parents, with 90% of participants supporting disclosure. The study notes that follow up research is required in order to ascertain whether 'support' is translated into actual disclosure at follow up. This study also indicated that up to 40% of participants wanted additional information and support following treatment, highlighting the need for a greater understanding of how professionals can support these families.

A Dutch study regarding the use 'open-identity' donors examined differences in disclosure patterns of 105 parents choosing 'open-identity' or anonymous donors (Brewaeys, Bruyn, Louwe & Helmerhorst, 2005). All those choosing open donors intended to disclose, whilst 83% of parents using anonymous donor did not intend to tell. This is a replication of findings from a 2003 USA study (Scheib, Riordan & Rubin, 2003), lending further support to the influence of 'open-identity' donors in disclosure decisions.

In the UK, legislation requires that all donor conceived offspring conceived after April 2005 have access to identifying information about their donor at age 18. Crawshaw (2008) investigated changes in disclosure patterns following the implementation of this legislation via infertility counsellors' perception of prospective parents' stated intentions. Members of the British Infertility Counselling Association completed questionnaires regarding changes in parents' stated intentions. Of the 75% of respondents reporting changes following removal of anonymity, two thirds stated that parents were more likely to say they would disclose and less than a tenth felt parents were less likely to do so. This further replicates findings

from Swedish and USA studies supporting a link between 'open-identity' donors and greater disclosure. The UK study, however, is limited by the use of third party perceptions and lack of follow up regarding whether disclosure intentions are acted upon.

A recent UK study indicates that caution should be taken in the assumption that a simple distinction can be made between disclosing and non-disclosing families (Readings, Blake, Casey, Jadvá & Golombok, 2011). This study explored disclosure decisions in families using donor conception and/or surrogacy, and suggested that parents engage in "layers of disclosure", in which information may be given in part, both to the child or family and friends and highlights that disclosure can be an on-going issue throughout the development of the child. This fits with the findings from the 2008 USA study (Shehab *et al.* 2008) regarding the complexity of factors influencing disclosure.

The results of the literature search suggest further UK based studies exploring parental disclosure decisions would be beneficial in understanding the complexities of this process. Following the 2005 changes in UK legislation, the links highlighted between disclosure and 'open-identity' donors appears particularly relevant in emphasising the need for UK based research in this area.

The process of disclosure.

A number of studies have explored the approach taken by parents who have shared information with their offspring. Across these studies there is a general consensus towards sharing of information at a young age, namely five years or younger (Blyth, Langridge & Harris, 2010; Kirkman, 2003; Lalos, Gottlieb & Lalos, 2007; Lycett, Daniels, Curson & Golombok, 2005; Rumball & Adair, 1999; Scheib, Riordan & Rubin, 2003). Reasons for early

disclosure included wanting the child to not remember a specific moment of being told, wanting to normalise the information and wanting children to grow up knowing the information.

A number of these studies also looked at how parents had disclosed the information to their child. In a New Zealand study using self-administered questionnaires 30% of a sample of 78 couples had shared information with their child (Rumball and Adair, 1999). Of these parents, 59% spoke to their child about the information 'sometimes' and 17% 'often'. The majority of parents felt that they themselves initiated conversations, whilst 48% felt that discussion was in response to children's questions. Some participants (20%) had some apprehensions about what may arise in the future as a result of telling. Parents' reported methods of telling their children included the use of analogy (usually 'seeds' for sperm) and specially written story books provided by the fertility clinic.

A similar pattern was found in a later UK study (Lycett, Daniels, Curson and Golombok 2003), in which a small number of participants (6/46) had already shared information with their children. Thematic analysis of the responses identified; use of analogy, use of story books and spontaneous conversation. In their Swedish telephone interview study, Lalos, Gottlieb and Lalos (2007), also found that parents who had disclosed to their children used methods of analogy (including "seeds" and "a kind man") and using the child's spontaneous questions such as 'Where do babies come from?' to introduce the topic.

Findings regarding the use of analogy and story books have been further replicated in a recent UK study using thematic analysis of interview data (Blyth, Langridge and Harris, 2010). The study highlighted the importance for parents' of the use of story books, particularly '*My Story*' (Infertility Research Trust, 1991).

Kirkman (2003) conducted a narrative analysis of interview data with 55 donor recipient parents in New Zealand. For those who had already shared information with their child, family stories played a significant role in the construction of the narrative identity of offspring. This supports suggestions from social constructionism and narrative theory about the impact of narrative for identity and sense of self. From the analysis, Kirkman identified that disclosing parents had been able to assimilate the use of donor conception into their own narrative identities and therefore had confidence and ability to assist in incorporating the story into the narrative identities of their children.

The use of story books to support telling may represent the importance of building narrative about one's life in order to support sense of self and identity. The preference demonstrated for disclosure before the age of five also links with understandings of the need for a coherent narrative of one's life as well as with thoughts from developmental theory regarding the potential for young children to understand complex information that is directly related to their experience.

Findings from such studies offer valuable insights into the ways in which families go about sharing information regarding donor conception. Replication of findings across studies suggest that such methods are useful to a number of families. The research literature, however, is lacking an understanding of why and how these methods are useful and a lack of follow up studies means that it is difficult to assess how helpful these methods are throughout development of the child and family.

Such research is also missing the perspective of donor conceived individuals themselves in relation to being told about their conception and their perceptions of the methods of telling used. Whilst Kirkman's study (2003) offers a more detailed description of the

processes involved in disclosure, as opposed to strategies used for telling, such studies appear yet to be implemented in the UK.

Whilst research findings offer some understanding of the reasons for, and processes involved in, being open about genetic origins, there is a need for further exploration from the perspective of donor conceived offspring as well as further research regarding the implications of such methods for child and family functioning.

Donor conceived offspring's experiences of openness

There is limited research available that looks directly at the experiences of donor conceived offspring in relation to disclosure (Jadva, Freeman, Kramer & Golombok, 2010a). This lack of data is likely to be due to the limited availability of participants caused by the history of secrecy, leaving many offspring yet to be told. The discourse of openness and 'right to know' has contributed to an increase in the number of parents disclosing their use of donor conception, resulting in a growing pool of offspring who are aware and willing to share their experiences. Research in this area is therefore growing.

As part of a Swedish questionnaire study parents were asked about their child's response to the information (Scheib, Riordan & Rubin, 2003). Parents reported responses as either neutral or no response with reasons given for this including being too young to understand and never knowing anything different. Responses regarding current feelings about donor conception were reported as either neutral or positive and reasons given included that their parent had been honest with them, that donor conception was not a major focus in their life and not having known any different. Such findings indicate positive experiences linked to disclosure at an early age, however, follow up studies are required in order to explore

whether this experience continues into adolescence, as well as studies which obtain data directly from offspring rather than through their parents.

A further questionnaire study by the same authors, asked Swedish 12-17 year olds with 'open identity' donors directly about their experiences of growing up aware of their donor conception (Scheib, Riordan & Rubin, 2005). Questionnaires were sent to 48 households with a 60.4% response rate (n=29). The majority (75.9%) reported having always known and most reported feeling somewhat to very comfortable with their origins. Reasons given were either that having a donor did not affect their life (44%) or that they felt very loved and wanted by their family (40%). Only two participants reported feeling somewhat uncomfortable with their origins and this appeared to be linked to desiring a traditional family structure.

A New Zealand study conducted focus groups with adolescents from the general population to ascertain their views on how parents should talk with donor conceived adolescents about their conception (Kirkman, Rosenthal & Johnson, 2007). Views of adolescents who were naïve to donor conception issues were consistent with those of donor conceived adults, including a preference for parental honesty and adaptation to the needs of individual children. A minority held a preference for non-disclosure and all participants felt that any disclosure should be by the parents. Whilst this study suggests that adolescents are likely to experience similar responses to disclosure to those suggested in research with parents, the findings are limited by the fact that participants were not directly affected by the issues themselves.

A UK study by Jadv, Freeman, Kramer & Golombok (2010a; 2010b) recruited participants via the Donor Sibling Registry (a worldwide internet registry enabling offspring to search for

and contact their donor half-siblings and/or donor) to complete a web-based survey regarding their feelings about their origins, feelings towards their parents (2010a) and experiences of searching for their donor and/or donor siblings (2010b). Data for the study were obtained from two sets of participants; offspring aged over 18 years (n=63), and offspring aged 13-17 years (n=102).

Findings from the first phase of the study (2010a) showed that offspring from single mother and lesbian couple families learnt of their origins earlier than those from heterosexual couples. Most participants reported feeling curiosity in response to disclosure. Significant associations, using chi-square analysis, were found between reported feelings and age of disclosure. Those told during adulthood were more likely to report feeling confused, shocked, relieved, numb or angry. The findings showed that 40% felt no difference towards their mother following disclosure, with offspring told as children being more likely to report this. Those told in adolescence or adulthood were more likely to report feeling angry about being lied to and feeling a sense of betrayal.

In heterosexual couple families chi-squared analysis examined feelings towards mothers and fathers separately. The most common feeling reported towards the mother was anger at being lied to, whilst the common feeling towards the father was sympathetic. Those told during childhood were more likely to report that disclosure made no difference in how they felt towards their mother. There was no significant association between feelings towards father and age of disclosure; however, the authors report a non-significant trend between older age of disclosure and feeling of being betrayed.

Findings regarding experiences of searching for donor siblings and/or donors (2010b) reported that 15% of participants were searching for their donor siblings, 13% were

searching for their donor and 64% were searching for both. Participants who had found out about their origins in adulthood were more likely to be searching for medical reasons and those who found out earlier were more likely to be searching out of curiosity. The majority of participants who had found donor relations reported positive experiences of this and had continued regular contact with them.

This study was able to access a large sample covering a broad age range and elicited responses regarding a number of issues related to disclosure and openness in donor conception. The findings gained, however, are mainly descriptive and focus on reported feelings in relation to specific people or issues whereas a qualitative analysis of responses may allow for a detailed exploration of the processes involved in creating those feelings. Whilst such studies are important in highlighting potential areas to be investigated a qualitative analysis of these areas may allow for an enriched understanding of the individuals' experiences of openness.

Findings appear to suggest that early disclosure brings more positive outcomes for offspring; however, Kirkman (2003) adds caution to this understanding in her narrative analysis of interviews with donor conception offspring in New Zealand. As part of a larger study, offspring constituted 10.4% of total participants. Narrative analysis identified that whilst positive experiences were associated with being told early in life, the relationship offspring had with information could change over time and life circumstances, and early disclosure should thus not be considered a panacea. The experience of openness within the family was found to assist construction of narrative identity and stable sense of self for donor conceived offspring and one participant spoke of this feeling of security supporting

her in her mixed feelings regarding donor conception. The relationship between openness and identity thus appears to be complex and multi-faceted.

Findings suggesting that individuals reporting knowing about their donor conceived origins from an early age feel comfortable with the information, and loved and wanted by their families, can be linked to theoretical understanding from attachment theory and the provision of a secure base (Bowlby, 1969). Such findings suggest that openness can add to the quality of the parent-child relationship as a mechanism of conveying feelings of attachment.

The fact that individuals who reported knowing about being donor conceived from a younger age reported more positive outcomes is in line with understanding from narrative theory and theory of identity development, in regard to the significance of having a coherent narrative to one's life supporting the development of a stable sense of self and identity.

The fact that individuals who reported later disclosure also reported increased negative feelings associated with knowing fits with understanding of a ruptured sense of identity (Breakwell, 1986) and the negative implications of family secrets described by Imber-Black (1998).

In summary, research conducted to date suggests that early disclosure is associated with more positive outcomes for offspring in regard to feelings about their donor conceived origins and feelings towards their parents. Offspring reporting having always known about their origins reported feeling comfortable with the knowledge. Findings also suggest, however, that feelings regarding donor conception can fluctuate over time and that a stable

sense of self and identity, constructed through openness within the family, can support offspring with this.

Further research is required to add to the limited, but growing, evidence base regarding openness in donor conception. Greater understanding is required in order to understand the processes involved in creating the positive outcomes seen in order to enable professionals to support families to be open. The fact that feelings regarding donor conception have been reported to fluctuate over time requires exploration of the issues that cause this fluctuation and potential ways of supporting individuals with this. The fact that not all respondents to surveys reported positive experiences with early disclosure suggests that more needs to be known about how the process can falter in order to be able to support families in achieving positive outcomes.

Conclusions and future research

Following a move towards a culture of greater openness and focus on the child's 'right to know', research has begun to explore disclosure patterns of parents and processes involved in 'telling'. Over time a higher proportion of donor conceived children have been made aware of their origins, and may participate in research regarding their experiences. Future research would benefit from exploration of the impact of disclosure for the continued emotional, social and psychological development of children throughout development into adolescence and adulthood, reflecting the changing nature of experience over time. Much of the existing research involves questionnaires, allowing for large sample sizes, but neglecting the possibility of in depth responses which can reflect the complexity of the subject matter. Qualitative exploration of the experiences of donor conceived young people

in relation to openness and its impact on child and family functioning would add to the existing knowledge.

In conclusion, changes in legislation reflect the legal and ethical rights of donor conceived individuals to information regarding their genetic origins. The disclosure decisions of parents of donor conceived children, however, remain varied. Whilst research has begun to explore the experience of openness for individuals and their parents, there is still much to know about the complexities involved in the experience of openness and the implications for therapeutic work with donor conceived individuals and their families.

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MAJOR RESEARCH PROJECT

NICOLA SHORTEN BSc Hons

Section B: An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.

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Abstract

Aim: The study aimed to build a grounded theory of the experience of openness in donor conception families in relation to the social and emotional experience of young people.

Method: Participants were 8 mothers, 7 fathers and 5 young people from 11 UK heterosexual families. Young people were aged between 12 and 25 years. Semi-structured interviews were conducted and the data analysed using Charmaz's constructivist grounded theory model (2006).

Results: The constructed grounded theory extends current research and highlights the complexity involved in the process of being open about donor conception. The constructed model presents a cyclical process reflecting the on-going nature of the experience and demonstrates that openness is not a one-off event, but is continually negotiated throughout the development of the child and family. The model suggests that positive outcomes for the child and family can be achieved through openness.

Conclusion: The constructed model highlights the cyclical nature of the process and the need for issues regarding openness to be re-negotiated at various points in the development of the individual and the family. Overall participants' experiences reflected positive outcomes from openness but illustrated how complex the entire process is, adding to existing understanding of this area.

Introduction

A longstanding historical debate around donor conception has been whether children should be informed of the details of their conception. Legislation from the Human Fertilisation and Embryology Authority (HFEA) now advises professionals providing treatment to offer counselling for prospective parents and encourage them to be open with their children (HFEA, 2004; 2007), and as of 2005 allows donor conceived individuals to access identifying information about their donor at age 18. The sharing of information with any donor conceived children remains, however, a parenting choice.

Evidence suggests that despite encouragement from professionals many families continue to choose not to be open with their children (Golombok *et al.*, 1996; 2002a; Freeman & Golombok, 2012). Conversely, the main support network for UK parents using donor conception (Donor Conception Network) predates the changes in legislation, and suggests that a factor in the drive towards openness has been families wanting to be open. The choice to be open therefore involves more than a compliance with professional advice.

National Institute for Health and Clinical Excellence (NICE) guidelines state that couples using donated gametes should receive counselling regarding physical and psychological implications of treatment for themselves and potential children (NICE, 2004). The provision of relevant research will assist professionals by providing understanding of potential difficulties faced by families choosing to be open as well as assisting potential parents to make informed choices regarding openness.

Why it matters

The debate over ethical and psychological implications for donor conceived individuals is long standing (Murray, 2003). Long term implications include issues around decisions of whether to tell and the psychological repercussions involved, both in telling or not telling

(Pettle, 2003a; 2003b). Arguments for advocating openness have drawn on systemic theory regarding the psychological ramifications of secrecy (Karpel, 1980; Imber-Black, 1993).

Research with donor conceived individuals who have found out about their conception later in life reports feelings of mistrust between family members as well as anger and resentment at not being informed (Pettle, 2002; Turner & Coyle, 2000). Such evidence supports the relevance of theories of identity development and narrative theory, reflecting the potential ruptures to the understanding of one's identity following a sudden change in the narrative of one's life (Breakwell, 1986).

The legal-ethical debate around openness in donor conception also points to issues regarding significance of medical implications in awareness of genetic origins. In a context of secrecy an individual may be unaware of potential medical risks related to their genetic history, and hence be denied access to appropriate medical advice and care through this omission.

A family building model

The function and purpose of donor conception may be viewed as a method for treating infertility, a process ending with the birth of the baby. Alternatively, donor conception is increasingly viewed as a method of building families, reflecting the on-going process of its involvement in the past, present and future of family life (Daniels & Thorn, 2001).

The family is not a static being; a multitude of external and internal factors are entwined in the responses and interactions of family members and add to the ebb and flow of family life, which require reflection in research.

Social constructionism assumes that knowledge is shaped by our historical, cultural and social context (Burr, 1995). The changing nature of the cultural context in relation to donor conception is likely to influence the experience of families. Families with adult donor

conceived offspring who have chosen secrecy may face very different issues now, with wider media coverage and public awareness of donor conception, than when their child was first born.

Likewise, the issues faced by families change throughout development and maturation. Carter and McGoldrick's family life cycle model (1989) reflects the various points of development and transition experienced by families, and the need for negotiation and adjustment for successful progression. Such transitions are likely to be salient points in the consideration of donor conception issues.

Previous research

A number of studies have looked at quality of relationships, marital relationships, child development and functioning (Brewaeys, 2001; Golombok *et al.*, 2002a; Golombok, MacCallum, Goodman & Rutter, 2002b; Golombok, Jadva, Lycett, Murray & MacCallum, 2004; Golombok *et al.*, 2004; Golombok *et al.*, 2011). Such studies have found no significant difference between donor conception families and traditional families.

A caveat to the findings of such research is presented in the fact that large numbers of participating families had not disclosed to their child that they were donor conceived. Such research therefore is limited in what it can inform us about processes within families being open. Findings from the small samples of disclosing families, however, have shown indications of more positive parent-child relationships compared with non-disclosing families (Lycett *et al.*, 2004; Golombok *et al.*, 2011) and an association between disclosure and lower levels of mother-son conflict (Freeman & Golombok, 2012).

Findings from such studies must be interpreted with caution. Methods used have included the standardised coding of semi-structured interview responses and standardised questionnaires. Whilst the use of such methods allows for increased reliability and validity,

the potential to capture the complexity involved in family processes is limited. The data gathered also involves a snapshot in time and does not necessarily reflect family functioning overall. The potential for confounding influences outside of disclosure decisions is also vast, and only suggestions of association may be drawn. The ethical implications of involving children in research studies when they are unaware of the purpose of the study must also be considered.

A further caution lies in the assumption that a simple distinction can be made between disclosing and non-disclosing families. A recent study suggested that parents engage in "*layers of disclosure*", in which information may be given in part, both to the child or family and friends (Readings, Blake, Casey, Jadva & Golombok, 2011).

Research directly involving donor conceived individuals who are aware of their origins is limited. One study reported the majority of individuals to feel somewhat to very comfortable with the knowledge of being donor conceived, with reasons for this including the knowledge not impacting on their life and/or feeling very loved and wanted by their family (Scheib, Riordan & Rubin, 2005). A further study reported those told during adulthood were more likely to report feelings of anger and confusion while those told in childhood more likely to report no difference in their feelings towards their parent (Jadva, Freeman, Kramer & Golombok, 2010).

These studies used surveys, allowing for greater numbers of participants, and thus increased generalisability of findings, however, the responses available to participants are limited. The methodologies used in the research described appear to represent a simplistic position of either/or, with openness being either good or bad. The complexity of family functioning and interpersonal relationships would perhaps be more deeply explored

through a qualitative and post-modernist position, incorporating the influence of the changing nature of the context in which the individual and the family find themselves.

What is left to be explored is the potential for feelings of 'both/and', being both comfortable and at times uncertain about issues related to donor conception. A narrative analysis study by Kirkman (2003), conducted in New Zealand, highlights the potential for this position, suggesting that the experience of openness within the family assisted in the construction of narrative identity and sense of self, which in turn supported an individual in their mixed feelings about being donor conceived. Such findings, however, require replication with UK participants.

Rationale for the present study

Legislation requiring professionals to encourage parents in being open, together with the removal of donor anonymity, supports a move towards greater openness in donor conception. Previous research lacks an understanding of the experience of families over time, as they incorporate openness about donor conception into their family narrative and individual identities.

This represents a shift in the debate, moving on from discussion of whether to be open, to a discussion of what families being open are experiencing, what helps or hinders openness, where are the potential stumbling blocks or areas of resilience and growth, and how can professionals use this knowledge to support families both in being open, and continuing to grow as a family with openness.

The present study aimed to investigate the experiences of families being open about donor conception by conducting semi-structured interviews with mothers, fathers and donor conceived young people (aged 12-25) from heterosexual families. A qualitative methodology was used in order to allow for findings to emerge directly from the accounts of

participants. The study aimed to elaborate theoretical knowledge of the experience of openness and to inform clinical practice with regards to working therapeutically with individuals and families .

Aims and Research questions

The present study aimed to build a grounded theory of the experience of openness in donor conception families in relation to the social and emotional experience of young people, addressing the following specific research questions:

1. What are the experiences of young people age 12 years and older in regard to openness and disclosure?
2. What are the experiences of parents of young people age 12 years and older in regard to openness and disclosure?
3. What do young people and parents describe as the impact of openness for the young person's and the family's social and emotional experience?

Method

Participants

Participants were 8 mothers, 7 fathers and 5 young people from 11 UK heterosexual families. Young people were aged between 12 and 25 years. Those younger than 12 years were excluded in order that participants could fully participate in interviews and reflect on experiences throughout their development. Participants from single parent and lesbian couple families were excluded due to differences created by the absence of a male parent. Of the 11 families, 7 had conceived using donor sperm, 3 using donor egg and 1 using donor egg and sperm. Two families had used a known donor and the remaining 9 anonymous donors. Demographic data are included in Appendix 2. All participants were members of the

Donor Conception Network (DCN). The DCN is a UK parent-led charity, supporting families using donor conception.

Ethical considerations

Ethical approval for the study was granted by the Canterbury Christ Church University Research Ethics Committee (Appendix 3). The study adhered to the Health Professionals Council (HPC) and British Psychological Society (BPS) code of ethics and conduct (BPS, 2006; HPC, 2004).

Design

The study used a non-experimental, qualitative design. Data were gathered using semi-structured interviews and analysed using constructivist grounded theory methodology (Charmaz, 2006). The use of semi-structured interviews involved open-ended questions and allowed for additional questions based on the interviewee's responses, allowing for generation of rich data.

Interview schedule

The interview schedules for parents and young persons (Appendix 4) were based on the research questions. Questions were adapted and follow up questions included based on the responses given, as expected in grounded theory methodology. The language and content of the interview schedule was reviewed by a clinical psychologist with experience working therapeutically with donor conception families. The feedback was positive and the questions were reported to reflect the research questions.

Procedure

Participants were recruited through placing an advert (Appendix 5) in the DCN monthly ebulletin. Interviews were conducted individually in participants' homes by the principal researcher. A private room was used to ensure confidentiality. To ensure informed

consent, information sheets for parents and young persons were provided prior to interview (Appendix 6). Prior to interview the purpose and procedure of the study were discussed and the right to withdraw was highlighted. After an opportunity to ask questions, an informed consent form was signed (Appendix 7). Where participants were under the age of 18 a parent also signed the informed consent form. Interviews were between 30 and 60 minutes long and were audio recorded and subsequently transcribed by the principal researcher. Interviews were followed by an informal debrief and the opportunity to ask any further questions.

Data Analysis

Data were analysed using a constructivist grounded theory approach (Charmaz, 2006), which assumes that the research process involves an interpretation of the studied phenomena rather than a precise understanding of it. The generation of a grounded theory is therefore viewed as a co-construction of reality, between researcher and the participants.

Grounded theory was chosen for the present study due to the capacity to reflect the complexities emerging from rich data. The development of theoretical knowledge in this area is hoped to inform clinical practice of those working therapeutically with families using donor conception.

Analysis linked raw data with the generation of theory through a process of stages of coding, including:

1. Line by line coding. Where appropriate, codes were focused on actions in order to ensure connection to the data and reduce the influence of the researcher's own constructions (Charmaz, 2006). The first three interviews were coded line by line.

2. Focused coding. Initial codes placed into broader codes. Constant comparison was used to ensure codes remained connected to the raw data. Theoretical saturation was achieved when no new codes emerged from new data.
3. Theoretical coding. Focused codes were analysed in regard to their relation to one another in order to generate a theory.

Written memos were used throughout, to capture concepts emerging from the data and inform theory development (Appendix 8).

Quality assurance

The process of coding involved regular consultation with research supervisors experienced in grounded theory. Line by line coding of the first three interviews were cross-checked by supervisors, as well as focused coding and the constructed theory model. An audit (Elliott, Fischer & Rennie, 1999) was completed by an independent colleague of the researcher, through coding of a section of transcript, with no major discrepancies found.

Respondent validation was obtained through providing a summary of the generated theory to participants (Appendix 9) and feedback given regarding whether the summary was reflective of their responses (Appendix 10).

Credibility of data was ensured through the use of quotations linking the generated focused and theoretical codes to the data (Williams & Morrow, 2009). Omitted data within quotations is identified using square brackets. Quotations are linked to participants through the use of a code for participant type; M (mother), F (father) or YP (young person), participant number and family number (coded f1-f11), for example the first participant in the study is identified as M1(f1).

Finally, the researcher kept a reflective diary to increase awareness of her reactions to the data and reduce the influence of researcher bias (Appendix 11).

Results

The theoretical coding stage enabled the construction of a theory describing the process of openness and resulting outcomes in the families studied.

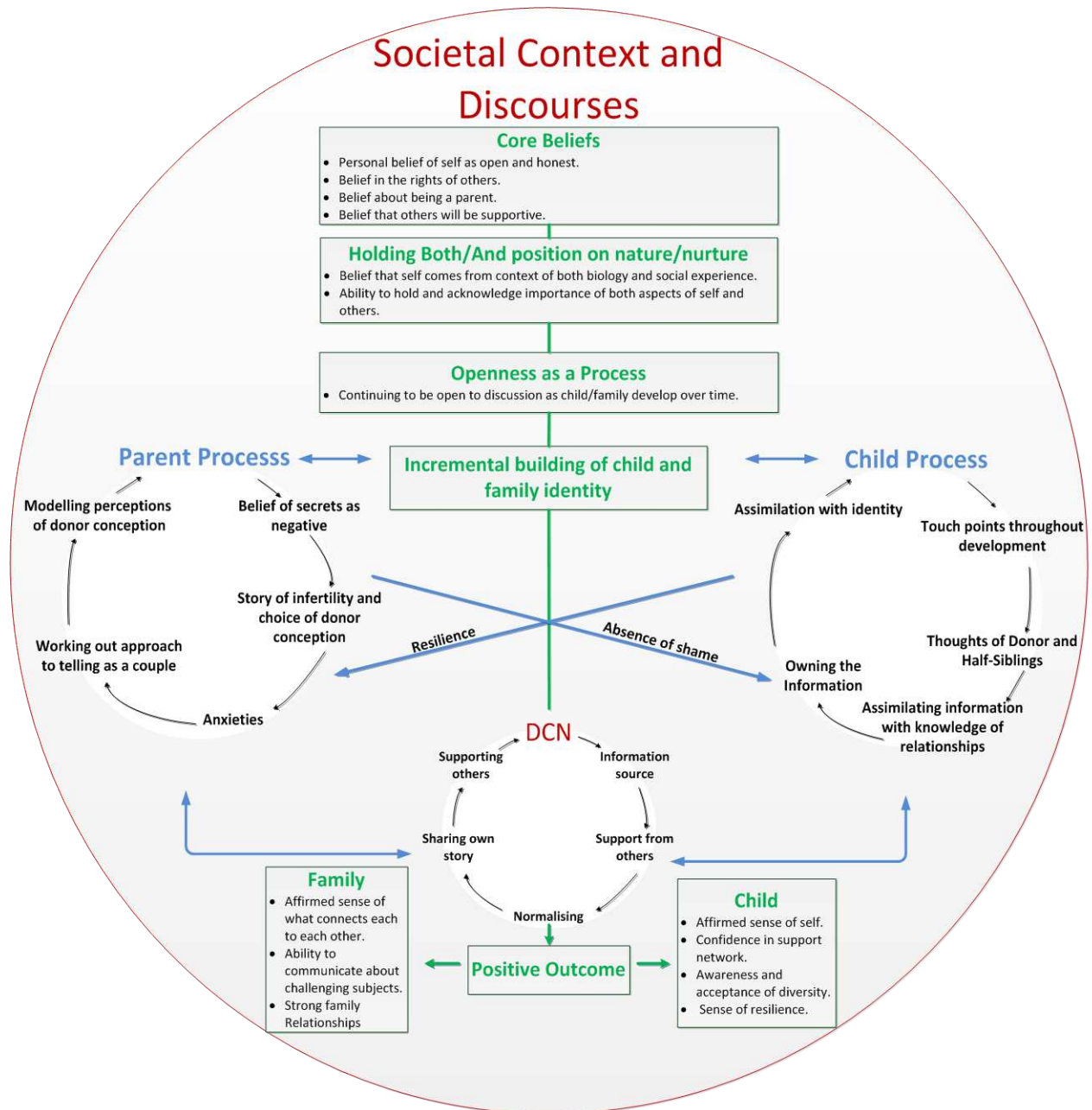


Figure 1: Constructed model of process of openness.

Summary of model

The model constructed from the theoretical coding describes a hypothesis regarding the process of openness, based on the experiences of the families interviewed. If the various stages of the model are negotiated then the resulting positive outcomes can be seen. The cyclical nature of the processes reflects the on-going nature of the experience and demonstrates that the outcome is not a one-off event, but is continually negotiated throughout the development of the child and family.

Societal context and discourses

The encompassing circle of the model represents the influences of wider societal and cultural discourses. The data reflected an awareness of the way that different family formations are viewed in society.

“But modern medicine means that [] you can make families in all sorts of different ways too now, so that’s why we went down that route to being open about it” (L.271-275, M1(_1))¹

There was also an awareness of the impact of professional opinion and advice.

“what clinician’s, therapists and the world in general says to you is very influential on what you what you do” (L.198-208, F4(_8))

Finally the influence of cultural differences was highlighted in the data.

“friends who haven’t told the children yet because they haven’t told her parents because she’s [ethnic background] so culturally it’s very different” (L.7-9, F5(_9))²

¹ Family identification numbers have been removed from the electronic copy to preserve anonymity

² Data has been removed to preserve anonymity

The influence of these factors appeared to be salient throughout the process and is thus presented as an encompassing circle.

Core beliefs

The term 'core beliefs' has been used to describe the internally held beliefs participants described about themselves and others. This term, although more commonly associated with cognitive behaviour therapy (Beck, 1976) was used to reflect the emergence in the data of beliefs that were central to the individual and how they considered themselves as a person.

"I am just a very honest person" (L.17, M7(_7)).

The core beliefs conveyed a sense of self as an open and honest individual who would not be secretive.

"I'm someone who I couldn't possibly keep that sort of secret I mean it would be absolutely impossible for me I'm just not like that" (L.20-21, M4(_4))

"it almost to us openness was the norm and we would have to make a very conscious decision not to do that [] and I think that's probably just a reflection of the sort of people we are" (L.13-18, M2(_2))

Parents referred to specific beliefs about the task of parenting, reflecting a desire as parents to assist children to develop as an individual in their own right and support them to feel comfortable in their sense of themselves.

"to be respected that helps you to [] have a consistent sense of yourself and [] it's supporting those things []cos that's all you want for anybody isn't it really" (L.238-242, M6(_6)).

There was also a reflection of ethical beliefs regarding the rights of others, in particular the rights of children to information regarding their own personal history.

“there’s ownership in information and it’s important that information about ourselves remains in our ownership” (L.11-12, F2(_6)).

The data also reflected core beliefs held regarding others, with a focus on seeing the potential for others to be supportive.

“also I think you can get a lot of guidance and comfort and moral support by sharing what’s going on in your life” (L.153-154, M1(_1))

Holding a both/and position on nature/nurture

Linked closely with core beliefs was a sense of believing in the interplay between genetics and social experience, and the emergence from the data of a position of holding and acknowledging the importance of both aspects for relationships and development.

“there is a difference because he has a donor so somewhere there may be somebody with a family album with pictures in it that look like him because they’re genetically close to him []and important to recognise that but that doesn’t mean to say that you’re emotionally less close” (L.37-42, F4(_8)).

“I mean there’s what’s nurture and what’s nature what have you genetically inherited and what have you learnt [] and I think I’ve always been conscious that _(Daughter)_ might have another skill set naturally []so I think we’ve been quite aware to let her find her path” (L.143-148, F6(_10)).

This was also reflected in data regarding connections formed in spite of the absence of a genetic link.

“like a connection with him which possibly to me is more powerful than a genetic connection [] you can be genetically related to a dad who’s a drunk and leaves you so it’s so much more powerful a relationship [] what he’s done and continues to do for me as a dad” (L.191-197, YP2(_4)).

The category was also reflected in data regarding the acknowledgement of the absence of a genetic link.

“she said to me, oh mummy look, I’ve got red in my hair and at that point I said, oh yes how lovely do you think maybe one of our donors had red hair? [] and if I was to build on those and say oh yes just like mummy [], I would be building up this alternative understanding about who she is, physically connected to me, that would be wrong” (L.198-209, M1(_1)).

Openness as a process

The previous categories appeared to set a background to the reasons for and ability to embark on the next stage in the model, which involved the actual act of being open. The data reflected that previous categories appeared to lead to this stage.

“we went down that route to being open about it and to be honest I just can’t imagine doing it any other way” (L.275, M1(_1)).

The data reflected a sense that the act of being open was not a one off event, but a process which changed and developed over time.

“absolutely essential you tell them [] but that’s really only the beginning of the story” (L.439, F1(_3)).

This category reflected changes over time and development and included sub-categories of:

- **How to tell**

This included data regarding how the topic of donor conception was discussed in families and also reflected the change in form and content of discussions over time.

“as she gets older I just expect that her questions will become more sophisticated and so my answers would become more sophisticated.” (L.333, M1(_1))

“So I suppose yeah it’s different stages really of their development changed it and of course now it’s you know it’s introduced another layer to it again I suppose as she thinks more about her identity” (L.41-44, M3(_3)).

- **Who to tell**

This sub-category reflected data regarding who participants told the information to and also reflected the sense emerging from the data that the process involved a dilemma between telling on behalf of the child when they were young, in order to create awareness, but wanting the child to be able to choose who knew, as a reflection of the child’s ownership of that information. The process reflected in the data was therefore one of the information being placed more in the hands of the child as they grew up.

“I’m talking to people about it now [] so that if he needs to talk about it the information isn’t met with shock or horror [] but once he’s big enough to advocate for himself [] he can decide for himself whether he tells” (L.55-60, M6(_6)).

“I want him [] to be in ownership of who knows that information as he grows up so he can choose who is aware of it [] but that’s not simple” (L.24-27 F6(_6)).

- **Continuing the discussion**

This sub-category reflected an active process of making sure the topic continued to be discussed.

“Definitely keen to you know keep this on the agenda to keep it out there in the family discussion [] I think you’ve got to work at it a bit” (L.319-322, D1(_3)).

- **Donor conception moving to the background**

A further part of the process emerging from the data was the salience of donor conception for families lessening over time. This reflected a process in which the tasks of

parenting and/or daily life and development become the forefront of the families' functioning, and issues regarding donor conception are thought about less.

“that actually, once you’ve had the child they’re just your child, and your worries become, you know, how to deal with colic” (L.46-49, M2(_2))

“the main thing that’s on my mind is like school [] like during normal school I just like I never really think about it” (L.272-279, YP1(_3)).

Incremental building of child and family identity

The sense of openness as a process rather than a one off event appeared to link with a gradual building of the child and family identity, as the child and family develop their way of discussing the information throughout stages of development, and negotiating transitions and stages in the process.

“although we might not talk about it a lot [] it’s part of what we are and it does crop up in different ways []there are things to be negotiated” (L.492-495, F1(_3)).

The data reflected links between this category and the following two categories of parent process and child process. Figure 1 links the three categories using bi-directional arrows, to reflect the emergence in the data of the cyclical nature of the process of building a sense of identity, both for the child and the family.

Parent process

Data from the interviews with mothers and fathers reflected a process specific to the parents in regard to their own experiences and the nature of the infertility that brought them to the decision of using a donor. The cyclical nature of the process reflects the way in which the various sub-categories feed into each other, and again demonstrates the on-going nature of the process through the growth and development of the family.

Each of the sub-categories within the parent process category are described below:

- **Belief of secrets as negative**

Parents all stated that they perceived secrets as negative and the interview data reflected a sense of not wanting to keep secrets.

“not tell him or to say you’ve got this information and it’s a secret both very bad” (L.150-151, F5(_5)).

“how much resentment there is about having kept a secret [] and how you only feel negatively about it” (L.253-255, M3(_3)).

- **Story of infertility and choice of donor conception**

The data reflected a sense that the pathway to the point of choosing donor conception influenced parent thoughts about being open.

“there’s a different history [] that changes things slightly and similarly if you’ve got donor egg, but father’s sperm, or donor sperm but mother’s egg, all of those scenarios change the story just a little.” (L.251-254, M1(_1))

- **Anxieties**

The data reflected the presence of anxieties, both for the child themselves and for the parents’ relationship with the child. The cyclical nature of the parent process was particularly relevant in this sub-category, as it emerged that anxieties eased with time but were replaced by new anxieties, related to the child’s stage of development. A further sub-category also fed into this aspect of the parent process, and is reflected in figure 1 as a uni-directional arrow, linking the child process to parent anxieties. This arrow represents the impact of child resilience, as it emerged from the data that resilience seen in the children eased parental anxieties.

“I feared you know that it would confuse them about their dad and I think as time went on I’ve realised that’s not the case at all [] it just doesn’t have any bearing emotionally on it or in practical terms so my fears are kind of unfounded” (L.162-170, F1(_3)).

“when she was 9 she talked about it in class [] and there were a couple of attempts after that by a couple of girls to sort of bully or tease her about it and they were they were completely deflated when _(Daughter)_ just wouldn’t get upset about it” (L.220-224 ,M4(_4)).

- **Working out approach to telling as a couple**

This sub-category arose from data reflecting potential for differences and how couples negotiated this together.

“I tend to bring it up more than _(Mum)_ does in fact I think I definitely do [] also I probably wear my emotions on my sleeve a bit more” (L.301-304, F1(_3))

- **Modelling perceptions of donor conception**

A sense emerged of parents providing a positive model for how donor conception is perceived by the child.

“if you feel ok about it yourself, it should all come out well” (L.426-427, M1(_1)).

“I have the capacity to be open [] so I think if we model that then I think that’s something that _(Son)_ ’s gonna find normal” (L.220-223, M6(_6))

This sub-category was linked to the previous sub-categories through a sense of needing to move through the various stages before reaching a point where the information could be presented to the child in a way which reflected an absence of anxiety or shame.

“the point is if he can come to terms with it himself then she’ll be fine about it, but if he can’t then that will in some way communicate itself” (L.448-450, M1(_1))

A further sub-category of ‘absence of shame’ emerged, which links the parent process category to the child process category. This is represented in figure 1 as a uni-directional arrow linking parent process to the child process sub-category of ‘owning the information’.

The data reflected a sense of sharing information with children in a loving way supported them to feel ok with the information.

“they’re not quite sure how to feel and I’m not quite sure how to put it across so I think kind of fumbling towards some understanding some non-threatening discussions and loving discussions and I mean in the end its positive if they feel positive” (L.388-391, F1(_3)).

The two uni-directional arrows displayed in figure 1, representing ‘resilience’ and ‘absence of shame’, link the parent and child process in a figure of eight. This emphasises the sense of on-going interactions of time, development and personal growth, as the family continues to change and mature.

Child process

Data from the interviews with young people also reflected a process specific to the donor conceived child and their experiences of knowing. Similarly to the parent process, this reflects the way in which the various sub-categories feed into each other, and the on-going nature of the process through individual growth and development.

Each of the sub-categories within the child process category are described below:

- **Touch points throughout development**

This sub-category reflects the way that openness appeared to become more or less salient during different points in development. Young people described a sense of knowing but not really understanding the information when they were very young, and coming to understand the information more as they grew.

“well when I was younger I was kind of like I wasn’t really listening [] another daddy that’s really cool but like now I kind of think about it more like oh I have this huge decision if I meet him” (L.496-499, YP1(_3)).

“now I’m at that age where if I wanted to I’m able to contact my half siblings and [] I might have thought like 2 or 3 years ago I would have been anticipating how I would be feeling now in making those decisions” (L.119-126, YP4(_8)).

- **Thoughts about the donor and donor half-siblings**

The data reflected a process of thinking about the donor as the young person’s understanding matured.

“as I got a bit older and was doing science more I thought a bit more about like the genetics side of it and I was like in some ways it would be quite nice to know a bit more about not him but his like medical history” (L.187-191, YP5(_10)).

“sort of discovering a potential other branch of the family [] suddenly adding that new part of the family is that going to take anything away from what I have currently which is what I’m thinking about most often I think at the moment” (L.127-133, YP4(_8))

- **Assimilating information with knowledge of relationships**

There was a reflection of a process of understanding and making sense of what the information meant for the relationships that the young person has within their family.

“with my sister like we have different donor dads so we’re kind of like half-sisters [] like if we had the same donor dad we’d be like oh yeah we’re sisters” (L.323-325, YP1(_3)).

“sometimes I’m just sitting there and I think that’s not actually my real dad but like five minutes passes and he’s just my dad again” (L.56-59, YP3(_7)).

- **Owning the information**

The data reflected a process of becoming able to take ownership of the information and make decisions regarding how the information was shared or not shared.

“occasionally I tell friends like if it comes up and it is something that’s relevant to the conversation” (L.48-51, YP4(_8)).

“cos a couple of the boys in my class I know they’re like really immature [] I don’t really want them to know until they’re like older and like mature and stuff” (L.148-153 YP1(_3)).

This sub-category also linked with the parent process category via the sub-category of ‘absence of shame’. This was reflected in data describing the way parents had shared the information.

“made knowing a lot easier cos like they’re comfortable telling me and they’re comfortable for me to ask questions [] so it hasn’t made it anything that’s been like a worry” (L.91-93, YP4(_8)).

- **Assimilation of the information into identity**

The previous sub-categories within this category appeared to lead into a process of assimilating the information into the young person’s identity. This was reflected in descriptions of this being an acceptable part of themselves and who they are.

“it’s something that like err no big deal but it’s a large part of me and its integral to who I am” (L.234-235, YP2(_4)).

“I accepted it as being something about me another fact about me that I’ve got brown hair and brown eyes and I’m a donor baby it’s just one of those things” (L.101-104, YP5(_10)).

DCN

The extent to which participants engaged with the DCN varied, however, common codes emerged from the data reflecting that the organisation was used at different times and was helpful in various ways. This cycle in turn, fed into the parent process and child process categories, as reflected in figure 1.

The sub-categories of the DCN category are described below:

- **Information source**

Data reflected the use of the DCN as a source of knowledge and information regarding the process of openness.

“a little workshop that I went to called Talking and Telling, which is fantastic,” (L.412-414, M1(_1))

- **Gaining support from others**

The data described a process of gaining the support of others in similar situations.

“the other mother whose children were donor conceived and I spoke together to _(daughter1)_'s teacher” (L.339-340, M1(_1))

- **Normalising**

A key role of the DCN that emerged from the data was in normalising the process, both for parents and for young people.

“one of the great benefits of the DI network is erm it normalises all this stuff you think well you know this is just what happens” (L.187-188, F1(_3)).

“I started meeting kids when I was like 6 or 7 [] it definitely normalised it for me” (L.214-215, YP2(_4)).

The cyclical nature of DCN engagement was reflected in the following two sub-categories, of ‘sharing own story’ and ‘supporting others’, in the way that participants had begun to share their own experiences with other members of the DCN, reciprocating the support and normalisation that they had experienced.

- **Sharing own story**

“asked to speak about my experiences and I had so many people coming up to me and being like the stuff that you said has been so important to me and that like blew me away” (L.69-71, YP2(_4)).

- **Supporting others**

“I’ve had conversations on the phone with people who’ve been suggested by the DCN [] and rather than having a set thing to say it’s usually a response to their fears” (L.228-231, F6(_10)).

Positive outcome

The model (figure 1) represents the hypothesis that if the various stages of the process are negotiated then the resulting positive outcomes for the child and the family can be seen. The categories related to positive outcomes include 'outcomes for the child' and 'outcomes for the family'. The sub-categories related to each are described below.

Outcomes for the child

The outcomes that emerged in regard to the child included:

- **Affirmed sense of self**

This reflected a sense of the openness allowing for young people to have a stronger sense of themselves as donor conceived individuals and feeling accepting of this.

"just the way that my family is about being open to talk about stuff maybe that's made a difference in how sort of I'm quite laid back in talking about anything" (L.275-277, YP5(_10)).

- **Confidence in support network**

Young people conveyed a sense of feeling able to talk about issues with family members and seek support when needed.

"it's about trying to give them confidence about how to negotiate around this thing so [] that they feel that their family supports them in this" (L.325-328, F1(_3))

"my strongest opinion growing up was just that I really really respected my parents for being honest with me" (L.87, YP2(_4)).

- **Awareness and acceptance of diversity**

The openness created a greater acceptance of difference in others both in the young persons' views of themselves as well as parents' views of their children.

"I think if I didn't know about it I wouldn't be as accepting to other people [] so I think that when other people are slightly different I like accept them more than like other people do" (L.95-100, YP3(_7)).

"I know it will make them more tolerant of other people and other families' differences" (Line 365, F1(_3)).

- **Sense of resilience**

The process was linked to the building of a sense of resilience in young people.

"how he builds his resilience is by it being hard and he comes out the other side and its ok [] that's how you learn when something is difficult you survive it" (L.295-297, F2(_6)).

Outcomes for the family

The outcomes that emerged in regard to the family included:

- **Affirmed sense of what connects each individual to each other**

The data reflected a sense of a deep relationship between family members that is based on attachment rather than genetic links.

"I also felt very devastated not to have a child that was genetically mine I don't feel the strength of those feelings anymore [] I'm more used to being around _(Son)_ you know and all the attachment that's there how much that means" (L.341-343, M6(_6)).

"that I am her real and only mother, she has a donor, she doesn't have two mothers, she has one mother, and a donor" (L.391-393, M1(_1)).

- **Ability to communicate about challenging subjects**

There was an emergence of a belief that talking about donor conception set a context for other challenging subjects to be spoken about.

"I think it's taught them that openness is accepted in this family and the lessons that we've learnt from being open [] have extended into lessons about being open with all sorts of things" (L.199-201, M2(_2))

- **Strong family relationships**

The data described a sense of robust, close relationships within the families, and reflected a sense that openness had contributed to the sense of closeness achieved.

“I think it’s brought us closer it perhaps makes us feel special in some way” (L.351,F1(_3))

The data reflected a strong sense that openness was positive overall, although there was a clear picture of negotiating the process around the subject throughout the child’s development and life of the family.

Discussion

The constructed theory from this study provides a model of the process occurring within a sample of families who are being open about donor conception. The model provides an opportunity to recognise the processes relating to positive outcomes for these families, and factors which facilitate openness, hence informing the provision of support and therapeutic work with other families who have chosen, or are considering donor conception.

Importance of societal context

The influence of societal context and discourses is highlighted in relation to impact on decision to be open and feelings of acceptance of the information, both by the individual and by systems external to the family. This is a replication of findings from previous research (Crawshaw, 2008; Blyth, Langridge & Harris, 2010) and adds further weight to the necessity for considering social context in relation to donor conception issues.

The interplay between societal context and the various stages of the constructed model is in line with theoretical understanding of the impact of social representations for identity. Breakwell (2001) described a process whereby social representations become integrated

with personal representations, and thus incorporated into identity. In order for integration to occur the information must be assimilated with pre-held internal cognitions and emotional responses, thus anchoring the information to something already held within the individual.

The model constructed represents the interplay between pre-held beliefs and taking a position of both/and in relation to genetic and social relationships, and demonstrates a link between these concepts and the choice to embark upon the process of openness. This appears to demonstrate Breakwell's theory of a need for a pre-existing level of cognition and emotion, in regard to the ability to integrate the changing societal representation of donor conception into the individual's own beliefs about openness. This suggests that there is a particular aspect of pre-existing personality and belief system in the sample which facilitates the subsequent processes.

This perhaps provides some explanation for the fact despite changing legislation and advice from professionals in support of openness, large numbers of parents continue to not disclose to their children (Golombok *et al.*, 2011; Freeman & Golombok, 2012). Discussion with families embarking on donor conception regarding their personal beliefs, and subsequent therapeutic work in relation to this, may assist families to be open regarding this topic.

Importance of parent-child relationship

The categories of 'parent process' and 'child process' within the constructed model were interlinked, demonstrating their complex and dynamic interaction. The links between parental modelling of perceptions of donor conception, via 'absence of shame', and the young person 'owning the information' mirror concepts described in attachment theory (Bowlby, 1969).

Modelling of a positive perception of openness by the parent, together with remaining open to discussion and a willingness to think together as a family about the issues, can be viewed in Bowlby's terms of provision of a 'secure base'. This provision allows for the young person to build their own internal representations of what it means to be donor conceived, as described in the category of 'assimilation with identity'. This process reflects Bowlby's concept of an 'internal working model' of relationships, in which the young person builds an internal representation of donor conception as positive, and thus is able to assimilate this into a positive view of the self. This also links to the category of 'resilience', in that provision of a secure base is linked to development of resilience (Bowlby, 1969).

The fact that anxieties and dilemmas were present in the data and the constructed model, and yet outcomes were perceived as positive, can be linked to theoretical understanding of 'good enough' parenting (Winnicott, 1965), in which challenges may be experienced but are perceived as manageable and are thus able to be repaired.

The category of 'openness as a process' reflects an ability of parents to consider the current and future needs of their children as they develop. This reflects a capacity for mentalisation (Luyten, Fonagy, Lowyck & Vermote, 2012) in the awareness of the parents own needs and cognitions, such as needing to discuss the topic with family members, as well as the potential needs and cognitions of the child, such as wanting them to have a support network who are aware, but also wanting them to be able to choose who knows the information. Concepts of mentalisation may therefore play a useful role in working therapeutically with families wanting to be open about donor conception.

Significance of social versus genetic relationship

The category 'holding both/and position on nature/nurture' replicates findings from previous research with donor conceived families regarding kinship relationships. This

highlighted parents' perceptions of genetics as both irrelevant, as strong and secure attachment relationships can be developed without a genetic link, and also relevant, in relation to specific issues such as knowledge of medical history (Grace & Daniels, 2007).

Research with donor conceived individuals who have made contact with their donor half-siblings has reported the significance of a desire to know about genetic origins (Jadva *et al.*, 2010). Qualitative exploration of the individuals' desire to search reported the significance of drawing on both genetic and non-genetic aspects of identity (Blyth, 2012). The present study offers further insight into this aspect of the donor conception experience, by placing it within the process of what is happening for the family.

Impact of support networks

The constructed model highlights the role of the DCN in the process of achieving positive outcomes. The nature of involvement, moving from gaining support to supporting others, and the continuing cycle of learning from others' experiences, reflects a virtuous circle (Keeney & Kenney, 2012) in which the individuals re-enter the process with a greater understanding than on first entering, in a continual process which nurtures growth. This highlights the value of peer support in assisting families considering openness.

Limitations

There are limitations to this study regarding its applicability across a range of individuals and families using or considering donor conception. The fact that all participants were members of the DCN means that the sample were already experienced in thinking about and discussing the issues raised by openness and responses will therefore have been influenced by the perceptions and constructions formed through these discussions. The experiences of individuals not involved in such support networks would be an important further area of research. The samples were also all White British and from a professional

background, hence the constructed model may not fully or accurately present the experiences of individuals from other backgrounds.

The findings may also be affected by self-selection bias, as it is likely that individuals who had positive experiences of openness were more likely to take part. This may have further impacted the participation of young people as participants under the age of 18 had participated due to being informed of the study by their parents, with it being less likely that parents of children experiencing difficulties with openness would inform them of this.

Clinical implications

The constructed model provides some insight for professionals working therapeutically with donor conceived families into the complexity and subtleties of the processes involved in achieving the outcomes identified within this sample.

The findings have implications for the provision of counselling advocated in HFEA legislation. The constructed model suggests that pre-held beliefs and assumptions have a significant role in the process of openness, as well as on-going issues which change throughout development, highlighting the importance of a thorough exploration of these issues prior to treatment and the possibility that they will need to be revisited later.

The categories identified in the analysis point to factors which may be of significance in therapeutic work, including pre-held cognitions and emotions regarding donor conception treatment, attachment relationships, mentalisation skills and access to peer support.

In the wider therapeutic field, the associated psychological repercussions of late disclosure (Pettle, 2002; Turner & Coyle, 2000) demonstrate that donor conceived individuals may well present within mental health services. Dissemination of research findings regarding the potential for positive outcomes related to openness can inform clinicians working therapeutically with cases which have donor conception as a feature.

Finally, Imber-Black (1998) discusses the significance of carefully opening family secrets within a therapeutic context. Research that provides clinicians with a heightened awareness of the potential for secrecy in donor conception and the number of families affected by these issues may prompt exploration of the potential for secrets within families presenting to services, hence potentially allowing individuals and families to explore issues in therapy that might otherwise have remained secret.

Future research

The use of grounded theory methodology ensures that the constructed model is grounded in the data and emerged from the experiences of participants. The methodology has however required a relatively small sample and the findings would benefit from replication.

Involvement with the DCN emerged as a significant element in the constructed model. Further research is required in order to explore the experiences of openness in families who are not accessing the DCN in order to ascertain any differences in experience. Further research is also required to explore the experiences of individuals from other social and cultural backgrounds.

Finally, whilst the constructed model provides tools for therapeutic work with families, in identifying potential processes related to positive outcomes, research regarding potential for therapy to support this process would further inform how the constructed model can be utilised therapeutically.

Conclusion

The present study highlights the complex and dynamic processes involved in the achievement of positive outcomes related to openness. The constructed model highlights the cyclical nature of the process and the need for issues regarding openness to be re-

negotiated at various points in the development of the individual and the family. This reflects a process whereby successful negotiation of the various stages of the model results in positive outcomes for the child and family. Overall participants' experiences reflected positive outcomes from openness but illustrated how complex the entire process is, adding to existing understanding of this area.

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SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

MAJOR RESEARCH PROJECT

NICOLA SHORTEN BSc Hons

Section C: Critical Appraisal

Word Count: 1,933

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1. What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

This project is the first large scale piece of research which I have conducted independently and as such has involved both a rewarding experience and a steep learning curve. The experience has helped me to develop my understanding of the process of conducting research, from the design of a project through gaining ethical approval, implementation and report writing, but most significantly has helped me to develop my own personal approach as a researcher and to be able to maintain a critical and reflective stance in the process.

The process of selecting an appropriate methodology for the study involved a consideration of my own epistemological position. In the process of researching grounded theory approaches I found that Charmaz's constructivist approach (2006) fitted with my own views regarding the nature of our knowledge and the impact of individual and shared constructions on perceptions of what we know (Burr, 1995). Through adopting this approach I was able to develop skills which assisted me to minimise the influence of my own constructions on the emerging categories, such as use of bracketing, memo writing and maintaining a research diary, whilst also accepting that the influence of my own perceptions is an inevitable part of the research process.

In the early stages of planning the project I was disheartened to read Glaser's view that if a researcher is limited in conceptual ability they should not attempt grounded theory (1992). I was, however, pleased to read on to find that the grounded theory methodology is designed to bring out skills of conceptual analysis (Glaser, 1992). I feel that the process of completing this project has developed my conceptual skills and increased my confidence in my ability to draw on concepts emerging from the data.

The process of data analysis was at times overwhelming due to the large amounts of interview data that I had. I was also struck by the amount of time involved in the initial coding phase, however, I came to realise that spending more time at this in depth initial coding phase allowed me to really immerse myself in the data and facilitated the later coding stages.

The process of recruitment and interviewing has helped me to develop a realistic view of the challenges of conducting this form of research. In order to recruit participants I had to develop a relationship with staff at the DCN (Donor Conception Network) and to communicate and liaise with them regarding my research advertisement. At times this was challenging, particularly in regard to being reliant on the timescales of other parties. The reality of arranging mutually convenient interview times with participants in locations across the country has also required me to be flexible and efficient in my approach.

The process of conducting research interviews was also new to me and this project has helped me to develop skills in this area. The use of semi-structured interviews allowed for open responses from participants but meant that I needed to ensure that the questions were posed in an open and neutral way so as not to influence responses. Conducting interviews with participants as young as 12 and 13 also meant that I needed to be flexible in the way that I asked questions to ensure participants were able to give full responses.

Finally, I found the process of conducting a grounded theory project, particularly in regard to conducting interviews, a stimulating and enriching experience and I hope to gain further experience of this methodology and continue to develop my skills throughout my career.

2. If you were able to do this project again, what would you do differently and why?

The time limitations imposed on this project, due to being part of a doctoral dissertation, placed some restrictions on the way the study was conducted. An area which I gave particular consideration to in planning the project was that of recruitment of the young person participants. A number of methods of recruiting this part of the sample were discussed with supervisors, however, time restrictions and issues of gaining ethical approval led to the decision for the method used. Given a greater amount of time the recruitment process could have been changed in order to allow for a broader sample of young people, with this providing the bulk of the research data and utilising parent participant data as a method of triangulation (Kimchi, Polivka & Stevenson, 1991).

I had initially planned to recruit young people directly, via a young person's group run by the DCN. This would have allowed participants direct access to the research advert rather than via parents. Unfortunately, the fact that the group was only run bi-annually with small group numbers (approximately 8-12 members), and I could not guarantee the number of group members that would be interested in taking part, this method of recruitment seemed unrealistic. This recruitment method, however, involved its own limitations as the DCN groups may have already discussed issues covered in research interviews, causing participant responses to be similar and also only included an age range of 8-14 years.

A further possible recruitment method could have been to recruit donor conceived individuals via the Donor Sibling Registry (DSR) and UK Donor Link. These are self-registering organizations for donor conceived individuals, aged 18 years and over, which provide a list of donor conceived individuals used for locating genetic half-siblings and donors. This would allow access to a wider range of participants; however, all participants would be over the age of 18. Given a greater length of time for recruitment, a combination of these methods may have been possible.

On reflection, given the opportunity to repeat this project I would have made better use of memo writing and the research diary during the early stages of the project. I found both of these strategies extremely useful during data collection and analysis in assisting with recognizing my own responses to the data and being able to allow the analysis to emerge as fully as possible from the data presented. If I had known how useful these tools would be I would have made more use of them during the early stages of background reading and planning. I am aware that I had thoughts regarding the project during this time that would have been building up my perceptions of the subject area and could have contributed to the analysis. Following discussion with a colleague after completing my analysis I would have also liked to have requested a colleague interview me about my initial thoughts and expectations before beginning data collection to assist with bracketing of my own perceptions.

3. As a consequence of doing this study, would you do anything differently in regard to making clinical recommendations or changing clinical practice, and why?

I found completing this project an extremely enriching experience in regard to my own understanding of the subject area and I feel that I have gained a greater insight into the complexities of the issues faced by families using assisted reproduction technologies. This has certainly increased my awareness of the number of families affected by these issues and during the course of the project I had discussions with two colleagues and a close friend, all who had been experiencing issues connected to donor conception. My new awareness of the subject matter allowed me to have conversations with these people that would otherwise not have happened.

A major consequence of the study for me is an increase in awareness, through publication and dissemination, of the high potential for individuals and families that clinical

psychologists meet in services being affected in some way by these issues. The constructed model offers potential for understanding where families may find areas of strength or difficulty and can inform potential clinical work.

In regard to professionals working directly with donor conception treatment centres the constructed model offers insights into areas to be considered in initial assessment of families seeking treatment. Assessing factors related to the category of 'Core Beliefs', for example, may allow the therapist, or other professional, insight into the level of support that may be required in regard to openness. Similarly factors related to the categories of 'Child Process' and 'Parent Process' may prompt assessment questions related to these specific areas.

Links made between the emergent categories and psychological theory can inform potential therapeutic interventions that may be useful in working with donor conceived individuals and their families, the significance of interactions between the parent and child processes could indicate that attachment and mentalisation based therapies may be appropriate in working with these families.

Finally, centres providing treatment are currently only required to provide access to counselling for potential parents, meaning that it is not a requirement of treatment, or that it has to be provided and paid for by the treatment centre. An increased understanding and awareness of the issues faced by these families can assist in informing professionals providing treatment of the potential importance of counselling for these families, including offspring as well as parents, and assist in promoting access to this.

4. If you were to undertake further research in this area what would that research project seek to answer and how would you go about doing it?

A limitation of the current study is the fact that all participants were DCN members, with the majority being from a White British and professional background. Participants highlighted that information they had been given by the DCN was useful to them and it is therefore inevitable that the responses given were influenced by the perceptions and constructions formed through involvement with the DCN.

Further research with participants who are not accessing support networks such as the DCN would be useful to explore similarities and differences between these two populations. The historical legacy of secrecy in donor conception, however, means that access to participants not accessing such networks is limited and is often through direct recruitment from treatment centres, whilst this offers access to a wider range of participants it minimises the potential for accessing parents who may have completed their treatment several years ago, and the resultant offspring of this treatment.

An additional area of research therefore may be in relation to DCN membership itself, research exploring factors which promote or inhibit engagement with such organisations may inform organisations of ways of expanding their membership base and become more inclusive of a range of families.

The current study has highlighted the significance of social context and discourses in facilitating openness. The shift in discourse spoken of is, however, predominantly a western shift, with other cultural contexts perhaps conveying a different picture. Further research is needed in order to understand how openness can be facilitated in families outside of a western, White British population.

In relation to the constructed model, potential areas for therapeutic assessment and intervention are highlighted. It is argued that counselling prior to, during and following

donor conception treatment may be beneficial in supporting openness. Research using pre and post outcome measures, quantitatively and qualitatively, is needed to support this.

Finally, the analysis completed and resultant constructed model have highlighted categories which are significant in the experience of the current sample. Investigation regarding the lived experience of specific categories, for example the need for assimilation of information with knowledge of relationships, would further highlight how professionals may assist individuals, either directly or through advising families, with managing this issue. An interpretative phenomenological analysis study may provide a useful methodology in gaining a deeper understanding of the lived experience of this issue.

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SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

MAJOR RESEARCH PROJECT

NICOLA SHORTEN BSc Hons

Section D: List of Appendices

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Appendix 1: Section A search strategy

A search of the following electronic databases: was conducted. Reference lists of relevant articles were scanned for any literature missed in the electronic searches. The following search terms were used, with no limits for time period and a restriction to articles in English:

- Donor Conception/Conceived
- Donor Insemination
- Assisted Reproduction
- Reproductive Technology/Techniques
- Fertility Treatment

Together with

- Open/openness
- Disclosure
- Communicating/communication
- Truth
- Telling

Abstracts from the articles generated were scanned to identify articles relevant to an exploration of openness in donor conception for young people.

2.2 Inclusion and Exclusion Criteria

To ensure articles included addressed the review questions, the following inclusion criteria had to be met:

- Studies involved research with donor gamete recipients and/or donor conceived offspring where parents were/or were considering openness

The following were excluded:

- Articles solely outlining debate or opinion regarding disclosure in donor conception.

Appendix 2: Demographic data³

Participant Number	Gender	Ethnicity	Marital Status	Occupation	Donor Type	Known/Unknown
Mum1(_1)	F	White British	Married	Professional	Egg + Sperm	Unknown
Mum2(_2)	F	White British	Married	Professional	Sperm	Known
Mum3(_3)	F	White Caribbean	Married	Professional	Sperm	Unknown
Dad1(_3)	M	White British	Married	Professional	Sperm	Unknown
YP1(_3)	F	White British	Single	School age	Sperm	Unknown
Mum4(_4)	F	White British	Married	Professional	Sperm	Unknown
YP2(_4)	F	White British	Single	Student	Sperm	Unknown
Mum5(_5)	F	White British	Married	Professional	Egg	Unknown
Dad2(_6)	M	White British	Married	Professional	Egg	Known
Mum6(_6)	F	White British	Married	Professional	Egg	Known
Mum7(_7)	F	White British	Married	Professional	Sperm	Unknown
Dad3(_7)	M	White British	Married	Professional	Sperm	Unknown
YP3(_7)	M	White British	Single	School age	Sperm	Unknown
Dad4(_8)	M	White British	Married	Professional	Sperm	Unknown
YP4(_8)	M	White British	Single	Student	Sperm	Unknown
Mum8(_9)	F	White British	Married	Professional	Egg	Unknown
Dad5(_9)	M	White British	Married	Professional	Egg	Unknown
Dad6(_10)	M	White British	Married	Professional	Sperm	Unknown
YP5(_10)	F	White British	Single	Student	Sperm	Unknown
Dad7(_11)	M	White British	Married	Professional	Sperm	Unknown

³ Some demographic data (Age and age of children) have been removed from the electronic copy to preserve anonymity

Appendix 3: Canterbury Christ Church University Research Ethics Committee Approval

* This has been removed from the electronic copy

Appendix 4: Interview schedules

An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.

(Parent Interview)

The questions listed below, and prompts indicated, will be used to guide the content of discussion.

Questions in italics are not relevant where participants have been open with their child since infancy/early childhood.

Interview questions:

- Can you tell me some of your thoughts about why you chose to be open with your child about donor conception?
 - ⇒ Reasons related to yourself
 - ⇒ Your partner
 - ⇒ Your child
 - ⇒ Wider family
 - ⇒ Wider influences

- What were your first thoughts about the possible effects of your child knowing – or what it might mean for you or for your child?
 - ⇒ Have these changed at all?

- Can you tell me a little about how the topic of donor conception comes up in your family, if it does?
 - ⇒ Who initiates it
 - ⇒ Who does your child talk to about it
 - ⇒ Where do you choose to talk about it

- *Do you think that anything has changed or not since telling?*
 - ⇒ *At home?*
 - ⇒ *At school?*
 - ⇒ *With friends?*

- What meaning do you feel knowing that they are donor conceived has had for your child – if any? Has knowing had any bearing on:
 - ⇒ Their relationships? (with family/friends/other children)
 - ⇒ Their personality?
 - ⇒ Their behaviour? (at home/at school)

- What do you think are the positives and negatives about having shared the information with your child?
 - ⇒ For your child
 - ⇒ For you/your partner
 - ⇒ For your relationship

- If someone wanted advice about telling their child they were donor conceived what advice would you give them?

An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.

(Young Person Interview)

The questions listed below, and prompts indicated, will be used to guide the content of discussion.

Questions in italics are not relevant where participants have been open with their child since infancy/early childhood.

Interview questions:

- Do you remember finding out about having a donor – or have you always known?
 - ⇒ *Can you tell me a little about how your parents told you that you were donor conceived?*
 - ⇒ *Do you remember how old you were?*
 - ⇒ *Do you remember what you thought about it?*
 - ⇒ *Can you tell me how you felt about knowing?*
 - ⇒ *Have your thoughts or feelings about it changed since you first knew about your donor.*

- Is the topic of donor conception talked about much in your family?
 - ⇒ Who starts the subject?
 - ⇒ Who do you choose to talk to about it?
 - ⇒ Where do you talk about it?

- Did/do you talk to anyone else about it?
 - ⇒ Who did/do you choose to talk to?
 - ⇒ What was it like talking to someone else about it/not talking to anyone about it?
 - ⇒ Was/is there anyone you would have really liked to talk to about it?

- Does anyone else know about you having a donor?
 - ⇒ Friends
 - ⇒ Family
 - ⇒ Teachers
 - ⇒ How do you feel about them knowing?
 - ⇒ Can you tell me what you think they might feel about it?

- Is there anybody that you choose not to tell about being donor conceived?
 - ⇒ Can you tell me about why that is?

- Do you think that knowing has had any effect on your relationships with other people?
 - ⇒ Parents/siblings
 - ⇒ Grandparents/wider family
 - ⇒ Friends/other children

- Over the years /as you have got older, what are the different issues that you have thought about/talked about?
 - ⇒ Did any of them upset you?
 - ⇒ How did you cope with that?

- Is being donor conceived something that you think about often?
 - ⇒ Or just part of life?
 - ⇒ Are there times when you think about it more/less? Can you tell me about these times?

- *Do you think that anything has changed or is different since you were told*
 - ⇒ *At home?*
 - ⇒ *At school?*
 - ⇒ *With friends?*

- Are there any aspects of being donor conceived that you have found awkward or upsetting?
 - ⇒ How did you cope with this?

- In what ways do you think the information that you are donor conceived has influenced you?
 - ⇒ Do you think it has some positive aspects? What are they?
 - ⇒ Do you think it has some negative aspects? What are they?

- If you had the choice to know or not – what would you opt for?
 - ⇒ Can you tell me a little about why that is?

- If someone wanted advice about telling their child they were donor conceived, what advice would you give them?

Appendix 5: Research advert

* This has been removed from the electronic copy

Appendix 6: Participant information sheets



Salomons Campus at Tunbridge Wells

Department of Applied Psychology

Faculty of Social and Applied Sciences

An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.

Parent Information Sheet.

Thank you for taking the time to consider taking part in this study. The information given below aims to explain what will be involved should you decide to take part

What is the study about?

This study aims to explore the impact of openness in donor conception on the social and emotional experience of children and young people. It is intended to identify factors regarding openness which are important to children who are donor conceived, and their parents.

Who is conducting the study?

The study is being carried out by Nicola Shorten, Trainee Clinical Psychologist, as part of the doctorate in Clinical Psychology qualification, awarded by Canterbury Christ Church University. The study is supervised by Dr Sarah Harmon, Chartered Clinical Psychologist, and Dr Sharon Pettle, Chartered Clinical Psychologist.

What do I have to do?

Parents who decide to take part will be invited to take part in an interview with me, Nicola Shorten. The interview will last around 60-90 minutes. I will come and meet you at your home for the interview. I will ask you to talk about your experiences of being open with your child about donor conception and what this has been like for you. The interview will be audio recorded and analysis of the discussion. The recording will not be heard by anybody else. I will also ask you to complete a short questionnaire which asks you about your child's relationships and behaviour. If your child is taking part in the study I will ask them to complete the questionnaire too. Young people who decide to take part will be asked to take part in an interview with me, Nicola Shorten. The interview will be approximately 30-60 minutes and will ask participants to talk about their experiences of being aware of their donor conception. These interviews will be audio recorded to aid analysis of the discussion.

Who is taking part?

Participants will be young people, aged 12 years or older, who are donor conceived, and parents of donor conceived children and young people.

What are the possible benefits of taking part?

The findings of the study will help us understand more about the impact of openness for donor conceived children and their families. This may help other families to make decisions about how and when they choose to be open with their children. The interview will also be a chance to share your thoughts and feelings regarding openness and what this has been like for you.

Do I have to take part?

No. If you do not want to take part in the study you do not have to. If you decide to take part and then change your mind you are free to withdraw at any time.

What do I do if I want to take part?

If you would like to participate please complete the notification of interest form below and email it to Nicola Shorten at n.e.shorten8@canterbury.ac.uk

Will taking part be confidential?

Yes. Some of the things you say may be included in the final written report in the form of quotes, but no names or other identifying information will be included. The recordings of interviews will be viewed only by the researchers involved in the study. All data, both written and audio recorded will be stored in a secure location. The audio recordings will be destroyed at the end of the study in 2012. Written data will be kept by Canterbury Christ Church for ten years after the study has finished and then it will be destroyed.

In the event of information being disclosed which relates to possible risk to self or others, confidentiality may be broken.

What will happen to the results of the study?

The results of the study may be presented or published; however, no personal information would ever be shared. I will send a written report of the findings from the study to you. If your child takes part they will also be sent a copy of the report. I will also send the report to the Donor Conception Network so that they can share it with other members. Your name will not be in the report as all your information will be anonymous. The report will include a summary of the results and contact details to obtain further information should you have any questions.

What if I have questions or concerns?

If you have any further questions about the research, please feel free to contact the researcher via email at:

n.e.shorten8@canterbury.ac.uk

Who has reviewed the study?

The study has been reviewed and approved by the Salomons ethics panel of the Academic Standards Board at Canterbury Christ Church University.



Salomons Campus at Tunbridge Wells

Department of Applied Psychology

Faculty of Social and Applied Sciences

Notification of interest to participate in research

Project Title: **An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.**

Principal Researcher: **Nicola Shorten**

Trainee Clinical Psychologist

Participant Name:..... Date.....

Please give details of your preferred method of contact.

Email.....

OR

Telephone.....

If you are under 18 years of age, your parent(s) will need to consent to you taking part. Please ask your parent to complete the details below.

Parent Name:..... Date.....

Please give details of your preferred method of contact.

Email.....

OR

Telephone.....



Salomons Campus at Tunbridge Wells

Department of Applied Psychology

Faculty of Social and Applied Sciences

An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.

Young Persons' Information Sheet.

We are asking if you would join in a study to find out what children and young people, and their parents, think about being open about donor conception. Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family or friends if you want to.

Why are we doing the study?

We want to find out more about what children and young people, and their parents, think about being open about donor conception and what this means for the social and emotional experiences of young people. By finding out about the experiences that people have had we can help other people who are trying to make decisions about being open.

Who is conducting the study?

The study is being carried out by Nicola Shorten, Trainee Clinical Psychologist, as part of the doctorate in Clinical Psychology qualification, awarded by Canterbury Christ Church University. The study is supervised by Dr Sarah Harmon, Chartered Clinical Psychologist, and Dr Sharon Pettle, Chartered Clinical Psychologist.

Who is taking part?

Participants will be young people, aged 12 years or older, who are donor conceived, and parents of donor conceived children and young people.

What do I have to do?

If you decide to take part you will be asked to take part in an interview with me, Nicola Shorten. The interview will last around 30-60 minutes. I will come and meet you at home for the interview. I will ask you to talk about your experiences of being aware of your donor conception and what this has been like for you. The interview will be audio recorded to make sure everything you tell me about is remembered and included in the study. The recording will not be heard by anybody else. I will also ask you to complete a short questionnaire which asks you about your relationships and behaviour. I will ask your parents if they would like to complete this questionnaire too. Parents who decide to take part will be invited to take part in an interview with me, Nicola Shorten, to talk about their experiences of being open with their children, and the decisions they made about this.

What are the possible benefits of taking part?

The findings of the study will help us understand more about the impact of openness on donor conceived children and their families. This may help other families to make decisions about how and when they choose to be open with their children. The interview will also be a chance to talk about your thoughts and feelings about being donor conceived and what knowing about this has been like for you.

Do I have to take part?

No. It is up to you. If you decide to take part and then change your mind, you are free to stop taking part at any time during the study without giving a reason.

Will taking part be confidential?

Yes. Some of the things you say may be included in the written report in the form of quotes, but no names or other information that could identify you will be included. The recordings of interviews will only be seen by the researchers involved in the study. All data, both written and audio recorded will be stored in a secure location and people who are not involved with the study will not be able to see it. The audio recordings will be destroyed at the end of the study in 2012. Written data will be kept by Canterbury Christ Church for ten years after the study has finished and then it will be destroyed.

If something is said in an interview that raises concern about your or anyone else's safety then the research staff may need to tell somebody else.

What will happen to the results of the study?

The results of the study may be presented or published; however, no personal information about you would ever be shared. I will send a report of what I found in the study to you. If your parents take part they will have a copy of the report too. I will also send the report to the Donor Conception Network so that they can share it with other members. Your name will not be in the report as all your information will be anonymous. The report will include a summary of the results and contact details to obtain further information should you have any questions.

What if I have questions or concerns?

If you have any further questions about the research, please feel free to contact me via email at: n.e.shorten8@canterbury.ac.uk

Who has reviewed the study?

Before any research study goes ahead it has to be checked by a Research Ethics Panel. They make sure that the study is fair. This study has been checked by the Canterbury Christ Church University Research Ethics Panel.

What do I do if I want to take part?

If you would like to participate please complete the notification of interest form below and email it to me at n.e.shorten8@canterbury.ac.uk If you are younger than 18 you will need to ask your parent(s) to complete part of the form.



Salomons Campus at Tunbridge Wells

Department of Applied Psychology

Faculty of Social and Applied Sciences

Notification of interest to participate in research

Project Title: **An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.**

Principal Researcher: **Nicola Shorten**

Trainee Clinical Psychologist

Participant Name:..... Date.....

Please give details of your preferred method of contact.

Email.....

OR

Telephone.....

If you are under 18 years of age, your parent(s) will need to consent to you taking part. Please ask your parent to complete the details below.

Parent Name:..... Date.....

Please give details of your preferred method of contact.

Email.....

OR

Telephone.....

Appendix 7: Informed consent forms



Salomons Campus at Tunbridge Wells

Department of Applied Psychology

Faculty of Social and Applied Sciences

PARENT CONSENT FORM

Title of Project: **An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.**

Name of Principal Researcher: **Nicola Shorten, Trainee Clinical Psychologist**

Please initial box:

1. I confirm that I have read and understand the information sheet provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3. I agree to my participation being audio recorded. I understand that the recording will be heard only by staff conducting the study.

4. I consent to anonymised quotes being used in the written report of the study.

5. I agree to take part in the above study.

Name:

Signature:

Date:

.....

.....

.....

Researcher Name:

Researcher Signature:

Date:

.....

.....

.....

YOUNG PERSONS' CONSENT FORM

Title of Project: **An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.**

Name of Principal Researcher: **Nicola Shorten, Trainee Clinical Psychologist**

- | | |
|--|--------|
| 1. Do you understand what this project is about? | Yes/No |
| 2. Have you asked all the questions you want? | Yes/No |
| 3. Have you had your questions answered in a way you understand? | Yes/No |
| 4. Do you understand it's OK to stop taking part at any time? | Yes/No |
| 5. Are you happy to take part? | Yes/No |
| 6. Are you happy for your interview to be audio recorded? | Yes/No |

If any answers are 'no' or you don't want to take part, don't sign your name!

If you do want to take part, please write your name below

Name:	Signature	Date:
.....

Your parent needs to write their name too.

Please Initial Box:

- | | |
|--|--------------------------|
| 1. I confirm that I have read and understand the information sheet provided. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. I agree to my child's participation being audio recorded. I understand that the recording will be heard only by staff conducting the study. | <input type="checkbox"/> |
| 3. I consent to anonymised quotes being used in the study. | <input type="checkbox"/> |
| 4. I consent to my child taking part in the above study. | <input type="checkbox"/> |

Name:	Signature	Date:
.....

Researcher Name:	Researcher Signature:	Date:
.....

Appendix 8: Example memos

Parent Interview1

I was struck and surprised by Mum's thoughts regarding the impact of openness for her children's personalities. She was hopeful that the experience of honesty and acceptance within the family would create a nature of acceptance of others and of difference for her children. I would be interested to pursue this with the young people I interview and to explore whether this is felt by other families.

Transcribing Mum1

Something around the nature of having a close, supportive family meaning that openness is natural/inherent – an automatic process that does not need to be considered or debated.

Mum1 line 174

There is a line to be drawn between secrecy and privacy. Openness as a positive thing when sharing with those who need to know but not needing to share with anyone who makes a comment such as "doesn't she look like you".

Mum1 line 191

Points in conversation which DC can be worked into where the child has initiated the conversation and parent uses the question/comment to discuss or mention DC.

Mum1 line 254

Something around the subtleties which impact on the story. Many different permutations which will impact in different ways e.g. donor sperm, egg, both, embryo....all come with different history and therefore different story.

Question for me as a researcher: Are there similarities which give a common thread or do the subtleties create too big a difference? Should this have been considered in selecting sample?

Mum1 line 272

Is she saying they chose openness because medical discourse makes it easier to be open about infertility?

Mum1 line 285

Shock of change to story of ones identity as destabilising, impacts on identity and shakes knowledge of who you are.

Mum1 line 287

Wanting it to be part of the story. Parents as story tellers, parental role in helping children have a sense of themselves/identity/story. Is this linked to parental thoughts around child as their own person, separate to parent?

Mum1 line 367

“in this day and age” – something around the importance of modern times, time to accept difference? Acceptance of difference as expected in current times.

Mum1 line 499-500

Gaining support from having a 100% genetic connection to a sibling – conflict between which factors are important, relationship or genetics?

YP1(f3) line 261

Had thoughts about Importance of overt differences in forcing more openness – potentially easier for secrecy in heterosexual families?

YP1 line 296

Feeling donor siblings will have same thoughts about DC because they have the same donor – something about beliefs about/emphasis put on genetic relatedness and how it brings similarities.

YP1 line 446

What helps YP to think positively about DC – is there a connection with parents approach to openness?

YP1(f3), 5.4.12, line 451-459

Something around knowing about DC making person ore likely to be thoughtful about reactions/feelings/responses of others – perhaps noticing more than the obvious.

?? Is this linked to knowing there is something about themselves that others may not know and therefore having awareness that may not know everything about people. Awareness of not making assumptions??

Dad1 line 99

A move in choices about telling as children get older. Participant refers to “what’s happening for the kids now” – Now that children are older decisions around telling are based on whether children are comfortable with it.

Dad1 line 130

Different ways of being open. A more private way (sharing with children and people you trust) versus being open with everyone and shouting about openness.

Dad1 line 275

Does openness allow DC to move into the background? Do people move on after being open? Can the same happen if have not been open?

Openness moving to the background seems more of a statement of fact by parents rather than necessarily being brought about by openness – perhaps thinking that openness allows this to happen is my own assumption/hope?

Dad1 line 286

Is change in context/discourse the key factor in greater openness? Is it context or openness that creates impact for families or are the two intertwined?

Sense of self

Being able to intellectualise decision to be open and think about positives as well as negatives of secrecy but ultimately, bottom line was that secrecy was not in nature of the parent and therefore would not have been considered. Something around secrecy as being inconsistent with parent's sense of self.

Is this something about core beliefs? How parents view themselves/others/ the world?

If openness is not debated/deliberated but simply congruent with personality of parent, what is happening in families where openness is less congruent? Are these families typical of those that would access DCN – limitation of my sample?

Approaches to openness

Different approaches to openness, e.g. openness as the only way vs secrecy as the only way or is there more of a middle ground? What does your position on the continuum say about your level of comfort/acceptance of the issues?

Something here links with the process that parents go through in deciding to be open and how that impacts on level of comfort or approach to talking with child. This seems linked to the history of infertility and how the parent(s) came to use dc.

Both/And

Participants are talking about DC being a more “ever present” issue than you think but also becoming less important as the children get older and fading into the background in some ways. Is this a case of both/and scenario – both always present and just becoming part of life?

Both/And position seems to link more appropriately with sense of importance of genetic component of self and social/family relationships. Parents and YP are acknowledging that there is a genetic factor which they think about/acknowledge/discuss and is present for them and yet also talk about this being unimportant in relation to the position they hold in their family and their relationships with other members. DC is both important and not important.

Appendix 9: Summary of findings for participants and ethics panel

10th July 2012

Chair of Salomons Ethics Panel
Department of Applied Psychology
Canterbury Christ Church University
Salomons Campus
Broomhill Road
Tunbridge Wells, Kent TN3 0TG

Dear _____,

Study Title: **'Exploring the impact of openness in donor conception on young people's social and emotional experience'**

I am writing to inform you that this study has now been completed and in the process of being submitted to Salomons as part of the DClinPsy qualification. Please find attached a copy of the summary report, detailing the results of the study. A copy of this report has also been provided to all participants who took part in the study.

An alternative version of the report was provided to all participants below the age of 18 and is also attached for your information.

Should you require any further information please do not hesitate to contact me.

Yours Sincerely,

Nicola Shorten
Trainee Clinical Psychologist
Department of Applied Psychology
Canterbury Christ Church University
Salomons Campus
Broomhill Road
Tunbridge Wells, Kent TN3 0TG

An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.

Summary Report.

Thank you again for your participation in the above study. Below is a brief summary of the study aims and methodology, together with a description of the findings.

Aims: The aim of this grounded theory study was to explore the impact of openness for the social and emotional experience of young people conceived using donor conception, and their families.

Method: Twenty participants from eleven families took part in the study. Participants included 8 mothers, 7 fathers and 5 young people, aged between 12 and 25 years. Of the 11 families, 7 had conceived using donor sperm, 3 using donor egg and 1 using donor egg and sperm. Two of the families had used a known donor and the remaining 9 anonymous donors. Each participant took part in an individual interview with the researcher. Interview data were analysed using Charmaz's version of grounded theory (Charmaz, 2006).

Results: The main categories which emerged from the data are shown in the table below.

Category	Description
Societal context and discourses	Awareness and impact of societal influences on openness
Core Beliefs	Internally held beliefs regarding honesty and openness
Holding both/and position on nature/nurture	Acknowledgment of the influences and impact of both genetics and social relationships
Openness as a process	Continuation of discussion and negotiation of openness throughout development.
Incremental building of child and family identity	Adjustment of child and family and assimilation of information into identity throughout development.
Parent process	Awareness of parent processes in choosing openness and continuing to be open with child and others.
Child process	Child thoughts and beliefs regarding openness developing over time
DCN	Influence of involvement with DCN in supporting openness
Child outcomes	Positive outcomes reported for child, including affirmed sense of self, confidence in support networks, awareness and acceptance of diversity and a sense of resilience.
Family outcomes	Positive outcomes reported for families, including affirmed sense of what connects each individual to each other, ability to communicate about challenging subjects and strong family relationships.

The model constructed from the categories describes a hypothesis regarding the process of openness, based on the experiences of the families interviewed. If the various stages of the model are negotiated then the resulting positive outcomes for the child and the family can be seen. The cyclical nature of the processes reflect the on-going nature of the experience and demonstrate that the outcome is not a one-off event to be achieved, but is continually negotiated throughout the development of the child and family.

Should you have any questions or require any further information please do not hesitate to contact me at n.e.shorten8@canterbury.ac.uk

An exploration of the experience of openness in donor conception families in relation to the social and emotional experience of young people.

Young Persons' Summary Report.

I wanted to thank you again for taking part in my study and for the thoughtful answers you gave to my interview questions.

I have written a short summary of the findings from the study for you to read. If after reading the summary you would like to ask me any questions you can contact me at n.e.shorten8@canterbury.ac.uk

Aims of the study: The study aimed to find out about what young people, and their parents, think about being open about donor conception and what this means for the social and emotional experiences of young people and their families.

What we did: Twenty participants from eleven families took part in the study. Participants included 8 mothers, 7 fathers and 5 young people, aged between 12 and 25 years. Each participant took part in an individual interview with me. The answers given in the interviews were analysed to see what categories came out from the responses. The categories were then used to create a model which describes the impact of openness for young people and their families.

What we found: The categories which came out from the responses are described in the table below.

Category	Example
Societal context and discourses	Participants talked about how common beliefs and views in society affected them being open.
Core Beliefs	Participants spoke about their beliefs about the importance of honesty and openness.
Holding both/and position on nature/nurture	Participants spoke about their thoughts and beliefs about both genetics <u>and</u> relationships being important.
Openness as a process	Participants spoke about talking about donor conception in different ways as they got older and understanding more about it over time.
Incremental building of child and family identity	Participants spoke about donor conception becoming just another part of who they
Parent process	Parents spoke about the decisions they made about telling their child and how they went about this
Child process	Young people spoke about how their thoughts about being donor conceived changed and developed as they got older
DCN	Participants spoke about support they gained from the DCN helping them to know how to talk about issues around donor conception
Child outcomes	Participants reported positive outcomes for young people, including affirmed sense of self, confidence in support networks, awareness and acceptance of diversity and a sense of resilience.
Family outcomes	Participants reported positive outcomes for families, including affirmed sense of what connects each individual to each other, ability to communicate about challenging subjects and strong family relationships.

Appendix 10: Example respondent validation

* This has been removed from the electronic copy

Appendix 11: Excerpts from research diary

May 2010

Met with supervisor. Have confirmed idea for project, going to be looking at social and emotional development of young people in donor conceived families where there is openness. Pleased to be able to involve families, in particular young people, rather than doing study with professionals. I feel this project suits my interests more and will help me to develop interview skills with participants not working as professionals in health services. A little daunting though!

April 2011

Have sent research advert to the DCN to be placed in this month's ebulletin.

Had responses from 2 participants, both mothers with children under 5 yrs. Hoping to get some responses from participants with older children in order to be able to interview young people themselves.

May 2011

Have not had any further participants respond to research ad. Feeling quite concerned about recruitment and have arranged to meet Supervisors to discuss. Am a little concerned that the research and perhaps is not worded well and may cause potential participants to feel that I am assuming openness is not a good thing and may have a negative impact, but at the same time do not want to influence recruitment by conveying that I am looking for positive aspects.

August 2011

Have had to apply for ethics approval for amendments to the design of the study. Due to low recruitment have decided against parent focus groups as this will be too difficult to organise geographically if I have to accept all participants that respond due to low numbers. Have arranged for ebulletin advert to be sent in next 3 issues.

Have arranged first three interviews for October.

September 2011

Have had more responses from participants included some fathers and young people. Feeling very relieved!

October 2011 Interview 1

This will be my first research interview. Feeling excited to get started and nervous to meet my first participant. Feeling aware of importance of language I use and not wanting to cause upset/distress through discussion of difficult or previously unconsidered issues.

Post Interview – Experienced the interview as extremely positive. Mum was extremely keen to talk about her experiences and advocate openness as a necessity in terms of the right of the child. I found Mum’s enthusiasm and passion for the subject moving and felt a strong sense of a genuine and equal relationship between her and her children.

Mum told her story of her and her husband’s journey towards having a family. There was much grief and sadness entwined with huge joy for the birth of her two daughters. I felt a strong sense of respect for her determination in creating her family as well as for her determinedness to acknowledge the grief of her losses and allow this sadness to be present alongside her obvious joy at having her much longed for family.

I was struck and surprised by Mum’s thoughts regarding the impact of openness for her children’s personalities. She was hopeful that the experience of honesty and acceptance within the family would create a nature of acceptance of others and of difference for her children. I would be interested to pursue this with the young people I interview and to explore whether this is felt by other families.

October 2011 Interview 2

Travelled to (South West) for interview. Struck again by how open Mum was to speak about her experiences. Repetition of views from previous interview that openness has permeated into other areas of family life and feeling that the family can talk about challenging subjects that they may otherwise not have been comfortable discussing.

I was struck by how warmly mum spoke about her family and the respect for her children as individuals in their own right, rather than as belonging to her or dad. It will be interesting to see if this comes up in further interviews.

October 2011 Interview 3,4 &5

First interview with different members from one family. Was at the house for 3 hours, struck again by how keen to discuss the topic the family were and by them giving up their Friday evening to have me in the house. Possible limitation of the study in that my sample is a very specific group (i.e. DCN members) and are very keen to discuss the topic.

Was really interesting to see the same issues discussed by different members of the family. Similar thoughts came through from previous interviews.

Issue of importance of language came up. In part of my questioning I referred to having ‘a donor in the family’, which Dad questioned and disagreed with. Although Dad was not distressed by this I felt very aware of the potential to use the wrong language and this to be painful or difficult for families. Will need to maintain awareness of the difficulty of discussing potentially challenging ideas with these families when it comes to my analysis – will my fear of causing distress censor my findings?

October 2011 Interview 6 & 7

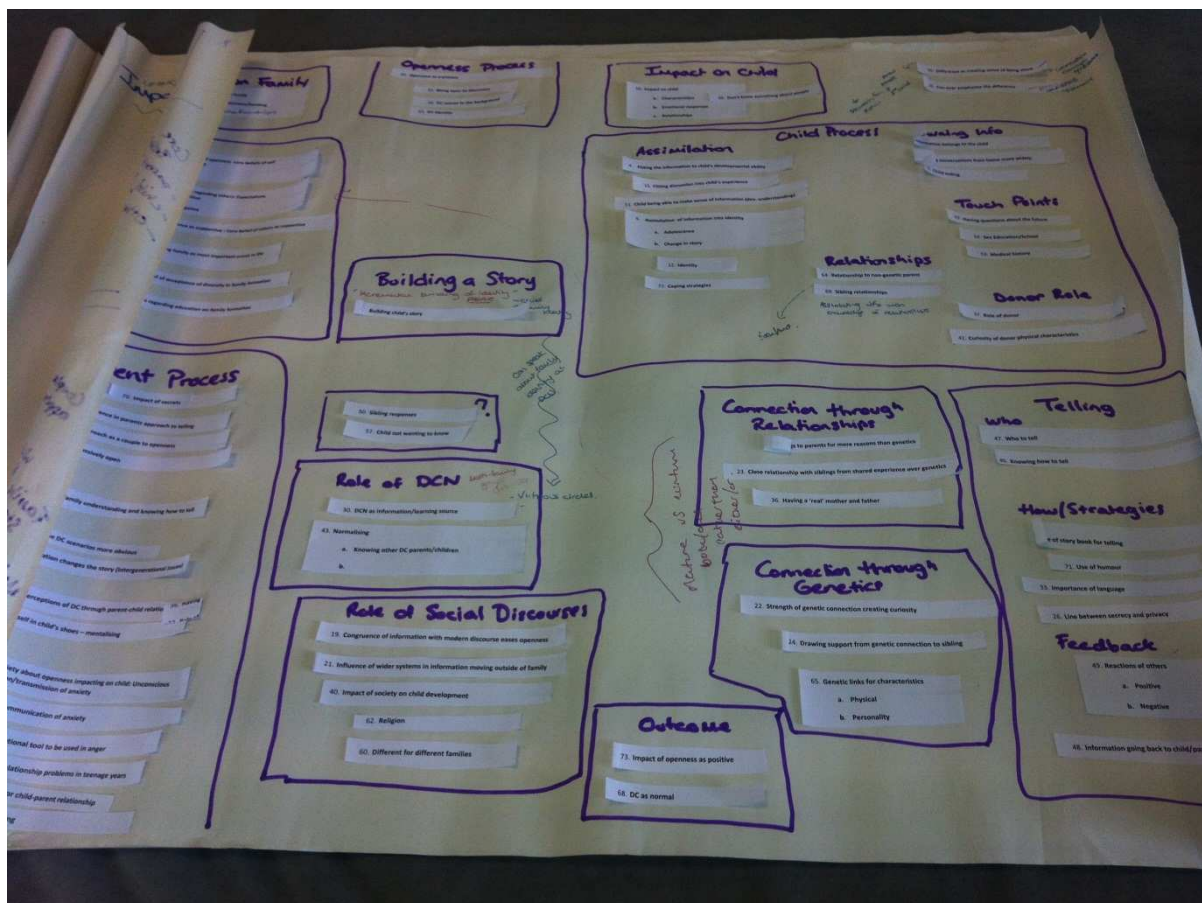
Interview with 25 year old DC young person. Really interesting to hear her speak about how her thoughts about DC changed over time and her understanding developing as she got older. Potentially something to follow up in further interviews.

November 2011 initial coding

Completed initial coding for first three interviews. The process takes a really long time but it was interesting to see how much emerges from the data when looking at line by line analysis.

From the initial coding it seems that all the participants have had very positive experiences of openness in regard to its impact for the child and the family too. It seems that the outcomes for the child and family are interlinked and play into one another. The coding has brought out categories which describe potential difficulties or stumbling blocks but further categories illustrate how these are seen as part of the process of development and that the difficulties are manageable.

There is so much data! It is quite overwhelming! Have resorted to cutting and sticking in order to look at focused codes.



November 2011

Completed a further 4 interviews. The data match well with the categories generated from initial coding, it is looking positive that I will reach saturation for these and no new categories have emerged for a while. So far however I have only interviewed two fathers so it will be interesting to see if new categories emerge from the next interviews with fathers. I have begun to try and diagram

the codes for interviews with each of the families to see what the process is there, hopefully this will help to integrate the categories when I am constructing the model.

December 2012

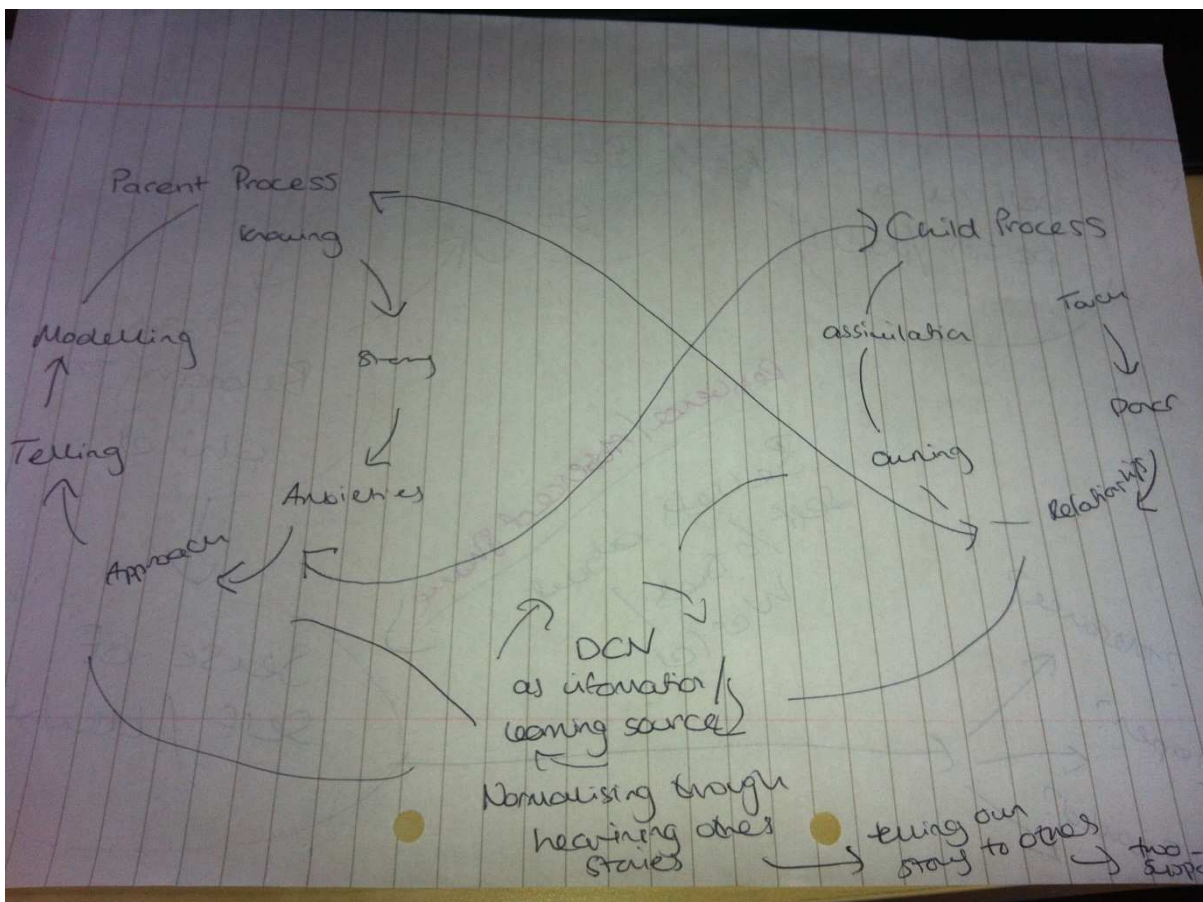
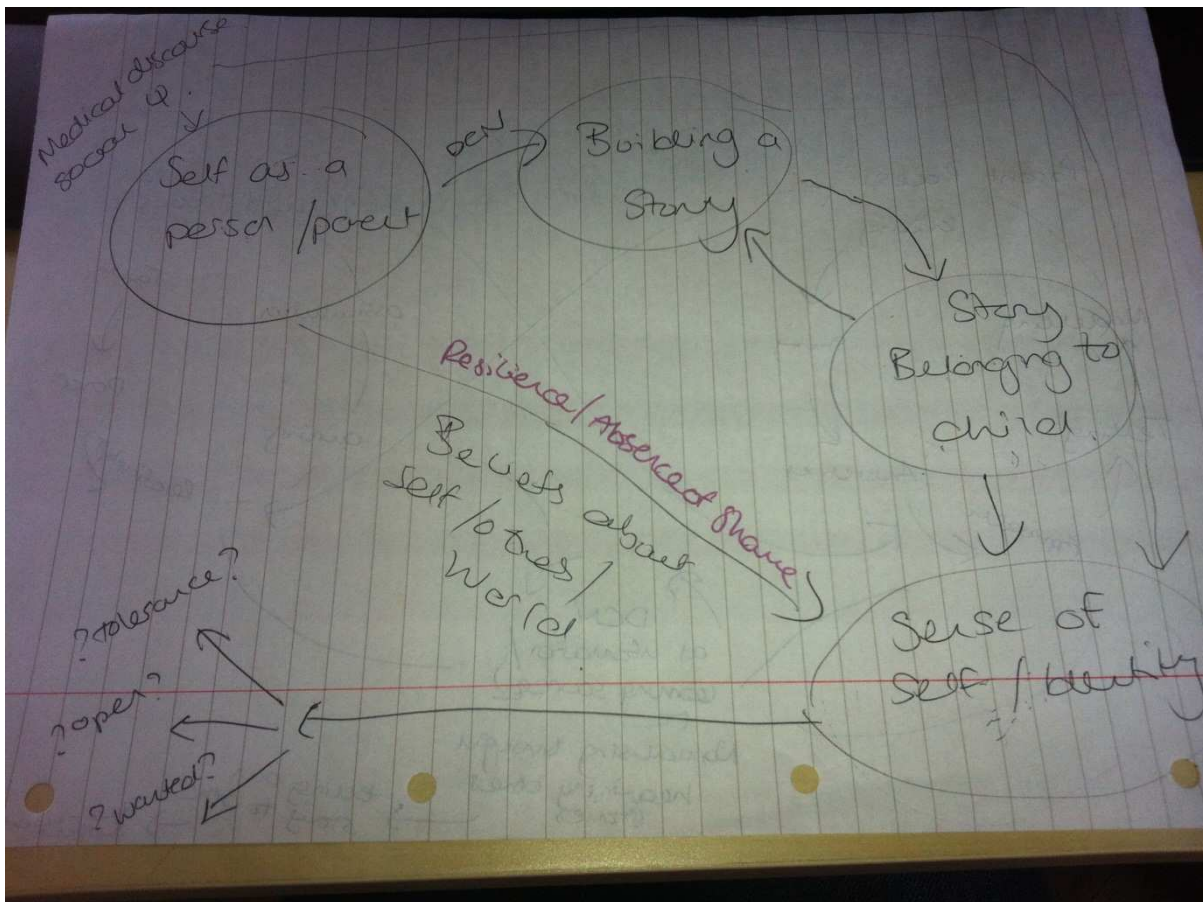
Have begun working on section A, this feels really difficult as I have not yet completed data collection and I am mindful of my own constructions being influenced by the literature. Have made some notes throughout my reading to try and minimise this by bracketing those thoughts but feel that I will probably return to section A at the end of January when I have completed the data collection and analysis.

February 2012

Conducted a further 9 interviews, makes 20 participants altogether with a good mix of mothers, fathers and young people. Can't believe I managed to get that many. All the interviews are transcribed and have analysed using the focused codes, no new categories since interview 16 so looking like I have reached theoretical saturation. I am really pleased with this but feeling quite overwhelmed with the amount of data I have. Next step is to construct the model based on the categories. I think that the theoretical memos I made during initial and focused coding have been a really useful way to bracket my own assumptions and constructions and also to think about what is emerging from the data.

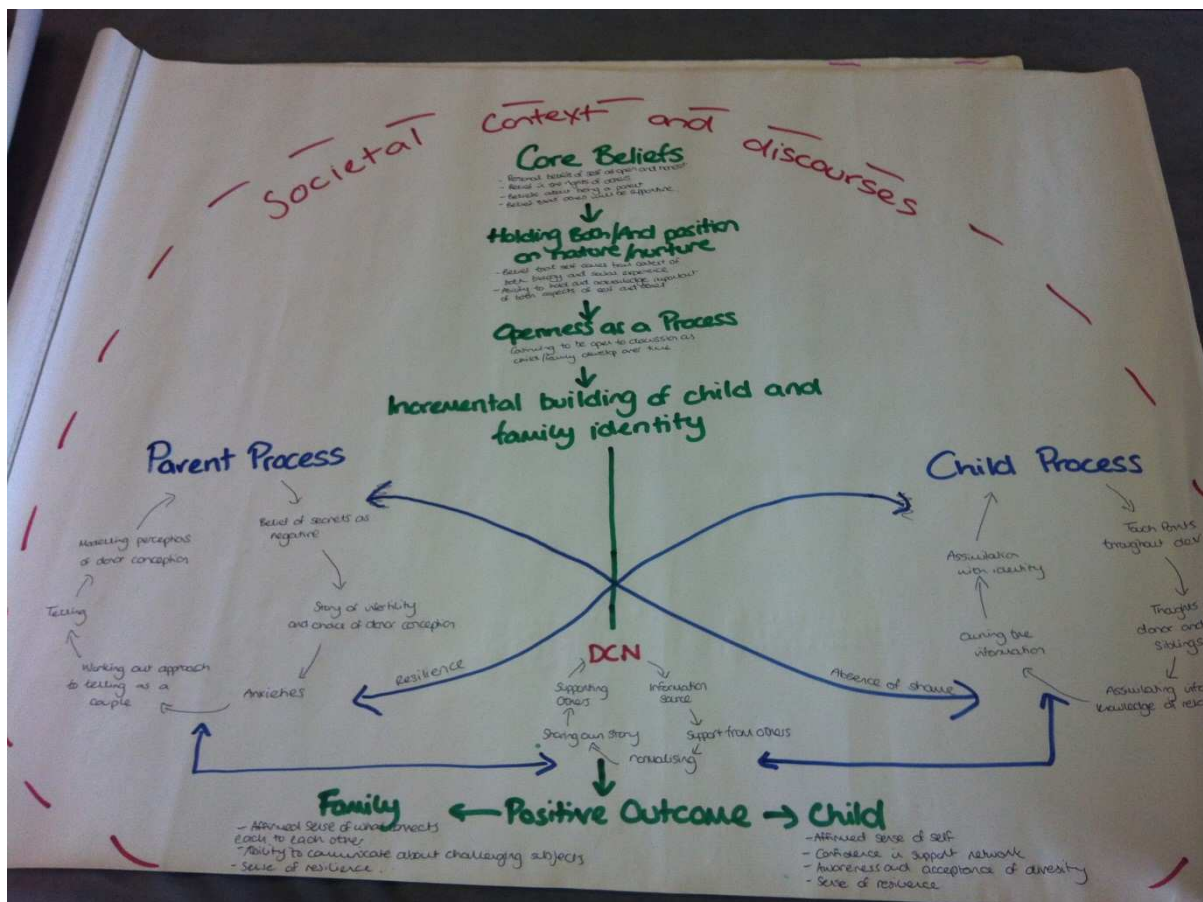
May 2012

Have been focusing on drafting section A and felt quite disconnected from my data. Spent some time this week re-reading transcripts and checking focused coding to ensure I have not missed any possible emergent categories. The child process and parent process categories are definitely linked and interact with one another. From looking at the data again I think the main sources of interaction come from the way that parents communicate about the issues with children, in a way that means there is no sense of shame or guilt or anything to be hidden/played down. I have called this sub-category 'absence of shame'. The parent process is also definitely affected by the feedback received through the child's responses to the information and general coping, I have called this 'resilience'. Have started to look at diagramming this out in the hope that it will help with the constructed model.



June 2012

Can't believe how quickly time is going! Met with supervisors to discuss my constructed model. Both agreed that the model seems to fit well with the data and captures the complexity well. Phew!!



June 2012

Have now completed draft of section B. I have some concerns that the emergent categories and constructed model don't quite fit with my research questions. Whilst they cover the general area of the research questions I think that the model goes further to explore the processes within the family. The project was initially designed to explore the impact of openness for young people, I think that this model shows just how interconnected that process is with the impact for the family. Whilst I'm aware that this type of emergent finding is in keeping with the grounded theory methodology, I have some anxieties about how I convey this in the write up, so as it doesn't look as though I just haven't achieved my research aims.

July 2012

Am looking back over this research diary today, adding the photos I have taken and the early excerpts from my notebook in order to put everything together for section D. Looking over it I'm struck by what a process this has been. I feel very grateful for having had the experience of a qualitative project, I think this has made the research a particularly enriching experience as I have had to really thoughtfully consider the impact of my own assumptions and constructions on the research process.

Appendix 12: Audit trail: Categories from constructed model

Categories	Sub-categories	Focused codes	Quotes
Societal context and discourses		<p>Congruence of information with modern discourse eases openness</p> <p>Different for different families</p> <p>Influence of wider systems in information moving outside of family</p> <p>Impact of society on child development</p> <p>Religion</p>	<p>“But modern medicine means that erm, they’re actually now very openly, if you want to be open about it, then you can make families in all sorts of different ways too now. So erm, that’s why, that’s why we went down that route to being open about it”</p> <p>“I believe what clinician’s therapists and the world in general says to you is very influential on what you what you do [] so what is the climate of opinion it’s like people being persuaded to vote tory (laughs)”</p> <p>“ in this day and age, that they you know that they say that babies are made in lots of different ways, because they are, and there’s no problem”</p> <p>“well I’ve spoken to her teacher.... and told her how erm the children came to be err in order that she was aware in order that although at this stage of course at 4 in reception year it’s very unlikely that erm the subject comes you know will come up, about how babies are made it’s a bit early but you never know”</p> <p>“I’m thinking here of the teenage years although increasingly in children the teens happen at about 10”</p> <p>“friends who haven’t told the children yet because they haven’t told the children because they haven’t told her parents because she’s [ethnic background] so culturally it’s very different”</p>
Core Beliefs	Core beliefs of self	<p>Congruence of openness core beliefs of self</p> <p>Beliefs of parenting</p>	<p>“I am just a very honest person”</p> <p>“I’m someone who I couldn’t possibly keep that sort of secret I mean it would be absolutely impossible for me I’m just not like that”</p> <p>“So I’m not a secretive person by nature”</p> <p>“to be respected that that helps you to be robust doesn’t it erm and kind of have a</p>

		<p>Creating family as most important event in life</p> <p>Ethical belief of acceptance of diversity in family formation</p>	<p>consistent sense of yourself and so err I suppose I think its supporting those things I I don't think its laying the ground for anything that he is but I erm but I think its supporting him to to grow and to be comfortable in his own skin cos that's all you want for anybody isn't it really"</p> <p>"why wouldn't I do it about this most important thing of trying to create a family"</p> <p>" in this day and age, that they you know that they say that babies are made in lots of different ways, because they are, and there's no problem"</p>
	Core beliefs of others	<p>Expectation of others as supportive</p> <p>Parental family experience as supportive</p>	<p>"also I think you can get a lot of guidance and comfort and moral support by sharing what's going on in your life"</p> <p>"I'm from a big family, I'm one of five children, we're all close, we're close to mum and dad, it never had crossed my mind that erm we wouldn't be completely open with my family about what we were doing"</p>
Holding both/and position on nature/nurture	Connection through relationship	<p>Close relationship with siblings and family members from shared experience over genetics</p> <p>Child belongs to parents for more reasons than genetics</p> <p>Having a 'real' mother and father</p>	<p>"of course growing up together is the thing that makes the difference so she would still feel the connection"</p> <p>"those people don't know each other, and those, the egg and the sperm, would never have therefore have come together under any other circumstances unless by some extraordinary fluke, erm they were selected to, err , to be as close a match to us, to _(husband)_ and I, as individuals physically, as much as possible, so the chances of those two people ever having come together to create a baby otherwise are, are, are very small, obviously"</p> <p>"that I am her real and only mother, she has a donor, she doesn't have two mothers, she has one mother, and a donor, or two donors. But she has one mother, one father and two donors, and erm but we are her parents"</p>
	Connection through genetics	<p>Strength of genetic connection creating curiosity</p>	<p>"there is a difference because he has a donor so somewhere there may be somebody with a family album with pictures in it that look like him because they're genetically close to him []and important to recognise that but that</p>

		<p>Drawing support from genetic connection to sibling</p> <p>Genetic links for characteristics</p>	<p>doesn't mean to say that you're emotionally less close"</p> <p>"I mean maybe the the the urge to search, would be greater, if you had nobody by your side you were genetically connected to"</p> <p>"she has darker hair than me and darker eyes and we don't like the same things and she's skinnier than me because like maybe her donor dad was a bit skinny or something and like she inherited my mum's mathematicalness and I guess I didn't and it kind of all fit it fit into place really"</p>
Openness as a process	How to tell	<p>Knowing how to tell</p> <p>Use of story book for telling</p> <p>Importance of language</p> <p>Line between secrecy and privacy</p>	<p>"kind of fumbling towards some understanding some non-threatening discussions"</p> <p>"I bought the little books, the little storytelling books that were appropriate to _(daughter1)_'s and _(daughter2)_'s age and that's useful, they're very useful"</p> <p>"we read those as part of bedtime reading, not all the time but maybe once a month or something like that, just a reminder"</p> <p>"she was being open talking with her granddaughter about this topic but she didn't use the right language and of course this girl came back confused, cos as far as she knows, she's only got one daddy and she does only have one daddy, she's got one daddy and a donor"</p> <p>"so my view was just be open with everybody, that doesn't mean that you know when a plumber comes to fix the boiler and says ooh she looks just like you, that you say ooh well actually you're wrong there because in fact you know, you don't necessarily have to share it with everyone and their uncle."</p>
	Who to tell	Who to tell	<p>"was more like we felt sort of quite pragmatically we needed to tell _(Mum)_'s mum and her husband at the time"</p> <p>"my parents weren't alive so that didn't arise er as far as my immediate family my brothers I've got 2 brothers and a sister erm I didn't tell them immediately but I did tell them well I'm</p>

			not even sure I've told my eldest brother he's in _(overseas)_ er I don't see him very often but erm certainly my sister and my younger brother I told fairly soon"
	Continuing the discussion	Openness as a process Being open to discussion	"Well erm first of all absolutely essential you tell them I mean there's no question about that erm but that's really only the beginning of the story" "Erm well the topic of donor conception comes up almost entirely because we raise" "like he would tell us like if there was something we didn't know already that they haven't mentioned because we were too young and wouldn't understand he'd tell us now and stuff"
	Donor conception moving to the background	DC moves to the background	"that actually, once you've had the child they're just your child, and your worries become, you know, how to deal with colic" "the main thing that's on my mind is like school like during normal school I just like I never really think about it"
Incremental building of child and family identity		DC Identity Building child's story	"it is a really important thing to me in as much as its something that like err no big deal but it's a large part of me and its integral to who I am and my family so I do think its like important that new people that come into my life know" "And so I'm just planting seeds at the moment and what will happen I'm sure is that questions will come as she understands more" "I will weave that into the story, erm, before that dawning that sort of full realisation occurs"
Parent process	Belief of secrets as negative	Lack of control over a secret Impact of secrets	"you know the, the balancing act, the mental juggle of, well she knows this and he knows that but hold on they only knew this and so if that you know I just couldn't possibly, keep tabs on it" " I myself am aware of that very personal experience of having had a secret kept and how much that has er yeah erm you only feel negatively about it you know I just don't have any positive feelings about that"
	Story of	History of donation	"there's a different history, to how those,

	infertility and choice of donor conception	<p>changes the story</p> <p>Some DC scenarios more obvious</p>	<p>that, that donation occurred, that changes things slightly, and similarly if you know, you've got donor egg, but, but father's sperm, or donor sperm but mother's erm egg, you know all of those scenarios change the story just a little bit."</p> <p>"if for instance the donor person was like black or like Asian bit like both your parents they're like both black or like both white if you were mixed race bit your parents aren't like different then it would be kind of awkward like going into school you'd have to like tell everyone"</p>
	Anxieties	<p>Potential emotional tool to be used in anger</p> <p>Unconscious communication of anxiety</p> <p>Parental anxiety about openness impacting on child</p> <p>Parent-Child relationship problems in teenage years</p> <p>Downside to telling</p> <p>Fears for child-parent relationship</p>	<p>"she'll get to an age where if she wants to hurt us, she'll be old enough to realise that that could be a potential sort of erm point that she could make if she was, you know angry with us, and she could fling it out there and again"</p> <p>"who knows, what it, what's going on in his head but the point is if he, if he can come to terms with it himself, then, then she'll be fine about it, but if he can't then that will in some way communicate itself"</p> <p>she'll pick up on it, she'll pick up on the fact that he's a bit awkward about it and she will think there's something to be awkward about"</p> <p>"she could say something like well you're not my real mother, but you know the fact is, that children, children say that sort of thing anyway"</p> <p>"I mean the downside of telling everybody you're close to is, is if you've got a large group of people you're close to is, is you've gotta, you know, tell the story a lot, and obviously with all those failures"</p> <p>"because I'm the the person who had the infertility that led to having a donor and its (Mum)'s the mother I'm not sort of the genetic father so I felt potentially a little bit threatened by that that there might be some</p>

			sort of rejection”
	Working out approach to telling as a couple	Approach as a couple to openness Difference in parents approach to telling	“really _(Mum)_ and I I don’t think we’ve really discussed very strategically you know the different stages and steps and things” “he’s more passive about it, and so he will go with the flow, on it, I would say probably he might have some reserves, he’s never expressed them, but that doesn’t mean to say he doesn’t have any”
	Modelling perception of DC	Transmission of perceptions of DC through parent-child relationship	“if you feel ok about it yourself, it should all come out well” “they’re able to talk about it that they’re not inhibited from talking about it that they feel that their family supports them in this”
	Absence of shame	Absence of shame	“some non-threatening discussions and loving discussions and I mean in the end its positive if they feel positive” “I have the capacity to be open so I think if we model that then I think that’s something that _(Son)_’s gonna find normal”
Child process	Touch points throughout development	Medical history	<i>“as I got a bit older erm and was doing science more I thought a bit more about like the genetics side of it and I was like in some ways it would be quite nice to know a bit more about not him but his like medical history or like medical history in his family or something cos erm I think it was just like erm as you get older you hear more about that sort of thing”</i>
		Sex Education/School	“when we did erm reproduction like last year I felt a bit awkward cos they mentioned this thing about donors and stuff and I was like oh no I’m gonna be really stupid and like raise my hand about like knowing about it “we don’t know what the donor Dad’s allergies or illnesses or if he has like cancer or his family have cancer or like diabetes or something, would I ever get”
	Thoughts about the donor and donor half-siblings	Curiosity of donor characteristics	“most of my relatives are really mathematical but really I like suck at maths [] and erm I guess I just kind of like I’m not good at some stuff cos I don’t know if I would be cos I don’t know about my donor dad’s kind of personality and stuff I don’t know if I would be good at that”
		Meeting half-siblings	“it just like slips into my head and I get like oh

			yeah I will one day meet my donor siblings and its gonna be really cool and I'll find out that i'm actually really like them"
	Assimilating information with knowledge of relationships	Relationship to non-genetic parent Sibling relationships	"think I'm closer to my Dad cos I don't know I think I've just kind of unconsciously known that I'm not really related to him and so I want to be closer to him" "with my sister like we have different donor dads so we're kind of like half-sisters but we're not exactly we're like related but its just kind of awkward because like if we had the same donor dad we'd be like oh yeah we're sisters"
	Owning the information	Information belongs to the child Child telling	"how could you have your whole family and friends know and then your children, to whom the information belongs, actually, not know" "occasionally I tell friends like if it comes up and it is something that's relevant to the conversation or anything like that"
	Assimilation of the information into identity	Assimilation of information into identity Making sense of the information	"I accepted it as being something about me another fact about me that I've got brown hair and brown eyes and I'm a donor baby it's just one of those things" "cos it just makes sense to me I don't know what wouldn't make sense. It kind of all works, like, they can't have a kid so then someone donates like sperm or an egg and then they can and then I was like a donor child and stuff, I have two parents but one of them isn't my blood related parent and so it all kind of makes sense"
	Resilience	Resilience	"I don't like have a nervous breakdown or anything I just like I just try and think positively about them and just like tell myself its ok and stuff"
DCN	Information source	DCN as information/learning source	"a little workshop that I went to called Talking and Telling, which is a fantastic, I mean I have to say the donor, I have nothing but praise for the Donor Conception Network," "I've read a lot of the DCN information and stuff the newsletters and people's you know erm testimonies about it which has been really interesting"
	Gaining support from	Speaking with other DC parents	"the other mother whose children were donor conceived, and I spoke together to

	others		<p>_(daughter1)_'s teacher"</p> <p>"it will be interesting to go to this workshop that's coming up and also at some point to go to one of the meetings and meet some of the erm people with older children because I haven't met anybody yet with older children"</p>
	Normalising	Normalising	"one of the great benefits of the DI network is erm it normalises all this stuff"
	Sharing own story	Sharing own story	"network meeting and was asked to speak about my experiences and I had so many people coming up to me and being like the stuff that you said has been so important to me and that like blew me away"
	Supporting others	Supporting others	"I've had 3 conversations on the phone with people who've been suggested by the DCN to talk to so they've given our name or telephone number and rather having a set thing to say it's usually a response to their fears"
Outcomes for the child	Affirmed sense of self	Knowing Identity	"it's just another thing that about me that I don't feel at all like it's any different maybe to saying anything else about me like that I'm white I'm a donor baby I suppose it's just one of those one of those things that you'd put like down on a form like what you are"
	Confidence in support network	Confidence in support network	"from my own perspective I think it's the most integral part of why I feel comfortable with the way that I've been born in my family and stuff I think that that's always the thing that I felt most strongly if anything my strongest opinion growing up was just that I really really respected my parents for being honest with me"
	Awareness and acceptance of diversity	Awareness and acceptance of diversity	<p>"Erm I think it had a positive impact on me because its sort of like let me I don't know I think if I didn't know about it I wouldn't be as accepting to other people [] so I think that when other people are slightly different I like accept them more than like other people do"</p> <p>"yeah that not everyone is just brown hair and pale skin and what you see"</p>
	Sense of resilience	Sense of resilience	"now I always feel like I kind of know now and now it makes a bit more sense and its all going to work out a bit more and even if they

			don't want to know about me I still know about the whole thing and how it works and stuff so it won't make me feel scared or anything cos I can like refer back to it and it will calm me down if I get worried"
Outcomes for the family	Affirmed sense of what connects each individual to each other	Sense of connection from relationship	<p>"I also felt very devastated not to have a child that was genetically mine I don't feel the strength of those feelings anymore they're probably there but I I'm more used to being around _(Son)_ you know and all the attachment that's there how much that means"</p> <p>"this child of yours is genetically yours and that's that's a thing for a sense of pride and a sense of bonding so without that component erm it was it was new territory erm so I didn't I thought it would be different [] these thoughts were all before he was born erm at the moment he was born I didn't experience it as any different"</p>
	Ability to communicate about challenging subjects	Openness promotes talking in the family	<p>"there is a positive thing about it if its shared erm erm I hope its given them confidence to talk about it"</p> <p>"I think it's taught them that openness is accepted in this family that its and the lessons that we've learnt from being open about the, about having a donor, have extended into lessons about being open with all sorts of things"</p>
	Strong family relationships	Strong family relationships	<p>"Erm I think its brought us closer erm it perhaps makes us feel special in some way"</p> <p>"came home from school one day last week very upset because of something that had happened in school and it was really clear he was upset he felt he could he could share that with us and another friend I spoke to said oh what worries me is that that could be happening to my child and he would never tell me and and I thought gosh I'm so, I'm so glad that our children feel they can come home and say I'm not happy"</p>

Appendix 13: Example transcript with initial coding

* This has been removed from the electronic copy

Appendix 14: Journal submission guidelines

HOME / SOCIAL & BEHAVIORAL SCIENCES / PSYCHOLOGY / FAMILY THERAPY /



Journal of Family Therapy

[Published on behalf of the Association for Family Therapy and Systemic Practice](#)

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TopAuthor Guidelines

Manuscript submission

Papers submitted for publication should be original work not previously published in English and not currently submitted elsewhere for consideration. If accepted for publication, a paper cannot be published elsewhere in any language without the consent of both Editor and publisher. It is a condition of acceptance that the Association for Family Therapy and Systemic Practice automatically acquires the copyright throughout the world.

Manuscripts should be submitted to the following website: <http://mc.manuscriptcentral.com/jft>. Full submission instructions can be found on this website.

A cover letter should be submitted with your manuscript and must include a statement that the data have not been published, and is not under consideration for publication elsewhere. It will be presumed that all listed authors of a manuscript have agreed to the listing and have seen and approved the manuscript.

Format for Manuscripts

1. Manuscripts should allow for 'blind/anonymised' refereeing and **must** not contain author names or any identifiable data.
2. Manuscripts **must** be typed in double spacing throughout, including quotation, notes and references in the following order:
 - Title Page: to contain the title of the paper, word count, suggested running head (short title for your paper) and key words.
 - Abstract: on a separate sheet, the title to be repeated followed by a summary of not more than 150 words. The suggested running head should also be present.
 - Organisation of the text: see copy of Journal for the format currently in use.
 - References (in text)

these should be indicated by the name and date e.g. 'Carr (2009)'. If more than two authors are listed, cite the reference as 'McHugh *et al.* (2010)'. Quotations should include page numbers. Web sites should also be cited in this way, with a full reference appearing in the References section (see below).
 - Figures, tables, etc.: All figures and tables should be numbered with consecutive arabic numerals, have descriptive captions and be mentioned in the text. They should be kept separate from the text but an approximate position for them should be indicated. These will need to be uploaded separately. Please supply figures in the format in which they were created, if possible.
 - References

should be listed at the end of the paper in alphabetical order according to the first author and be complete in all details, again following the Journal's existing format.

Articles: Lerner, G Intergrating Family Therapy in adolescent depression: an ethical stance. *Journal of Family Therapy*, 31: 213-232.

Chapters: Woodcock, J. (2009) Love and hate and the oedipal myth: the perfect bridge between the systemic and psychoanalytic. In Flaskas, C. And Pocock, D. (Eds) *Systems and psychoanalysis: contemporary integrations in family therapy*. London: Karnac. Pp 129-146

Books: Rivett, M. and Street, E. (2009) *Family therapy: 100 key points and techniques*. London: Routledge.

Web sties: Alzheimer's Society (2009) *Counting the cost: caring for people with dementia on hospital wards*, retrieved 11 January 2012 from http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1199.

3. The word limit, excluding abstract and references will vary depending on the type of paper you are submitting. Please refer to the 'Advice to Authors' section below.

4. Style: Whilst Journal style is generally formal, originality in presentation does not necessarily preclude publication if clarity and readability is thereby enhanced. Sexist language forms are unacceptable.

Your manuscript will be returned to you if you fail to conform to these requirements.

Patient Consent Form

Authors using case material must also sign the appropriate form to confirm that patients/families have given their informed consent for their details to be included in publication.

Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

Evaluation of Manuscripts

The Editorial office will acknowledge receipt of manuscripts. The Editor will arrange for evaluation by at least two assessors. Following receipt of the assessors comments the Editor will advise the authors about the decision concerning the manuscript. This will be done as rapidly as possible with the aim being 12 weeks.

Exclusive Licence Form

Authors will be required to sign an [Exclusive Licence Form \(ELF\)](#) for all papers accepted for publication. Signature of the ELF is a condition of publication and papers will not be passed to the publisher for production unless a signed form has been received. Please note that signature of the Exclusive Licence Form does not affect ownership of copyright in the material. (Government employees need to complete the Author Warranty sections, although copyright in such cases does not need to be assigned). After submission authors will retain the right to publish their paper in various media/circumstances (please see the form for further details).

Copy Editing

Following acceptance for publication an article is copy edited for conformity to the style of publication, clarity of presentation, punctuation, standard usage of terms, etc.

Proofs

First-named authors will receive proofs for correction which must be returned within 48 hours of receipt. The corresponding author will receive an email alert containing a link to a web site. A working e-mail address must therefore be provided for the corresponding author. Acrobat Reader will be required in order to read this file. This software can be downloaded (free of charge) from the following web site:

<http://www.adobe.com/products/acrobat/readstep2.html>. Further instructions will be sent with the proof.

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These articles are fully peer reviewed, edited and complete and are considered fully published from the date they first appear online. This date is shown with the article in the online table of contents. The articles are available as full text HTML or PDF and can be cited as references by using their Digital Object Identifier (DOI) numbers. To view all the articles currently available, please visit [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1467-6427/earlyview](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1467-6427/earlyview). On print publication, the article will be removed from the Early View area and will appear instead in the relevant online issue, complete with page numbers and volume/issue details. No other changes will be made.

ADVICE TO AUTHORS

Writing is a very enjoyable and satisfying way of being involved in the world of family therapy. The exchange of ideas and experience is important both for the development of our chosen field and for the development of the individual practitioner. We intellectually sustain ourselves by creating a healthy and vibrant literature. Family therapy needs to develop authors and *The Journal of Family Therapy* wants to hear from you.

These are the types of papers that are regularly submitted to the *Journal of Family Therapy*:

Research Presentation (3,000-6,000 words)

A research paper should include:

- An introduction to the principal concepts and theoretical issues relevant to the study.
- Previous work.
- Brief description of methodology including participants.
- Results.
- Discussion of results, including implications for future research and practice.

Case Study (3,000-6,000 words)

The Journal of Family Therapy particularly welcomes case studies. A case study paper should

- Introduce the clinical dilemma posed by the case.
- Review relevant literature.
- Describe the intervention/treatment.
- Discuss the relevance of the intervention for general clinical practice.

CONSENT TO PUBLISH MUST ALWAYS BE OBTAINED FROM CLIENTS/ FAMILIES BEFORE SUBMISSION

Theoretical Discussions or Controversial Theoretical Papers (4,000-5,000 words)

Again there are few articles of this nature offered for possible publication. A paper of this type would include:

- A brief general introduction.
- A review of previous statements of the issues.
- A definition of problems and solutions.
- A development of an argument (Research based work which was undertaken for a thesis may be referenced).
- Relation of theory to practice.
- Issues to be resolved.

Often we will ask one of the reviewers to write a commentary on the paper to stimulate debate through the Journal pages.

Literature Review (3,000-5,000 words)

These are much sought after by the readership. Such a paper would have:

- A brief general introduction.
- A description of the way in which the themes in the literature are organised by the author for review. This may include conceptual and definition problems.
- The review.
- An overview of the review process including gaps in existing knowledge.

- Future directions.

PAPERS EXCEEDING 6,000 WORDS (including references) WILL BE RETURNED TO THE AUTHOR

PREPARING THESIS MATERIAL FOR PUBLICATION

From the outset, it needs to be appreciated that the audience for a thesis is very different to the readership of a Journal. A thesis is prepared to demonstrate candidates' knowledge of an area, their understanding of how theoretical matters link and their ability to use a wide range of sources to develop arguments. In presenting research material, the thesis will provide explanations about the process of deciding on a methodology, the utilisation of that methodology and a critique of its application. A Journal article by contrast seeks to make one or two points clearly and to link these with the current understandings and conceptions in such a way that there is the development of ideas. The Journal reader assumes that the author has a wide range of knowledge of the area and is looking for the author to make a few points well by building on what is already known.

The key to overcoming the difficulties of moving from a thesis to a Journal article is to be aware that one uses the thesis as a source rather than using it as an earlier version of the article. In preparing a Journal article you begin with a blank sheet of paper, a lot of knowledge and previous written material. What is available has the potential of being an article but further work will be necessary.

A thesis and a Journal article are very different pieces of writing and the process of preparing one for the other is more than just re-wording the title page!

Many Journal reviewers can easily identify thesis based material by the following common problems that appear: -

1. The introduction is over long and covers too broad an area.

Histories of where family therapy came from and descriptions of core elements of systemic practice are not necessary in Journal articles. Only the theoretical point germane to the article's principle aims need to be outlined.

2. Long explanations as to why particular methodologies are used.

For a Journal article there is no need to enter into discussions of this nature or to compare different methodologies. The decision was made to undertake the research on one particular methodology and this is what should be present.

3. Too many quotes from other authors.

There is a need in a thesis to seek validation from a wide range of sources, but in a Journal article the author's own arguments should be enough with a few selected quotes to emphasise points.

4. The attempt to write the journal article by following the same structure of the thesis.

In many cases this is not necessary as the article will demand a different type of structure.

5. Over long self critique of the work.

Although self criticism is a necessary part of any public presentation of one's work, it needs to be pertinent to the material presented. There is no need for a full descriptive account of the self reflective process.

6. De-emphasising the main findings of any research study in an attempt to fit it in with the fuller perspective of the thesis.

In an article the main findings of the research study need to be emphasised and examined and then linked to broader themes relevant to the issues discussed.

In short, writers of papers prepared from theses often attempt to include as much of their thinking that went into the thesis in the paper. There is a need to overcome the reluctance to cut out elements of the thesis in the preparation of an article to keep the writing solely relevant to the ideas being present.

Good Marks and Articles

Because the consumers of theses and papers are different, the potential author needs to be aware that if a thesis is praised it does not necessarily mean it is readily translatable into an article. It simply means a good mark towards the degree. Similarly, even if a thesis or extended essay just scrapes past the pass mark, it may contain some very useful material that can be worked with for future submissions as an article to a Journal.

The Question of Authorship

In many academic departments there is a tradition that material which is offered for publication which is based on a thesis should be seen as a joint endeavour between the student and the supervisor. The student is seen as being the senior author with the supervisor in a supporting role. Courses and supervisors are quite likely to have different views on this. There are no set rules. However in some situations it may be that by using the thesis material as a source a good quality article could be developed by the student and supervisor working on it jointly. This is a point that should be borne in mind by both students and staff of family therapy courses.

Visit <http://authorservices.wiley.com/bauthor> for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

Wiley's Author Services

Wiley's Author Services technology enables authors to track the production status of their accepted articles. Additionally, it offers authors free access to their published articles online and the ability to nominate up to ten colleagues for free access to the article. To find out more about Wiley's Author Services please visit <http://authorservices.wiley.com>

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Please note the Editorial Office is open on Thursdays