

**WHEN WOMEN WITH CYSTIC FIBROSIS BECOME
MOTHERS: PSYCHOSOCIAL IMPACT AND
ADJUSTMENTS**

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ABSTRACT

With advances in CF care, motherhood is now a realistic option for many women with CF. Research has taken place exploring the impact of pregnancy and motherhood on physical health parameters, however, there is little research on the psychosocial impact of becoming a mother on women with CF. The importance of information on this issue has been noted by both patients and professionals. As a result, this study aimed to explore the psychosocial impact of becoming a mother on women with CF, and how they adjust to manage this.

Eleven mothers with CF (mean age 30 years, FEV₁ 68%) were interviewed over the telephone, and the data subjected to a grounded theory analysis. Thirteen conceptual categories and 70 subcategories were developed into a coherent framework and represented as a theoretical formulation. This theory details three core categories related to each other through a central process. It highlights the significant and complex psychosocial impact becoming a mother has on women with CF, and the processes utilised to adjust. Managing the dual demands of CF and motherhood was found to be difficult, particularly in the early stages. However, the experience was found to be manageable, becoming easier to cope with over time. However, the mothers' own resilience, problem solving skills, and support systems were revealed to be of paramount importance in adjusting to motherhood. The theory developed in this study also details the potential adaptations to CF care that may be required when female patients have children. In coping with and adjusting to motherhood, participants discussed the importance of the support of their CF team. This support was noted to be of great importance during the planning and preparation phase, and upon having children.

The theoretical formulation developed and the study findings are discussed in the context of the existing literature, and implications for clinical practice and future research are discussed.

TABLE OF CONTENTS

<i>Section</i>	<i>Page</i>
ACKNOWLEDGEMENTS	3
ABSTRACT	4
TABLE OF CONTENTS	5
TABLES AND FIGURES	9
KEY	10
INTRODUCTION	11
Cystic Fibrosis (CF)	11
Psychosocial Impact of CF	11
Quality of Life	11
Emotional Functioning	12
Social Functioning	12
Self Care and Treatment Adherence	12
Developments in Outcomes	13
Becoming a Mother: Psychosocial Impact	13
Psychological, Emotional, and Social Impact	14
Coping and Adjustment	15
Summary and Critique	17
Motherhood and Chronic Illness	18
Psychological, Emotional, and Social Impact	19
Self care and Treatment Adherence	20
Coping and Adjustment	21
Theories of Mothering with a Chronic Illness	23
Summary and Critique	23
Reproductive Health in CF	25
Fertility and Contraception	25
Sexual Activity, Knowledge, and Awareness	25
Information Desired	26
Pregnancy and CF	26
Pregnancy Outcomes, Risk Factors, and Advice	26
Decision Making Around Pregnancy	27
Preparing for Pregnancy	28
Becoming a Mother with CF: Impact on Physical Health	28
Psychosocial Impact of Becoming a Mother with CF	30
Psychological, Emotional, and Social Impact	30
Self Care and Treatment Adherence	31
Coping and Adjustment	31
Models of Coping and Adjustment	32
Implications and Critique of the Models	34
Impact on the System	35
Rationale for the Current Study	37
METHOD	39
Design	39
Methodological Considerations	39
Service User Advisor	39
Qualitative Research	40
Grounded Theory	40

Rationale for use of Grounded Theory	42
Developing the Research Question	43
Ethics	44
Ethical Approval	44
Ethical Considerations	44
Confidentiality and Data Protection	44
Informed Consent	44
Managing Distress and Risk	44
Considering the Investigator as 'Expert'	45
Managing the Power Imbalance	45
Recruitment	45
Inclusion Criteria	45
Recruitment Method	45
Data Collection	46
Pilot Study	46
Semi-Structured Interviews	47
Telephone Interviews	48
Conducting the Interviews	49
Quantitative Data	50
The Hospital Anxiety and Depression Scale (HADS)	50
The CF Quality of Life Scale (CFQoL)	50
Data Analysis	51
Three Levels of Coding	51
Open Coding	51
Axial Coding	51
Selective Coding	52
Analytic Tools	52
The Use of Questioning	52
Constant Comparison	52
Negative Case Analysis	52
Theoretical Sensitivity	53
Diagramming	53
The Analytic Process: An Example	53
Step One: Open Coding	54
Step Two: Establishing Conceptual Categories	54
Step Three: Establishing Subcategories	55
Step Four: Returning to Previous Data	56
Step Five: Integrating the Data	57
Step Six: Adjusting the Working GT Model	57
Step Seven: Noting Relationships Among Categories	58
Step Eight: Updating Research Journal	58
Step Nine: Adapting the Interview	58
Final Selective Coding	58
Memo-Writing	60
Quality Standards in Qualitative Research	61
Supervision	61
Credibility Checks	62
Returning to Participants	62
Comments from Similar Others	63
Auditor Check	64

Verification	64
Reflexivity	65
Demographic Details and Experience	65
Personal Biases	65
Clinical Interests	66
Role of the Researcher	66
RESULTS	68
Overview	68
The Sample	68
Demographic Details	68
Pen Portraits	72
Quantitative Results	78
CFQoL	78
HADS	80
Qualitative Results	81
Theoretical Formulation	83
Core Category One: 'Living with CF'	84
Core category Two: 'Becoming a Mother'	103
Core Category Three: 'Pooling Personal Resources'	121
Central Process: 'Balancing Mother's and Child's Needs'	131
Summary	134
DISCUSSION	135
Overview	135
Summary and Synthesis	135
Psychological, Emotional, and Social Impact	135
Self Care and Treatment Adherence	139
Coping and Adjustment	141
Experience of CF Teams	146
Strengths and Weaknesses of the Research	148
Strengths	148
Contribution to the Literature	148
Sample	148
Methodological Rigour	149
Quality Checks	149
Limitations	149
Sampling Strategy	149
Sample	150
Researcher Bias	152
Access to Information	152
Grounded Theory	152
Clinical Implications	153
Relationship with the CF Team	153
Opening up Discussions	153
Information Giving	154
Needs Assessment	154
Managing Health and Treatment	155
Facilitating Support	155
Direction to the CFMothers Forum	156
Communication and Education	157
Following Guidelines	157

Future Research	157
Expanding the Theory	157
Informational Needs	158
Impact on the Partner	158
Impact on the Child	158
Fathers with CF	159
CONCLUSIONS	160
REFERENCES	161
APPENDICES	179
Appendix A: Ethical Approval	179
Appendix B: Information Sheet	180
Appendix C: Consent Form	182
Appendix D: Interview Schedule	183
Appendix E: Organising Open Codes	184
Appendix F: Conceptual Category Table	185
Appendix G: Re-analysis of Interviews 1-5	186
Appendix H: Reanalysis of Interview 6	187
Appendix I: Working Grounded Theory Model	188
Appendix J: Close Up: Working Grounded Theory Model	189

TABLES AND FIGURES

<i>Figure/Table</i>	<i>Page</i>
Table 1. Meaning units and allocated open codes: Examples	54
Table 2. Open codes and categories they were allocated to: Examples	55
Figure 1: Memo: Example	60
Table 3. Health and treatment status of participants	69
Table 4. Socio-demographic details of participants	71
Table 5. CFQoL scores	79
Table 6. HADS scores	80
Figure 2. Theoretical formulation	82
Figure 3. Conceptual and subcategories included in 'Living with CF'	85
Figure 4. Conceptual and subcategories included in 'Becoming a Mother'	104
Figure 5. Conceptual and subcategories included in 'Pooling Personal Resources'	122
Figure 6. Step 2: Organising open codes.	184
Table 7. Extract of conceptual and subcategory development table	185
Table 8. Extract of reanalysis of interviews 1-5	186
Table 9. Extract of reanalysis of interview 6	187
Figure 7. Working grounded theory model.	188
Figure 8. Close up: Working grounded theory model.	189

KEY

ART: Assisted reproductive technology

CF: Cystic fibrosis

CFQoL: Cystic Fibrosis Quality of Life Scale

FEV1%: Forced expiratory volume in one second percentage

GT: Grounded theory

HADS: Hospital Anxiety and Depression Scale

HIV: Human immunodeficiency virus

IPA: Interpretative phenomenological analysis

IVs: Intravenous (anti-biotics)

MS: Multiple sclerosis

PND: Post-natal depression

SES: Socio-economic status

INTRODUCTION

Cystic Fibrosis

Cystic Fibrosis (CF) is the most common fatal genetic condition affecting Caucasians, with a prevalence rate of one in 2500 people in the UK (Edenborough and Morton, 2010). It is a chronic life limiting condition which results from the absence of the cystic fibrosis transmembrane regulator (CFTR) protein gene, which functions as an ion channel and a regulator of other ion channels. Its classic presentation is associated with essentially absent CFTR functioning (Suade and Rubenstein, 2010). Various bodily systems are affected, mainly the lungs and digestive system. Individuals with CF experience the build up of mucus and bacteria in the lungs which is inefficiently cleared, resulting in increased susceptibility to infection and respiratory problems. Around 85% of individuals with CF do not produce enough enzymes for efficient digestion and absorption of food. Difficulties with liver function, diabetes, and osteoporosis are also common (Thomson and Harris, 2008). CF is a progressive disease, and ultimately, the most common cause of death is respiratory failure (Edenborough and Morton, 2010).

Psychosocial Impact of Cystic Fibrosis

The psychosocial implications of CF have been well documented and explored. However, research as to the extent of these difficulties has revealed inconsistent results.

Quality of Life

Research to date has revealed that individuals with CF have equally high or higher levels of overall quality of life in terms of psychosocial functioning when compared to their healthy peers (Pfeffer, Pfeffer, and Hodson, 2003, Wahl, Rustoen, Hanestad, Gjengedal, and Moum, 2005). However, it appears that individuals with CF do differ to their healthy peers in relation to physical aspects of quality of life, such as satisfaction with health and work (Britto, Kotagal, Hornung, Atherton, and Tsevat et al., 2002, Wahl et al., 2005).

Emotional Functioning

A number of studies have found no increased prevalence of anxiety and depression in those with CF as compared to healthy controls (e.g. Anderson, Flume, and Hardy, 2001, Havermans, Colpaert, and Dupont, 2008). Other research has found these psychological difficulties to be increasingly prevalent however (Burker, Sedway, and Carone, 2004, Riekert, Bartlett, Boyle, Krishnan, and Rand, 2007). It may be these difficulties *are* present, but they do not cause distress, which may account for the inconsistent results. Sawaki, Sellers, and Robinson (2008) found evidence to support this hypothesis. Other potential reasons for the variable results may be due to the differing measures used, the variable nature of the course of CF (Parkins, Parkins, Rendall, and Elborn, 2011), the degree of acceptance among patients (Casier, Goubert, Theuni, Huse, and De Baets et al., 2011), the age of samples (Anderson et al., 2001) and whether the studies are cross sectional or longitudinal (Cruz, Marciel, Quittner, and Schechter, 2009)

Social Functioning

Individuals with CF are now achieving greater levels of social integration as a result of increased physical functioning and developments in CF care (Parkins et al., 2011). A large study (n=670) by Besier and Goldbeck (2012) found that around two thirds of adults with CF were training for a job or employed, and living with a partner. Statistics from patient registries also illustrate the majority of adults with CF are living full and productive lives in regards to educational and occupational achievements, levels of independence, and relationship status (CF Foundation, 2012, CF Trust, 2013).

Self Care and Treatment Adherence

The demanding CF treatment regimen can affect quality of life (Cruz et al., 2009). Treatment regimes take place on a daily basis. They are time consuming and complex, involving chest physiotherapy, enzyme and nutritional supplementation, exercise, and the use of oral, inhaled, and intravenous (IV) medication (Abbott, Hurley, Morton, and Conway, 2013). CF care also involves the regular monitoring of lung function, given as a 'forced expiratory volume in one second' percentage (FEV1%, Thomson and Harris, 2008). A lack of

adherence to treatment is common in CF, with an estimated 50% of individuals not complying with at least one aspect of treatment (Pfeffer et al., 2003). However, adherence appears to be treatment specific, with higher rates of adherence to exercise and enzyme supplementation than physiotherapy and nutritional supplements (Abbott, Dodd, Bilton, and Webb, 1994, Llorente, Garcia, and Martin, 2008).

Developments in Outcomes

CF was once considered a disorder of childhood, given the short life expectancy (Thomson and Harris, 2008). Over the last 50 years however, advances in research and clinical care have resulted in a life expectancy reaching the late 30s (CF Trust, 2013). With increasing survival, the psychosocial issues likely to affect the ageing CF population need to be explored (Parkins et al., 2011). One such issue is the possibility of having children, given that pregnancy and motherhood are now realistic opportunities for women with CF (Carroll, Gallagher, and McKone, 2012). Indeed, more and more individuals with CF are becoming parents (Lauritsen, Hansen, Pressler, and Balslov, 2008). Many adults with CF have expectations of healthy sexual relationships, and hope for children (Roberts and Green, 2005, Edenborough, Borgo, Knoop, Lannefors, and Mackenzie et al., 2008). Fair, Griffiths, and Osman (2000) found that 72% of females with CF (median age 24 years, FEV1 60%) said that having children was important to them in the next 10 years.

Before considering motherhood in the context of CF, I will first discuss the psychosocial impact of motherhood more generally.

Becoming a Mother: Psychosocial Impact

Historically, motherhood has been discussed as a passive, joyful, and desirable experience. However, the challenging nature of the transition has also been acknowledged. Many studies have highlighted the significant, and often difficult, psychosocial impact of becoming a mother.

Psychological, Emotional, and Social Impact

Barclay, Everitt, Rogan, Shimed, and Wyllie (1997) conducted focus groups with 55 first time mothers to explore their experiences of new motherhood, and subjected the data to a grounded theory analysis. Six major categories emerged. 'Realizing' involved facing the consequences of becoming a mother. 'Unready' detailed the mothers' reflections of feeling unprepared. 'Drained' captured feelings associated with the constant demands of being a mother. 'Alone' captured feelings of isolation, and 'loss', captured things lost such as time to oneself. These losses were balanced by positive gains by many mothers, such as unconditional love from the child. Barclay et al. (1997) suggested becoming a mother involved moving through two phases, that of feeling their life wasn't theirs any more, to feeling in tune with their baby.

Nystrom and Ohrling (2004) conducted a thematic content analysis of 33 studies that aimed to explore first year parenting experiences. Regarding mothers, four themes emerged. These included 'being satisfied and confident as a mother', 'being primarily responsible for the child is overwhelming and causes strain', 'struggling with limited time available for oneself', and 'being fatigued and drained'. The overarching theme identified was 'living in a new and overwhelming world'.

Barlow and Cairns (1997) interviewed 11 mothers and identified a core category, 'expansion of the self', to capture the personal growth experienced. Conceptual categories included 'engagement', related to the first year of mothering. This was characterised by a number of psychological processes. These included making a conscious decision to have a child, considering their own experiences of being mothered, and committing to a new life prompted by the awareness of responsibility, increasing confidence, and loyalty to societal expectations. A further process identified was 'preserving self, preserving child'. This involved the mother attempting to balance connectedness with separateness from the child, and their own and their children's needs. Mothers often sacrificed themselves and their needs, which resulted in the loss of their personal identity.

Darvill, Skirton, and Farrand (2010) interviewed 13 mothers and identified a core category of 'altering self concept'. Participants discussed feeling they were not in control of their lives on becoming a mother, with their lives being dictated by the needs of the infant. Caring for the baby was described as challenging and

brought with it a sense of 'emotional turmoil'. However, participants also discussed many positive feelings, such as a sense of achievement at having created a life.

Wilkins (2006) interviewed eight first time mothers at six weeks post-partum. The core category 'doing it right' related to the need to carry out the mothering role effectively and safely. This was noted to be important for their baby's well being and their own self esteem. New mothers moved through a series of processes in attempting to 'do it right'. These included learning new skills to care for their children, establishing new ways to organise their lives, losing contact with their previous lives, feeling isolated, and perceptions that other mothers were more competent in caring for their children. A further category was 'restoring balance', whereby mothers began to reconcile their new roles with their former lives. Here they began to apply their new skills, restoring their confidence. The final category was 'falling into place', which involved mothers' gradual awareness they were able to meet the needs of their babies.

McVeigh (1997) conducted a content analysis study and identified a major category, 'conspiracy of silence' that seemed to exist in regards to the true nature of motherhood. Whilst participants loved their babies, the responsibility and work involved was a shock, and was described as relentless and boring. Maternal fatigue was described as unbearable, particularly when their infants had difficult temperaments. They discussed the amount of time needed to care for their children, and a lack of time to themselves.

Nelson (2003) reviewed nine qualitative papers exploring the experiences of motherhood and found five common areas of 'disruption'. These included commitment (e.g. feeling pressured to look after themselves), daily life (e.g. feelings of exhaustion), relationships (e.g. the marital relationship), work (e.g. deciding whether to return to work), and the self (e.g. loss of self esteem).

Coping and Adjustment

Currie (2009) interviewed nine mothers to explore the strategies used to cope with motherhood. She identified three ways in which mothers managed their day to day life, which they described as busy and challenging. The mothers reported obtaining help from significant others, such as husbands and their own mothers. A second strategy was 'having a plan or schedule'. The third strategy was 'gaining

time out'. This strategy was helpful for maintaining their well being, reducing stress and isolation, restoring their personal identity, increasing self esteem, and enhancing feelings of control. Feelings of guilt were sometimes experienced for this, but the importance of caring for themselves in order to remain mentally well, to be an effective mother for their children, was acknowledged by the mothers. Currie (2009) noted the importance of mothers finding a balance between their own and their families' needs, in attempting to maintain well being.

Throughout the studies discussed above, participants acknowledged the importance of support from their partners in reducing isolation and stress, increasing confidence, caring for the child, and providing emotional support (Barclay et al., 1997, McVeigh, 1997, Darvill et al., 2010). They also discussed their own mothers as important sources of practical and emotional support (Barclay et al., 1997, Darvill et al., 2010), other mothers for emotional and informational support (Barclay et al., 1997, Barlow and Cairns, 1997, Wilkins, 2006, Darvill et al., 2010) and midwives for emotional, informational and practical support (Wilkins, 2006). It appears that receiving help was not always simple, however. Some mothers reported ambivalence about asking for help from family and partners due to the feelings of guilt it created (Barclay et al., 1997, Currie, 2009). Gulik and Kim (2004) noted the importance of the amount and timing of social support matching the mother's needs and desires if it is to be helpful. Indeed, the volume of informational support received from professionals and their social networks often evoked feelings of panic and helplessness, particularly if it appeared vague or unrealistic (Wilkins, 2006).

In addition to utilising social support, a number of other psychological processes were discussed as facilitating coping and adjustment. The final category described by Barclay et al. (1997), 'working it out', detailed the developing skills and confidence the mothers exhibited. This took time, involved constant learning, and much 'trial and error'. Other mothers were perceived to be of most assistance, in addition to their own personal resilience. Over time, mothers increased in confidence, began to trust their own judgments, became more organised, and increasingly enjoyed being a mother.

Barlow and Cairns (1997) found mothers engaged in a process of 'self socialisation'. This involved striving to fulfil the mothering role by developing parenting skills. It involved seeking out suitable role models and expert

knowledge, assessing which of their behaviours they needed to adjust and change, developing empathy for their children, and establishing the support of other mothers. Barlow and Cairns (1997) also described a process of 'immersion'. This included redefining relationships to best meet the needs of their children, developing their own definition of mothering, accepting personal limitations, and acknowledging the rewards of being a mother which served as a source of energy.

Similarly to Currie (2009), Wilkins (2006) found that the key to 'restoring balance' for participants was organisation, and establishing new routines was vital for emotional well being. Participants' ability to plan and be organised developed as they were able to more fully anticipate the needs of their baby, and was associated with re-joining the outside world.

Nelson (2003) noted two processes which appeared crucial for managing the disruptions identified. These included 'engagement', making a commitment to be actively involved, necessary for the second process, to 'grow and transform'.

Summary and Critique

The studies discussed highlight the significant and complex psychosocial impact of becoming a mother and indicate potential areas of need. Those that developed theory (Barclay et al., 1997, Barlow and Cairns, 1997, Wilkins, 2006, Currie, 2009, Darvill et al., 2010) enabled hypotheses to be generated regarding variations in experience, providing guides for action for health care professionals. Nelson (2003) concluded however, that the transition to motherhood was unique to each woman. A number of factors have been proposed to act as 'mediators' to experience. These include the extent to which the mother's life changes (Emmanuel, Creedy, St John, and Brown, 2011), the temperament of the infant (Barclay et al., 1997, Wilkins, 2006, Homewood, Tweed, Cree, and Crossley, 2009), the mothers cognitive and attachment style and their cultural context (Homewood et al., 2009), their perceived levels of social support (Barclay et al., 1997, Homewood et al., 2009), and the mother's previous experience with babies (Barclay et al., 1997).

However, the majority of mothers in the studies reviewed were married, middle class, conceived naturally, only had one child, and were not working outside the home. It may be that other subgroups of women experience similar, but also unique, processes on becoming a mother. These include those who have

adopted (Fontenot, 2007), those who are single (Copeland and Harbaugh, 2010, Emmanuel et al., 2011), those who have conceived via assisted reproductive technology (ART, Sandelowski, 1995, McMahon, Gibson, Fisher, Hammarberg, and Wynter et al., 2009), those with more than one child (Emmanuel et al., 2011), those of a lower socioeconomic status (SES, DeLashmutt, 2007, Sperlich, Arnhold-Kerri, and Geyer, 2011), and those who work outside the home (Sperlich et al., 2011). Furthermore, there seemed to be an absence of post-natal depression (PND) in these women. This subgroup of women also experience unique processes (e.g. Homewood et al., 2009). Another difficulty with the studies described above is that all but Currie (2009) and Barlow and Cairns (1997) focused on the immediate post-partum period, therefore not exploring change over time. Finally, the papers described above focused on ‘low risk’ women, with the exclusion of those with chronic illnesses. Many have argued that the stresses and pressures associated with ‘healthy’ motherhood may be magnified in mothers with a chronic illness (e.g. Pakenham, Tilling, and Cretchley, 2012). I will now turn to this area of literature.

Motherhood and Chronic Illness

CF may be compared to other chronic illnesses on a number of bases. These include the presence of fatigue, the changing severity of physical symptoms, and the need to engage in extensive treatment regimes. As a result, I have reviewed qualitative studies exploring the experiences of mothers with asthma (Radtke and van Mens-Verhulst, 2001, van Mens-Verhulst, Radtke, and Spence, 2004), multiple sclerosis (MS, Payne and McPherson, 2010, Pakenham et al., 2012), diabetes (Rasmussen, O’Connell, Dunning, and Cox, 2007, Sparud-Lundin and Berg, 2011), and HIV (Ingram and Hutchinson, 1999, 2000, Nelms, 2005, Wilson, 2007, Sanders, 2008, Murphy, Roberts, and Herbeck, 2011). Qualitative studies and review papers including mothers with a range of disabilities (Malacrida, 2009) and other chronic illnesses such as cancer and arthritis (Vallido, Wilkes, Carter, and Jackson, 2010) have also been reviewed. Common themes emerged across all the studies.

Psychological, Emotional, and Social Impact

Mothers across all the studies described experiencing anxiety, guilt, and low mood. Guilt and worry often resulted from feeling it was unfair their child had an ill mother (Nelms, 2005). Guilt also resulted from feeling they were not fulfilling the parenting role as effectively as they would like (Ingram and Hutchinson, 2000, van Mens-Verhulst et al., 2004, Vallido et al., 2010, Murphy et al., 2011). This was particularly so during times of acute illness (Wilson, 2007). This often resulted from fatigue and, particularly for those in poorer health, not having enough energy (van Mens-Verhulst et al., 2004, Nelms, 2005, Vallido et al., 2010, Murphy et al., 2011, Pakenham et al., 2012). Guilt often resulted from this lack of energy (Nelms, 2005, Vallido et al., 2010), and the impact this had on their ability to fully engage in activities with their children (Pakenham et al., 2012). Some also expressed fears their condition may prevent them from protecting their children (van Mens-Verhulst et al., 2004, Sparud-Lundin and Berg, 2011). Mothers expressed anxiety in regards to the uncertainty and unpredictability of their symptoms, and how this may affect their ability to engage in mothering activities in the short and long term (Ingram and Hutchinson, 2000, Nelms, 2005, Sparud-Lundin and Berg, 2011).

Participants acknowledged other concerns as to the impact their condition may have on their children, such as worrying how having an ill mother may affect their emotional well being (Ingram and Hutchinson, 2000). Participants often felt fear and guilt at the thought of dying whilst their children were young (Ingram and Hutchinson, 2000, Nelms, 2005, Vallido et al., 2010). Some described worrying who would care for their children, and whether this would be good enough (Nelms, 2005, Vallido et al., 2010, Murphy et al., 2011). Mothers reported experiencing anxiety and fear around the issue of disclosing their condition to their children, often wanting to protect them from the realities of their illness (Ingram and Hutchinson, 2000, Nelms, 2005, Wilson, 2007). Mothers often worked hard to hide their diagnosis, worries, and treatment, in an attempt to minimise any negative impact as much as possible (Nelms, 2005, Wilson, 2007, Vallido et al., 2010). Some felt disclosure would be positive, such as enhancing the relationship and preparing the child (Ingram and Hutchinson, 2000, Vallido et al., 2010), but many were fearful of the negatives, such as the emotional burden and devastation the child may experience (Ingram and Hutchinson, 2000, Nelms,

2005). Some experienced a conflict between wanting their child to have a 'normal' childhood versus wanting to prepare them for their potential death (Wilson, 2007).

Other concerns included worry, upset, and guilt at having to have time away from their children (Vallido et al., 2010, Murphy et al., 2011). This was mainly due to physical illness, in particular fatigue and side effects of medications, resulting in hospitalisations and the missing of activities such as play time. Some expressed concerns as to the impact extended time away would have on their children and their relationship (Murphy et al., 2011).

Mothers often acknowledged their social and cultural context. Participants in a number of studies said they were consciously aware of the perception of an 'ideal' mother, and felt their illness or disability prevented them from meeting this (Malacrida, 2009). Some felt they would be met with judgement if they did not meet this (Payne and McPherson, 2010).

Self Care and Treatment Adherence

Some mothers said their children's needs and health should come first, and prioritised their children over themselves (Ingram and Hutchinson, 2000, Sparud-Lundin and Berg, 2011). Participants sometimes described themselves as a mother first and a 'patient' second (Vallido et al., 2010), and felt guilty for putting their own needs before their children's (Sparud-Lundin and Berg, 2011). Others described pushing themselves beyond their limits (Malacrida, 2009, Murphy et al., 2011), and acknowledged the difficulty of balancing the demands of an illness with the demands of a child (Sparud-Lundin and Berg, 2011, Pakenham et al., 2012). Some mothers stopped their treatment in favour of breastfeeding (Payne and McPherson, 2010), or to avoid side effects which may interfere with mothering (Murphy et al., 2011). Others reported a lack of energy in maintaining strict self care following pregnancy (Sparud-Lundin and Berg, 2011).

However, other mothers reported increased adherence. Some acknowledged the importance of maintaining their health for the wellbeing of their children and so they could effectively care for them (Ingram and Hutchinson, 2000, Sparud-Lundin and Berg, 2011). Some described feeling that being a good mother involved adhering to treatment, and described taking the best ever care of themselves since becoming a mother, to stay well and live as long as possible for

their children (Nelms, 2005, Wilson, 2007). Having children and the love they felt for them was a powerful motivation for some to stay healthy and look after themselves (Ingram and Hutchinson, 2000, van Mens-Verhulst et al., 2004, Nelms, 2005, Wilson, 2007, Sanders, 2008, Vallido et al., 2010).

Coping and Adjustment

Participants often experienced fatigue as a result of the demands and responsibility of mothering (Ingram and Hutchinson, 2000, van Mens-Verhulst et al., 2004, Wilson, 2007, Payne and McPherson, 2010, Sparud-Lundin and Berg, 2011, Murphy et al., 2011, Pakenham et al., 2012). They noted the time and attention children required (Ingram and Hutchinson, 2000), and a lack of free time on becoming a mother (Pakenham et al., 2012). Adjustments made to manage fatigue included making time to rest (van Mens-Verhulst et al., 2004, Wilson, 2007, Payne and McPherson, 2010, Pakenham et al., 2012), making an effort to conserve their energy (Payne and McPherson, 2010), and asking for help from others (van Mens-Verhulst et al., 2004). Resources that enabled free time were highly valuable (Pakenham et al., 2012).

Mothers often discussed adjusting their lifestyle, planning ahead, and being organised as a way of coping. They also placed limits on the activities they engaged in and how long for (van Mens-Verhulst et al., 2004, Payne and McPherson, 2010), or adjusted their perception of what the ideal mother was in order to fulfil it (Vallido et al., 2010).

In the majority of studies, mothers noted difficulties in attempting to mother with a chronic illness. They often reported being flexible with their mothering and finding creative ways to overcome difficulties and limitations, such as replacing exhaustive activities, such as roller skating, with slower paced ones, such as board games (van Mens-Verhulst et al., 2004, Payne and McPherson, 2010). Others took their children to play areas to provide them with play experiences they felt unable to provide them (Malacrida, 2009).

A major coping strategy was utilising the support of significant others. Some discussed utilising their children for practical and emotional support (van Mens-Verhulst et al., 2004, Wilson, 2007, Ingram and Hutchinson, 2000, Pakenham et al., 2012). This 'role-reversal' took place particularly when they were feeling ill, however often brought with it feelings of discomfort (Wilson, 2007). Participants

also received support from their families (Nelms, 2005, Payne and McPherson, 2010, Pakenham et al., 2012). This support included child care, emotional support, and practical support such as help with cleaning and shopping. Husbands were often described as the main source of support. This involved support in caring for the child, performing household chores, and parenting activities they found harder such as bathing the child. This was particularly important when participants were ill (Payne and McPherson, 2010, Sparud-Lundin and Berg, 2011, Pakenham et al., 2012). Husbands also played a role in illness management and took on large amounts of responsibility. Participants often felt guilty for this (Sparud-Lundin and Berg, 2011, Pakenham et al., 2012). Support was particularly important during times of acute illness (Wilson, 2007, Payne and McPherson, 2010, Pakenham et al., 2012), and in the first few months (Payne and McPherson, 2010, Sparud-Lundin and Berg, 2011). This support was noted to be important for both the care of the child, in addition to the mother's own self care (Payne and McPherson, 2010). This support was often established prior to embarking on pregnancy (Payne and McPherson, 2010).

There was considerable evidence of effective coping, adjustment, and resilience throughout the studies. Many felt satisfied with a number of their mothering activities. Radtke and van Mens-Verhulst (2001) noted the participants in their study did not appear to construct themselves as being different to healthy mothers, discussing a number of competing demands and stressors that any mother may experience. Their accounts indicated that it was the *negotiation* of these competing demands that may be more complex for women with chronic illness. Wilson (2007) noted the tales of strength evident in mothers' stories, relating to their attempts to maintain a 'normal' childhood for their children, in addition to tales of vulnerability. Payne and McPherson (2010) also noted the majority of women they interviewed felt that having MS did not overwhelm motherhood but simply added to the complexity of it. It was important for them not to be seen as different to other mothers. It appeared for some being a mother contributed to a sense of being part of the 'healthy' world (Radtke and van Mens-Verhulst, 2001), which many seemed to desire and felt a need to make a conscious effort to achieve (van Mens-Verhulst et al., 2004, Malacrida, 2009, Payne and McPherson, 2010, Sparud-Lundin and Berg, 2011). This sometimes involved trying to hide their condition, or pushing themselves beyond their limits to

challenge stigma. Stigma was often described as a barrier to feeling like an ‘ideal’ mother, and many were met with resistance (van Mens-Verhulst et al., 2004, Malacrida, 2009).

Theories of Mothering with a Chronic Illness

The studies discussed above utilised thematic analysis, discourse analysis, or phenomenological methods. A smaller number of studies in the area have attempted to build theory. Rasmussen et al. (2007) utilised a grounded theory approach to explore how women with diabetes managed transitions, including those who had become mothers. They found that a number of issues influenced their experience of the transition. These included feeling susceptible to fluctuating blood glucose levels, the responses of others, and the impact their diabetes had on others around them. The basic problem linking these themes was feeling in the ‘grip’ of blood glucose levels. It appeared the women managed this by attempting to create stability. This involved forming meaningful relationships, enhancing their attentiveness to their condition, as well as putting things in perspective, all of which enabled them to achieve balance in their lives. Indeed, the main difficulty described was the balancing of their diabetes management with the demands of their new mothering role. They said they were more vigilant in their diabetes management, feeling their previous knowledge and skills in managing their diabetes were now inadequate. Some mothers also spoke of their diabetes highlighting their dependence on their partners when they became a mother, which they found burdensome and frustrating.

A model of mothering in relation to HIV has been proposed, that of ‘defensive mothering’, proposed by Ingram and Hutchinson (1999). They suggested that mothers with HIV engage in defensive mothering as a result of an underlying fear of stigma. This defensive mothering enables psychological protection and involves preventing the spread of HIV and stigma, preparing their child for a motherless future, and protecting themselves using thought control.

Summary and Critique

There are similar themes in the experiences of mothers with varying chronic conditions, supporting various authors’ suggestions their results may be applicable to women with other chronic conditions (van Mens-Verhulst et al., 2004, Wilson,

2007, Vallido et al., 2010). The papers reviewed here share a number of strengths in regards to their clear aims, detailed description of data collection and analysis, the situating of samples, their grounding in examples, and their useful clinical implications. However, there are some weaknesses. Whilst the majority interviewed adequate sample sizes, Radtke and van Mens-Verhulst (2001) only interviewed three women. Three of the papers also failed to report any attempts at quality control (Nelms, 2005, Wilson, 2007, Pakenham et al., 2012). Whilst the majority of the papers appeared to interview women with a variety of experiences, Payne and McPherson's (2010) sample were restricted in regards to geographical location, and their diagnosis of relapse remitting MS, experiencing long periods where they experienced no symptoms. Nelms' (2005) sample was also atypical of a female HIV population, being financially comfortable with no evidence of drug abuse. Finally, the majority of papers failed to 'own their perspective' and acknowledge their role in the research process (van Mens-Verhulst et al., 2004, Nelms, 2005, Sanders, 2008, Payne and McPherson, 2010, Vallido et al., 2010, Murphy et al., 2011).

Whilst it may be logical to speculate that women with CF may experience similar issues to those described by mothers with other chronic illnesses, there are distinct differences between CF and these illnesses which means this may not be the case. For example, whilst women with CF *may* experience stigma and judgements, it is unlikely to be similar to the stigma experienced by mothers with HIV. Furthermore, many of the women in the HIV studies were also caring for partners and children with HIV, or did not have full custody of their children due to previous or current drug abuse (e.g. Sanders, 2008). The mothers with HIV were also often diagnosed after they had had children. Again, these experiences are likely to be very different to mothers with CF. Furthermore, the studies focusing on MS mainly focused on those with relapse remitting MS, who thus had extended periods of relatively 'normal' health, which may not be the case for women with CF. Indeed, a number of authors have suggested the complex and unique nature of CF means it cannot be likened to any other chronic illness (Rolland, 1988, Johannesson, Carlson, Bergston-Brucefors, and Hjelte, 1998).

I will now discuss the research that has been conducted in the area of CF and motherhood. This has focused on reproductive health, pregnancy, and the impact of motherhood on physical health parameters.

Reproductive Health in CF

Gage (2012) argued that awareness of the impact of CF on sexual and reproductive health is significant for providing quality care.

Fertility and Contraception

Up to 97% of males with CF are infertile. In females, despite healthy reproductive anatomy, mucus in the cervix and fallopian tubes can make conception difficult, and puberty and menarche are often delayed (Edenborough and Morton, 2010). Edenborough and Morton (2010) concluded that whilst the ‘official’ potential fertility of females with CF is unknown as yet, all menstruating females with CF should be considered fertile and offered contraception. Indeed, high rates of spontaneous pregnancy have been found. Odegaard, Stray-Pederson, Hallberg, Haanes, and Storrosten et al. (2002) found that 75% of women who wanted to get pregnant did so, with 15% conceiving using ART. Those who are unable to conceive naturally may consider ART (Edenborough and Morton, 2010). Some evidence has suggested however that these options are often not pursued (e.g. Johannesson et al., 1998, Boyd, Mehta, and Murphy, 2004).

Sexual Activity, Knowledge and Awareness

Surveys of young adults with CF have found that sexual activity begins at a similar age to those without CF. However, understanding of the risks of pregnancy is often limited, and as a result they are less likely to use contraception (Sawyer et al., 1995). Gage (2012) conducted a systematic review of the available literature on female patients’ awareness of reproductive health issues, and found that female patients frequently lacked physiological and psychosocial knowledge relating to sexual and reproductive health. These included issues such as rates of fertility, the impact of pregnancy, and the possibility of having a child with CF (Sawyer, Phelan, and Bowes, 1995, Korzeniewska, Grzelewski, Jerzynska, Majak, and Soloniewicz et al. 2009, Siklosi, Gallagher, and McKone, 2010). Gage (2012) concluded that female patients with CF are not fully equipped with enough information to make informed reproductive choices, and indeed patients in a number of the studies explicitly expressed desires for more information. A similar review was conducted by Havermans, Abbott, Colpaert, and De Boeck (2011).

These authors also concluded that CF patients tend to be ill informed in regards to matters of sexual and reproductive health.

Information Desired

Gage (2012) concluded that in order to promote and sustain quality of life, information regarding sexual and reproductive health should be clearly communicated to female patients with CF. Females with CF have reported desires for experiential information, wanting to be informed of the full experiences of other women with CF, feeling that purely medical information given by CF teams was inadequate and difficult to understand (Simcox, Hewison, Duff, Morton, and Conway, 2009). Johannesson et al. (1998) also found female patients reported a desire for experiential information from older women around sexual and reproductive health issues. Information regarding pregnancy and its potential short and long term impact (Fair et al., 2000, Simcox et al., 2009), fertility (Fair et al., 2000, Tuchman, Kalogiros, Forke, Schwarz, and Kinsman, 2010), and contraception (Gatiss, Mansour, Doe, and Bourke, 2009) was also desired. Patients have expressed a desire to receive this information in adolescence (Fair et al., 2000, Johannesson et al., 1998).

It appears that increasing numbers of female patients with CF wish to have children, and a significant proportion who want to do so. Gage (2012) noted the increasing rate of pregnancy in women with CF, an area that has been widely explored.

Pregnancy and CF

Pregnancy Outcomes, Risk Factors, and Advice

Possible effects of pregnancy on the mother include a decline in lung function (Edenborough, Stableforth, Webb, Mackenzie, and Smith, 1995, Lau, Barnes, Moriarty, Ogle, and Dentice et al., 2011), immuno-supression (Lau, Moriarty, Ogle, and Bye, 2010), difficulties in gaining and maintaining weight (McArdle, 2011), and the development of gestational diabetes (Gilljam, Antoniou, Shin, Dupuise, and Corey et al., 2000, Lau et al., 2011). Risk factors for poorer outcomes for mother and baby include a BMI lower than 18-20 (Kotloff, Fitzsimmons, and Fiel, 1992, Lau et al., 2011), a pre-pregnancy lung function of

less than 50-60% (Edenborough et al., 1995, Edenborough, Mackenzie, and Stableforth, 2000, Gilljam et al., 2000, Odegaard et al., 2002, Cheng, Goss, McKone, Galic, and Debley et al., 2006, Lau et al., 2011, Etherington, Peckham, Clifton, and Conway, 2011), pancreatic insufficiency (Gilljam et al., 2000), pulmonary hypertension (Whitty, 2010), diabetes (Odegaard et al., 2002, Etherington et al., 2011) and the presence of *B. cepacia* (Gilljam et al., 2000, Edenborough et al., 2000).

Researchers have concluded however, that with appropriate and aggressive MDT care and planning, pregnancy is something that can be tolerated in women with CF, with positive outcomes for mother and baby (Lau et al., 2010, Etherington et al., 2011, Buzzetti, Salvatore, Baldo, Forneris, and Lucidi et al., 2011, Carroll et al., 2012). This is especially true of women with mild to moderate disease severity, acceptable lung function, and good nutritional status (Whitty, 2010, McArdle, 2011). A number of studies have found that pregnancy itself is not associated with an accelerated decrease in lung function beyond what would be expected in the general CF population (Gillet, de Braekeleer, Bellis, and Durieu, 2002, Goss, Rubenfeld, Otto, and Aitken, 2003, McMullen, Pasta, Frederick, Konstan, and Morgan et al., 2006). The risk factors for mortality in pregnant women appear to be the same as those for non-pregnant woman with CF (Gilljam et al., 2000, Edenborough et al., 2008). However, despite promising results, all pregnancies in women with CF should be regarded as high risk, and this should be pointed out during pre conceptual counselling, especially to those who are at risk for poorer outcomes (Edenborough et al., 2008). It is understandable therefore, why the decision to become pregnant is an important and potentially difficult one for women with CF.

Decision Making Around Pregnancy

Simcox et al. (2009) aimed to explore the dilemmas faced by women with CF when considering pregnancy and motherhood. Participants reported considering the potential impact on their child of having a mother with CF, the impact it may have on their health both during and after pregnancy, and the impact having a child may have on their self care and social life. The women also discussed a number of personal dilemmas. They worried their decision was selfish, and

experienced uncertainty about their future health status, with the majority believing they would die whilst their children were young.

Preparing for Pregnancy

Gage (2012) suggested that negative effects on the female patient and her family can be planned for and/or avoided if women fully understand the risks associated with pregnancy and motherhood. Indeed, Edenborough et al. (2008) discussed the importance of planning for pregnancy, and published a comprehensive set of guidelines for the management of pregnancy in women with CF. Edenborough et al. (2008) proposed that preparation for pregnancy should not only include discussions as to the potential impact of pregnancy on short and long term health, and optimising health and treatment, but should also include discussions focusing on psychosocial issues. Edenborough et al. (2008) suggested these discussions should include the possibility of becoming a one parent family, the impact of caring for a child on treatment and rest time, in addition to the potential emotions that may be experienced as a result of parenting with the challenges of CF.

The study by Simcox et al. (2009) found that women with CF had many concerns in regards to motherhood, as well as those associated with the pregnancy itself. Indeed, research has documented the physical implications of becoming a mother on women with CF.

Becoming a Mother with CF: Impact on Physical Health

The little research that has been conducted in the area of CF and motherhood has focused on the impact becoming a mother has on physical health parameters. There is some evidence that lung function does not appear to decline in the mother with CF more than would be expected in the general CF population (Fitzsimmons, Fitzpatrick, and Thompson, 1996), and that reductions in lung function during pregnancy can recover to baselines within 6 months (Lau et al., 2011). However, other results have been less encouraging. Clifton, Bodey, McIntosh, Conway, and Peckham et al. found there were significant differences in lung function at two and four years post-partum between mothers with CF and matched controls. Furthermore, other studies have found large reductions in lung function between

birth and two years post-partum (Lauritsen et al., 2008, Brekke, Phillipsen, Lund, and Pressler, 2012) and an increase in the number of clinic visits and need for IV anti-biotics in the two years following childbirth (Etherington et al., 2011). Authors have speculated that health deterioration may be due to the demands of child rearing, an increased risk of infection from the child's day care, and/or less adherence to treatment (Clifton et al., Brekke et al., 2012).

Difficulties with the studies by Lauritsen et al. (2008), Etherington et al., (2011), and Brekke et al., (2012), include the absence of control groups. As a result, given the progressive nature of CF, conclusions are difficult to draw. Furthermore, all these studies included participants who had conceived and given birth themselves. Mothers who had adopted or had children via a surrogate were not included. Therefore, any health deterioration observed may be due to the long term effects of pregnancy as opposed to motherhood per se. Research which may address this issue has been conducted with fathers with CF. Dugueperoux, Hubert, Dominique, Bellis, and De Braekeleer et al. (2006) compared 48 fathers with CF to matched controls. They found no differences in health status, and concluded that being a parent did not appear to impact the course of the disease. However, Buzzetti et al. (2011) suggested this study provided potentially imprecise data, given the unexpectedly high percentage of natural paternities reported (25%). Indeed, a study by Etherington, Peckham, and Conway (2010) found less encouraging results. They found that whilst no significant changes in weight, clinic visits, or use of anti-biotics occurred on becoming a father, fathers did experience significant declines in FEV1%. The authors concluded that the added responsibility of caring for a child may negatively impact the father's health, and that these men may require heightened observation and more intensive treatment. These results may imply it is the act of caring for a child, as opposed to having been pregnant per se, that may have a negative physical impact on women with CF who have children.

However, despite potential health problems, many women with CF see motherhood as a natural outcome and have reported they would feel angry if a health professional challenged their decision (Fair et al., 2000).

Whilst the medical literature provides useful information as to the potential impact of motherhood, the importance of the psychosocial issues associated with motherhood has also been noted to be of great importance, although research is

significantly lacking in this area (Johannesson et al., 1998, Simcox et al., 2009). However, based on anecdotal evidence, a number of authors have speculated as to the potential psychosocial issues mothers with CF may face, and how they may cope with these.

Psychosocial Impact of Becoming a Mother with CF

In relation to CF and motherhood, the term ‘psychosocial’ has been used to refer to self care, emotional, and social experiences (Edenborough et al., 2008, Simcox et al., 2009). Authors have also made suggestions as to the adjustments mothers with CF may need to make, and how they may cope with motherhood.

Psychological, Emotional, and Social Impact

In regards to social issues, Gotz and Gotz (2001) speculated that in daily life, the parent with CF may have a difficult time trying to keep up with their child, in relation to their social life and activities. Duncan-Skingle and Pankhurst (2001) also suggested the mother with CF may have to adjust to becoming dependent on others.

A number of authors have speculated as to the emotions the mother with CF may experience. Tuchman and Gisone (2010) suggested she may feel overwhelmed as a result of attempting to balance the needs of the baby with her own self care. Lemke (1992) suggested mothers with CF may experience anxiety, worrying their involvement in child rearing may be limited. Duncan-Skingle and Pankhurst (2001) argued that parents with CF may have a number of concerns such as fearing and facing the possibility of not living long enough to see their children grow up. Indeed, Edenborough et al. (2008) noted the mother with CF may also have to face declining health, often whilst their children are young. Edenborough et al. (2008) referred to the possibility of PND in all mothers and argued screening and early intervention for this in women with CF should be considered. Some authors have also drawn attention to the potential emotional burden of disclosing the mother’s CF to their child (e.g. Duncan-Skingle and Pankhurst, 2001, Edenborough et al., 2008). Edenborough et al. (2008) noted the future may become more real, and ‘normal’ thoughts that other parents experience

around what may happen to their child if they were to die may be intensified in those with CF.

However, a study by Frankl and Hjelte (2004) found that parents with CF did not report any concerns about the impact of their illness on their children, or their ability to be good parents, seeing themselves as equal to healthy parents. They also reported they required no extra support from the CF clinic in regards to treatment, or support for their children. Frankl and Hjelte (2004) concluded that the psychosocial situation and family life appear satisfying for many parents with CF.

Self Care and Treatment Adherence

Some have suggested the demands of a newborn and child rearing may cause the mother with CF to prioritise her child and neglect her treatment (Wexler, Johannesson, Edenborough, Sufian, and Kerem, 2007, Edenborough et al., 2008, Lauritsen et al., 2008, McArdle, 2011, Tuchman and Gisone, 2010). The potential neglect of self care and treatment is a crucial issue to consider, given the negative consequences for the mother's health if this were to occur (Wexler et al., 2007, Edenborough et al., 2008). Indeed, women in Simcox et al.'s (2009) study expressed concerns as to how having a baby would impact on their ability to self care. Edenborough et al. (2008) suggested however, that treatment adherence may also be positively affected, with the child acting as a powerful motivator to stay well.

Coping and Adjustment

A number of authors have suggested a major adjustment that may need to be made for the mother with CF, would be the drawing on social support from family and friends, in order to ease the burden of caring for herself and her child (Gotz and Gotz, 2001, Duncan-Skingle and Pankhurst, 2001, Tuchman and Gisone, 2010, McArdle, 2011). Authors have noted this support to be essential in ensuring the health of the mother, particularly if self care and treatment become secondary to the demands of a new born (Edenborough et al., 2008). The partner of the mother with CF has been suggested to be of utmost importance, in being involved in all aspects of daily life to help prevent health deterioration (Edenborough et al., 2008, Tuchman and Gisone, 2010). Grandparents may also form a significant part

of the support system, and friends may be utilised if the mother does not have a partner or suitable relatives (Gotz and Gotz, 2001). Edenborough et al. (2008) suggested the mother with CF should get as much help for as long as possible, in enabling time to rest and overcoming practical obstacles. They also suggested homecare support should be taken advantage of. However, Wexler et al. (2007) hypothesised some women with CF may be reluctant to request support from others, in an attempt to 'prove' they are a good mother, and may take on too much responsibility in caring for their child.

Other potential strategies for coping and adjustment have also been acknowledged. The possibility of the mother adjusting her treatment regimen and lifestyle has been highlighted (Yankasas and Fernald, 1999, Edenborough et al., 2008). Edenborough et al. (2008) suggested that treatment and self care regimens could be modified to meet the abilities of the family. For example, they suggested physical exercise and physiotherapy may be adapted to include the child as it grows, and this may serve to bring the family closer together and help the child to learn about CF.

In considering the adjustments the mother with CF may need to make, it is useful to consider models of coping and adjustment in chronic illness.

Models of Coping and Adjustment Being diagnosed with a chronic illness involves a major process of adjustment. The term 'adjustment' has been used to refer to both a process of coming to terms with a situation, in addition to observable outcomes of this process, such as successful performance of adaptive tasks and the absence of psychological problems (Biesecker and Erby, 2008).

A related concept is that of 'coping', which is thought to form a central component of successful adjustment. Effective coping has been found to predict adjustment to genetic conditions such as CF (Biesecker and Erby, 2008). Coping has been defined as 'cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Folkman and Lazarus, 1988, p310). There exist clear variations amongst individuals in how well they adjust to chronic illness, and this may be explained by models of coping and adjustment, which have received much attention in the health psychology literature.

Leventhal and colleagues (1980, 1997) proposed the self regulatory model, which suggests that individuals are motivated to maintain a state of status quo. Once diagnosed with a physical illness, individuals begin by assigning meaning, and interpreting the problem. This interpretation influences the coping strategies the individual utilises, as a result of the individual's beliefs about the illness and their emotional responses to it. Finally, the individual appraises the effectiveness of their coping strategy and, as a result, either continues or develops an alternative one.

Taylor (1983) proposed a theory of cognitive adaptation, which suggests individuals engage in three processes in order to achieve this. These processes include searching for meaning, gaining mastery over the illness, and moving through a process of self enhancement. These processes allow for the development of positive interpretations of reality ('illusions'), which Taylor (1983) suggested are crucial for effective adaptation. Walker, Jackson, and Littlejohn (2004) argued Taylor's model places emphasis on well being as opposed to negative constructs, and acknowledges adjustment as being a process that continually changes.

The model of stress and coping proposed by Folkman and Lazarus (1984, 1988) is a widely used framework for exploring adjustment to chronic illness, and has been found to be an effective predictor of this (Biesecker and Erby, 2008). Folkman and Lazarus (1984, 1988) proposed a reciprocal relationship between emotion and coping, and heavily emphasised the role of appraisal. They suggested that when confronted with a stressor, individuals consider what they have at stake, which influences their emotional response. Individuals are also proposed to consider what they may do, which influences their choice of coping strategy. Folkman and Lazarus (1984, 1988) suggested that whether or not a coping strategy is effective depends on whether it fits with the possibilities for coping, i.e. the extent to which the stressor is controllable. Walker et al. (2004) argued that the stress and coping model provides a way of considering how individuals function with a chronic illness, maintain psychological well being, and explains why individuals demonstrate variance in outcomes.

A variety of coping skills can be drawn upon and are acknowledged by all the models. They are often distinguished as either emotion focused (efforts to manage emotions), or problem focused (efforts to alter the situation). Avoidance (e.g.

denial) versus approach coping (e.g. information seeking) have also been distinguished between (Folkman and Lazarus, 1984, 1988).

Implications and Critique of the Models The models imply a mother with CF may go through a process of appraising her situation, and developing a number of coping mechanisms as a result in order to adjust to her new situation. These coping mechanisms may be wide ranging and may be helpful or unhelpful. The models discussed have been widely researched and validated in their value in predicting adjustment (Walker et al., 2004). They prove useful in considering why individuals may vary in their adjustment to chronic illnesses, and why certain coping strategies may be more effective than others. However, the models share a number of limitations, meaning they may apply less well to individuals with CF:

- The models appear to focus on acute, time limited, non genetic illnesses, such as cancer, as opposed to life long progressive genetic conditions. Rolland (1987) argued the adjustment process varies depending on the onset and course of the illness. CF is generally diagnosed within the first year of life, meaning the affected individual is unlikely to be impacted in the way implied by the models. Instead, their adjustment process is likely to be gradual and continuous, as the individual grows up and navigates different life stages.
- The meaning one makes of a genetic condition diagnosed at birth is likely to be significantly different to that made of a condition with a sudden onset later in life such as cancer.
- Coping and treatment in CF is preventative for disease progression as opposed to a 'cure'. Again this may have different implications for assigning meaning, appraisal, coping, and resulting adjustment.
- Some of the models appear to focus on diagnosis. They pay less attention to adjusting to major life events once one has a chronic illness. Rolland (1987) described the acute, chronic, and terminal phases of chronic illness. The models tend to focus on the acute phase, however the chronic and terminal phases may be more relevant to individuals with CF.

- In considering the impact of illness and adjustment in the individual diagnosed, the family should also be acknowledged (Rolland, 1988). The models do not appear to do this.
- The models do not appear to account for individual characteristics and contextual factors such as access to resources (Biesecker and Erby, 2008).
- The literature is confusing, given difficulties and inconsistencies in conceptualising and measuring coping, adaptation, and adjustment (Stanton, Revenson, and Tennen, 2007). Biesecker and Erby (2008) suggested the related literature is flawed as a result.

Finally, the models such as that proposed by Lazarus and Folkman (1984), often do not account for positive feeling states, and appear to conceptualise illness as a negative event. Some have argued illness should not be viewed in this way, and instead framed as a psychosocial transition. Trivedi, Bosworth, and Jackson (2011) highlighted that negative outcomes resulting from illness are not inevitable. Indeed, around two thirds of those diagnosed with a chronic illness adjust well, with many demonstrating remarkable resilience (Biesecker and Erby, 2008). Indeed, there is much evidence of resilience in the CF population. Hofer, Hirt, Kurowski, and Boehler (2012) found that a group of 32 moderately ill adults with CF demonstrated higher levels of resilience than age matched controls from the healthy population.

The growing area of resilience research has focused on factors that may prevent negative outcomes resulting from chronic illness such as certain personality traits, coping styles, and access to supportive relationships (Trivedi et al., 2011). There has also been a move to incorporating families and systems in to resilience research, with the proposition that families as a whole can demonstrate collective resilience in the face of adversity. Black and Lobo (2008) found that resilient families are able to integrate a number of protective factors such as communication, optimism, social support, routines, flexibility, and effective time management.

Impact on the System

In speculating on the potential psychosocial issues mothers with CF may face, the potential impact on the child and wider family has also been acknowledged. In

regards to the child, Edenborough et al. (2008) highlighted they will have to cope with their parent's declining health and changes in their relationship. Indeed, Goss et al. (2003) found that 20% of mothers with CF die before their child reaches the age of 10, and Etherington et al. (2011) found the average age at which children lost their mothers was 6. Edenborough et al. (2008) noted the support children may require to deal with such issues. Duncan-Skingle and Pankhurst (2001) suggested children may experience anger and resentment at the role CF plays in their lives. They also highlighted the grief the child, and the rest of the family, will inevitably experience. Gage (2012) suggested that children of mothers with CF can be affected as a result of their mother's 'decreased availability' due to hospital appointments and intermittent admissions. Gage (2012) also suggested that the mother's health may prevent her from fully interacting and caring for the child.

Whilst the majority of psychological research into parenting has focused on mothers, the significant psychosocial impact of becoming a father has also been documented (Chin, Daiches, and Hall, 2011, De Montigny, Lacharite, and Devault, 2012). Some authors have speculated as to the potential experience of fathers who have a partner with CF. Duncan-Skingle and Pankhurst (2001) highlighted the possibility of him becoming a single parent, and the career and lifestyle adjustments he will potentially have to make. The authors also suggested he may experience anger, abandonment, and grief. Gage (2012) suggested that the mother with CF may struggle to support her partner, and the burden of her health he may experience. Indeed, there is evidence to suggest he may take on large amounts of responsibility. The important of the role of the father, and the mother having his support in coping with motherhood has consistently been acknowledged in research with both healthy mothers (e.g. Nystrom and Ohrling, 2004, Darvill et al., 2010, Currie, 2009) and those with chronic illness (e.g. Nelms, 2005, Payne and McPherson, 2010, Spraud-Lundin and Berg, 2011, Pakenham et al., 2012). However, some research has found support from the partner is often lacking, leading to resentment, conflict, and loneliness (e.g. Barclay et al., 1997, Barlow and Cairns, 1997, McVeigh, 1997, Darvill et al., 2010). Other studies have found that fathers would like to be more involved than they are, often feeling 'left out' (e.g. Nystrom and Ohrling, 2004) and can feel 'uncertain' as to what their role is (e.g. Chin et al., 2011).

Rolland (1988) suggested that the demands of an illness and the difficulties associated with childrearing may amplify one another, and may lead to family dysfunction, particularly if these combined demands exceed the family's resources.

Rationale for the Current Study

Whilst we can make considered assumptions as to the potential psychosocial impact of becoming a mother on women with CF, the available literature is limited, in that it is based on anecdotal, as opposed to research based, evidence. The lack of research with mothers with CF mirrors the small amount of research with mothers with chronic illness more generally (Wilson, 2007, Simcox et al., 2009). This research is important in order to understand the experiences of these women, and any potential needs they have (Radtke and van Mens-Verhulst, 2001, Payne and McPherson, 2010), and in order to develop a fuller understanding of the psychosocial impact of chronic illness (Wilson, 2007).

It appears that there is potentially inadequate education from CF teams regarding the psychosocial impact of motherhood, given that women with CF are often ill informed of these issues (Gage, 2012). Simcox et al. (2009) and Gage (2012) recommended the need for research exploring the psychosocial issues associated with motherhood. Participants in the study by Simcox et al. (2009) reported a desire for this psychosocial experiential information, as opposed to a sole focus on medical issues, which they felt were less important. Participants in the study by Johannesson et al. (1998) also reported a desire for psychosocial information about motherhood.

The desire for this information from patients mirrors the suggestion by many professionals in the field that CF teams need an understanding and awareness of the psychosocial issues associated with motherhood, to discuss them with women with CF from adolescence onwards (e.g. Wexler et al., 2007, Edenborough et al., 2008). Edenborough et al. (2008) also noted the importance of supporting women with CF when they become mothers in the psychosocial issues they may face, but acknowledged a lack of research exploring what these may be.

Due to the desire for, and significant lack of, information in this area, this research aims to develop an understanding of the psychosocial issues mothers

with CF experience, and their process of coping and adjustment. By exploring the psychosocial experiences and issues of importance to mothers with CF, the results will enable CF teams to provide more detailed information to women with CF on the psychosocial issues associated with motherhood as and when appropriate. This will support CF teams in helping women with CF to plan and prepare for motherhood, and raise awareness amongst teams of the psychosocial support she may require on becoming a mother.

As noted, there are a number of models relating to coping and adjustment in chronic illness, in addition to grounded theory studies relating to the mothering experience. However, there appears to be a distinct lack of theory combining the two, particularly in relation to CF. As a result, this research will utilise a grounded theory approach to begin to bridge the gap between theories relating to chronic illness, and those relating to the mothering experience.

METHOD

Design

The aim of this study was to explore the psychosocial impact of becoming a mother on women with CF, and the adjustments made to manage this. Due to the exploratory nature of the research, a qualitative methodology was utilised. Data was collected via semi-structured telephone interviews with 11 mothers with CF. The data was transcribed and subject to a grounded theory (GT) analysis, utilising the procedures outlined by Strauss and Corbin (1998). The systematic analysis of the data enabled the emergence of core, conceptual, and subcategories, to capture and explain the experiences of participants. The results are presented as a theoretical formulation, along with a detailed description of each category and their relationships. Quantitative data, demographic details, and information regarding health and treatment status was also gathered to enable the sample to be situated.

Methodological Considerations

Service User Advisor

I felt that having a service user involved would contribute to ensuring the research would be directly beneficial to those with CF. Emma Harris is 38 years old, with a son Teddy, aged three. Emma set up the CFMothers online forum in November 2009, after noting a lack of support and information in relation to the area of CF, pregnancy, and motherhood. The forum is used by mothers with CF, or those who would like to become mothers, to chat and share information and experiences. Emma acted as a consultant to the research, advising at all stages. This included the development of the interview schedule and participant information sheet, recruitment, and reviewing the results for credibility check purposes. Emma was also involved in important decisions, such as how interviews should be conducted.

Qualitative Research

Qualitative research aims to provide rich and detailed descriptions of phenomena, and enables the exploration of participants' experiences (Smith, 2008). In psychology, qualitative research aims to explore the unique meanings that participants attach to their experiences, in regards to their thoughts, feelings, and behaviour (Willig, 2008). The aims and benefits of qualitative research make it ideal for the topic under investigation here, given its understudied nature. It has also been argued that qualitative research enables the development of insight into the greatest areas of needs experienced by mothers (Nelson, 2003).

A diverse range of methods exist within qualitative methodology. These include interpretative phenomenological analysis (IPA, Smith, 2008), discourse analysis (Potter and Wetherell, 1987), thematic analysis (Braun and Clarke, 2006), and GT (Glaser and Strauss, 1967, Strauss and Corbin, 1998, Charmaz, 1990, 2006). These methodologies have a number of factors in common, such as the central role of the researcher, their analysis of words, and participants leading the process of data generation (Miles and Huberman, 1994). However, each of these methodologies has their own epistemological standpoint. These include those relating to the knowledge they aim to produce, assumptions about the world and the data generated, and the role of the researcher (Willig, 2008, Creswell, 2013). Furthermore, some methodologies, such as GT, have different schools of thought within them, such as realist versus constructionist approaches.

An approach that was carefully considered for this research was thematic analysis. Thematic analysis would have enabled a large amount of flexibility given its lack of theoretical underpinning. However, GT was deemed to be the most appropriate methodology for a number of reasons.

Grounded Theory

The term 'grounded theory' relates to both a set of procedures for analysis, in addition to the outcome of this analysis. GT was originally developed in a health care context by Glaser and Strauss (1967), as a 'bottom up' (inductive) approach, with the aim of facilitating discovery, generating theory, and providing rich descriptions. GT methods involve the development and integration of categories, by grouping together sets of data that share similar features. Categories begin with descriptive labels at a low level of abstraction, however, as analysis progresses,

categories at higher levels of abstraction are identified. These categories are analytic as opposed to descriptive. The theory that emerges is thus 'grounded' in the data (Willig, 2008).

Glaser and Strauss eventually went their own separate ways, resulting from disagreements as to the extent of objectivity that is feasible in research of this kind. Strauss, along with later collaborator Corbin, rejected positivist assumptions, and suggested that some level of researcher interpretation is necessary in order to develop theory. They suggested that 'truth is enacted' (Strauss and Corbin, 1994, p279), and emphasised the importance of allowing theory to emerge from the data, with a close relationship between the data and eventual theory (Strauss and Corbin, 1998). Constructivist manifestations of GT are also in existence, such as those advocated by Charmaz (1990, 2006). Charmaz argued that categories and theories do not emerge from the data, but are constructed by the researcher through their interaction with the data.

Birks and Mills (2011) argued that breaking down the different forms of GT into rigid categories is unhelpful, and suggested there is no 'right or wrong' approach to conducting a GT analysis. It has been argued that those using GT, particularly for the first time, should adopt the approach that best suits their style (Heath and Cowley, 2004). In conducting this study, it was felt that focusing on one text as a guide for analysis would be helpful in promoting creativity but also rigour. Prior to making any decisions, I read texts by Strauss and Corbin (1998) and Charmaz (2006). The text by Strauss and Corbin (1998) was chosen as the guiding text for the following reasons:

- Whilst Strauss and Corbin (1998) emphasised staying close to the data, Charmaz (2006) discussed the coding of memos. I felt this kind of analysis may feel too 'removed' from the data.
- By staying close to the data as advised by Strauss and Corbin (1998), I felt that a thorough understanding of participants' experiences would be developed, providing meaningful guides to action.
- The analytic tools and procedures described by Strauss and Corbin (1998) are designed to enhance creativity, aid in the consideration of large amounts of data, and force the researcher to consider a range of different possibilities. As a result, it was felt that following these procedures would

reduce the possibility of bias, and allow the data to speak. Again this was appealing, given my desire to stay close to the data.

The procedures described by Strauss and Corbin (1998) were used flexibly however, given criticisms that imposing a structure on data analysis can reduce the inductive nature of it (Willig, 2008). Indeed, Strauss and Corbin (1998) suggested their procedures were not designed to be followed dogmatically, but to be used creatively and flexibly to sensitise researchers to the data.

Rationale for use of Grounded Theory

There were a number of reasons for selecting GT as the methodology of choice:

- It was felt that building theory was important here, given the lack of theory combining mothering *and* chronic illness.
- The phenomena explored in this research involves change and process, which GT was designed to explore (Willig, 2008).
- A body of research in this area has utilised GT (e.g. Barclay et al., 1997). Therefore, utilising GT here enabled comparison and synthesis with other research.
- Theory developed in GT research aims to predict and explain phenomena, providing clinicians with courses and guides to action (Strauss and Corbin, 1998). Theory can also provide a framework for care (Rogan, Shimed, Barclay, Everitt, and Wyllie, 1997). Given the aim of the research was to enhance CF care, it was felt this approach would best meet the aims of the research.
- GT enables the development of alternative understandings of patients' experiences other than those that are available in clinical settings. This can improve communication between professionals and patients in relation to problems experienced by patients (Charmaz, 1990).
- GT offers procedures that promote rigour and credibility (Silverman, 2001).

Developing the Research Question

Willig (2008) argued the initial research question must identify the phenomenon of interest, be open ended, and orientate the researcher towards structure and process, without making assumptions. However, this is almost impossible to achieve, as the process of labelling itself makes an assumption (Willig, 2008).

Strauss and Corbin (1998) suggested that questions must be framed in a manner that provides flexibility and freedom to explore a phenomenon in depth. This is due to the assumption that all the concepts pertaining to a given phenomenon have not yet been identified, and as a result it is impossible to determine what variables need to be explored. Therefore, questions need to enable researchers to find answers to questions which seem important but remain unanswered (Strauss and Corbin, 1998).

Strauss and Corbin (1998) suggested the research question should start out broadly and become progressively narrowed and focused during the research process, as concepts and their relationships emerge. The research question should begin open enough to allow discovery, but not so open that it allows for an infinite number of possibilities. Bearing this in mind, the research question began as:

'What is the psychosocial impact of having children on women with CF and how do they adjust to manage this?'

Here 'psychosocial' refers to domains generally emerging in the CF and motherhood and chronic illness literature, such as psychological, emotional, and treatment issues. 'Adjust' refers to the process of managing and coming to terms with a situation, including ways of coping, thought to be a central component of adjustment (Biesecker and Erby, 2008). As data collection proceeded, the interviews gradually became more focused and refined, in order to further explore emerging categories and their relationships. However, the initial research question remained consistent throughout. No changes to it were felt to be necessary, given that the emerging categories continued to relate to the initial research question.

Ethics

Ethical Approval

Ethical approval was sought and obtained from the Medicine and Health Research Ethics Subcommittee at the University of Leeds in February 2012 (Appendix A).

Ethical Considerations

Confidentiality and Data Protection In order to protect confidentiality, all identifiable information was removed from the transcripts. Participants were given identification numbers, and transcripts were password protected and saved on an encrypted memory stick. Recordings were hand delivered to the transcribers, to ensure the safety and protection of recordings. Participants have been given pseudonyms for dissemination purposes.

Informed Consent The information sheet (Appendix B) contained sufficient detail to allow participants to give informed consent. They were informed they could choose not to answer certain questions, could withdraw at any point, and/or ask that I do not use parts of their interview in the analysis.

Managing Distress and Risk It was considered that the interviews may raise some difficult issues for participants. Indeed, Rose and Bisson (1998) noted that in-depth interviews may potentially arouse emotional responses to past and present issues. Furthermore, there is always the possibility that participants may disclose risk related issues, which places considerable responsibility on the interviewer. It was decided that any risk related issues would be managed by contacting participants' GPs or equivalent. In considering the management of distress, it was decided that each individual interview would only go ahead if and when participants had someone available to speak to immediately following the interview, such as a friend or family member, in addition to a member of their clinical team who they would feel comfortable to approach in case they wanted to further discuss any issues raised in the interview. It was felt that CF teams would be readily available, and well equipped, to deal with such issues. It was also

decided interviews would be stopped if participants were in distress and/or if they requested this. Participants were made aware of this possibility.

Considering the Investigator as an 'Expert' It was considered that due to the 'newness' of the area, and the fact that participants were part of an 'information seeking' forum, that participants may ask for information on pregnancy/motherhood and CF. It was decided that if this were to happen, they would be advised to speak to their CF team.

Managing the Power Imbalance Whilst research interviews are different to a clinical context, power imbalances may still be present. Indeed, Emma suggested participants may be 'aware' they were talking to a psychologist, which may feel intimidating. Therefore, I emphasised at the beginning of the interview there were no 'right or wrong' answers, and that I was interested in their individual experience of being a mother with CF.

Recruitment

Inclusion Criteria

The inclusion criteria for this study was any mother with CF living in the UK, who was a member of the CFMothers forum, and who had children under the age of five. Women were not excluded if they did not conceive and/or give birth naturally.

Recruitment Method

The sampling technique was purposeful in that I aimed to seek out mothers with CF who would have a wide range of experiences. Participants were recruited through the CFMothers forum, where the research was advertised, together with the information sheet and consent form (Appendix C). As a result, participants could contact me directly if they had any questions or wanted to take part. Within two weeks, eight mothers had contacted me expressing a desire to take part, with three further women contacting me over the following four months. Upon contact, participants were posted a consent form, and a time suitable for them to be interviewed was arranged. For some participants, this involved arranging to

contact them at a later stage to arrange the interview, in order to adhere to GT principles of analysing individual interviews sequentially to inform the next interview ('theoretical sampling'). All participants were happy with this, and a total of 11 participants were interviewed across the course of seven months.

There were five major reasons why participants were recruited through the CFMothers forum. Firstly, it was expected that these women would be comfortable sharing their experiences of being a mother. Second, it was thought the mothers may wish to discuss their experiences of their CF teams, and that this may be more difficult for them if they were recruited from a CF centre. It was felt that participants may feel more anonymous if they were recruited through the forum. Thirdly, it was felt there would be a reduced chance of participants feeling coerced into taking part if the research was advertised online, as opposed to being approached by a member of their clinical team. Fourth, given the main aim of the research was to inform CF teams' practice, it was felt that by recruiting nationally, participants would have a wide range of experiences of CF teams in relation to their experience of motherhood. Finally, given the small pool of potential participants, it was felt that recruiting through the forum would increase the chances of speaking to the desired 8-12 participants.

Data Collection

Pilot Study

A pilot study was initially carried out to test the suitability of the procedures and specifically of the semi-structured interview (Appendix D). A member of the CFMothers forum, 'Adele', volunteered for this after hearing about the research personally through Emma. The intention was to amend the interview schedule and/or other procedures if any difficulties were identified.

Adele did not express any difficulties in answering the interview questions. Following the interview she explained she felt she was being asked 'the right things' in discussing her experiences of being a mother. It appeared the interview schedule allowed Adele to speak about the major issues of relevance to her. One slight amendment was made to the semi-structured interview following Adele's interview to give it a more 'narrative' feel. Given this was a small change, it was deemed appropriate to include Adele's interview as part of the main study data.

Semi-Structured Interviews

The main body of the data was collected through the use of semi-structured interviews, the most widely used form of data collection in qualitative studies (Willig, 2008). Using a semi-structured interview enabled focus to remain on the research question, whilst also allowing participants the opportunity to introduce new issues.

In developing the initial interview schedule, questions were based on general domains existing in the available literature, but not existing theory, in line with an inductive approach. Strauss and Corbin (1998) suggested that in creating the initial interview, the researcher can turn to the literature to formulate questions that act as a departure point from which to begin data collection. Thus, initial areas of inquiry related to psychological, emotional and social issues, and those relating to self care. A general question about the phase prior to becoming a mother was included to give the interview a 'narrative' feel. In addition, the interview schedule included a question about participants' CF teams, given the aim of the research was ultimately to enhance CF care.

Strauss and Corbin (1998) suggested that as data collection progresses, the researcher can adapt the interview and turn to questions and concepts that emerge from data analysis. As a result, the interview evolves as does the analysis. Strauss and Corbin (1998) suggested that interviews should initially begin broadly in order to gather data on a wide range of ideas and generate as many categories as possible. Later in the process, interviews should hone in on specific areas, and data collection becomes more about filling out and verifying emerging categories. Strauss and Corbin (1998) suggested that if one adheres rigidly to initial guidelines this will hinder discovery as it limits the amount and type of data that will be collected.

One must be careful not to impose any assumptions on participants in the interview, so that the resulting theory is truly grounded. Although initial questions were informed by general domains in the literature, and prompts were used to remain focused on the research question, questions remained open ended, and I was very much led by participants' narratives and the emerging concepts.

Telephone Interviews

Some have argued that telephone interviews produce lower quality data, due to the absence of contextual and non-verbal data, and their potential to compromise the development of rapport. However, Novick (2008) argued that telephone interviews allow respondents to relax and feel more able to disclose sensitive information, and argued there is a lack of evidence that they produce lower quality data. Indeed, Hill, Knox, Thompson, Williams, and Hess et al. (2005) highlighted research that has shown that participants are more likely to give socially desirable responses in face to face interviews than in telephone interviews in psychological research. Emma felt this would be a particularly important issue to consider in relation to mothers with CF talking to a psychologist, given they may feel 'evaluated and scrutinised'. Other reasons for conducting interviews over the telephone included the following:

- The pool of potential participants was small, covering a wide geographical area. It was important to talk to mothers from a variety of locations to discuss variations in CF care. Telephone interviews allowed the recruitment of participants from all across the UK.
- Face to face interviews may have required arranging childcare, or induced pressure to 'entertain' me (e.g. making drinks, tidying the house). This may be the last thing busy mothers want to do, particularly so if they were unwell, and thus may have put them off taking part.
- Participants may have felt less able to withdraw from the study or cancel interviews last minute if they knew I had travelled a long way to interview them.
- Face to face interviews may have felt intrusive, particularly if they were conducted in participants' homes.
- More 'unwell' participants may have been less likely to take part if interviews were face to face, and it was important that a range of participants take part in order to develop a good quality grounded theory.
- It was felt participants would feel more in control of telephone interviews, and more able to stop them if they felt distressed.
- Telephone interviews enabled full flexibility in relation to the timing of interviews.

- It was thought that participants may want to speak about difficult and sensitive issues, and that they would feel more able to do this over the telephone. Telephone interviews provided a sense of anonymity, which participants were used to with the CFMothers forum. As a result, it was felt that richer information would be collected from telephone interviews.

Large amounts of rich data was generated from the interviews, which lasted between 45 and 75 minutes. The average interview lasted 57 minutes, and a total of 10.5 hours worth of data was collected.

Conducting the Interviews

Willig (2008) differentiated between the ‘abbreviated’ and ‘full’ versions of GT. In the latter version, the researcher moves back and forth between data collection and analysis. Data is collected and analysed for emerging categories and relationships, before returning to the field to collect further data, which is progressively focused and informed by the emerging theory.

In the current study, the full version of GT was adhered to, with interviews being conducted at a rate of once every three weeks. This enabled each interview to be transcribed and analysed prior to conducting the next interview. Interviews initially focused on gathering data on as many issues as possible. However, later interviews focused on validating and refining emerging categories, and exploring negative cases and variation, in order to enhance the explanatory power of the emerging theory (Strauss and Corbin, 1998). In this way, *theoretical sampling* was adhered to, and the chances of achieving *theoretical saturation* were increased (Willig, 2008).

Data collection was ceased following the completion of 11 interviews, when as many participants as possible had been recruited. It was also felt that the criteria for theoretical saturation as described by Strauss and Corbin (1998) had been achieved as much as possible by this point. These criteria include: a) no new or relevant data appears to emerge regarding a category, b) the category is well developed in terms of its properties and dimensions, and c) the relationships among categories are well established and validated. However, it must be noted that theoretical saturation is a goal as opposed to a reality, given that theory can always be developed and elaborated on (Charmaz, 1990).

Interviews were audio-recorded and transcribed by a transcriber. I then checked the transcripts against the recordings to adjust errors and fill in gaps.

Quantitative Data

Elliott et al. (1999) argued that an important guideline for good practice in qualitative research is to 'situate' the sample. This enables the reader to judge the range of persons and situations to which the results may apply. Quantitative data in regards to quality of life and psychological functioning was collected as part of this process.

The Hospital Anxiety and Depression Scale The HADS (Zigmond and Snaith, 1983) is a well validated and widely used self report measure, designed to detect the presence of two common mental health problems presenting in hospital settings, those of anxiety and depression. Due to the exclusion of somatic items it is felt to be the most appropriate for use with chronically ill samples (Cruz et al., 2009).

The Cystic Fibrosis Quality of Life Scale The CFQoL (Gee, Abbot, Conway, Etherington, and Webb, 2000) is a disease specific quality of life standardised self report measure. The CFQoL has demonstrated high reliability and validity and gives a transformed score on nine different domains including:

1. Physical functioning
2. Social functioning
3. Treatment issues
4. Chest symptoms
5. Emotional functioning
6. Concerns for the future
7. Interpersonal relationships
8. Body image
9. Career concerns.

Data Analysis

I will begin by outlining the procedures for analysis described by Strauss and Corbin (1998). I will then discuss how I applied these principles and procedures to my data, and give examples of how these were implemented, utilising a specific interview to illustrate the entire process.

Strauss and Corbin (1998) outlined three main steps in GT analysis: open, axial, and selective coding. These are not designed to be sequential in nature, but instead designed to be overlapping, with the researcher moving back and forth between them. Additional processes designed to complement the coding process, and the use of ‘analytic tools’ will also be discussed.

Three Levels of Coding

Open Coding Open coding is the first level of analysis and involves breaking down the data into meaning units and giving them a name. A meaning unit may be one word, sentence, or paragraph, given it is defined by its content rather than its length (Henwood and Pidgeon, 1992). However, Strauss and Corbin (1998) suggested that in the early stages of data analysis, line by line coding is an ideal place to start as it allows for the quick generation of concepts and categories. The next step is to review and compare all the open codes and group those together that are related in meaning or share similar characteristics into more abstract ‘conceptual categories’. At this point the researcher also begins to identify and consider the properties (general or specific attributes) and dimensions (location of properties along a continuum) of categories.

Axial Coding The next level of coding involves reassembling the data that has been broken down during open coding, and beginning to build theory. It involves the development of ‘subcategories’ that enhance the explanatory power of the conceptual categories identified during the open coding process. The subcategories pertain to the ‘why?’, ‘when?’, ‘where?’, ‘who’, actions and interactions, and consequences associated with a conceptual category. Axial coding also involves the identification of relationships between categories, which are the basis for the emerging theory.

Selective Coding Selective coding involves the integration and refinement of theory. Conceptual and subcategories are integrated into a larger theoretical scheme, through the development of ‘core categories’. Refining the theory involves the reviewing of categories, filling in gaps where necessary, the trimming of excess categories, and validating the categories, by returning to the data and coding for these specifically.

Analytic Tools

Strauss and Corbin (1998) discussed the use of analytic tools to aid the process of analysis and the development of categories and theory.

The Use of Questioning Asking questions is particularly helpful during axial coding for the development of subcategories. Asking questions such as ‘what is going on?’, ‘who is involved?’, and ‘how do things change over time?’ enables the researcher to further understand and develop conceptual categories and their relationships. Asking questions such as ‘is this the same for everyone?’ and ‘how might this vary under a different condition?’ also enables the researcher to develop categories in terms of their properties and dimensions and account for variation. Other questions provide direction for further data collection, such as ‘which categories are well developed and which are not?’

Constant Comparison Constantly making comparisons is vital for identifying and developing categories. It involves comparing incident to incident in open coding to classify data into conceptual categories, and comparing category to category during axial and selective coding to refine theory. It also involves comparing incoming data with existing categories to further develop and validate the theory. Straus and Corbin (1998) also suggested that if the researcher gets ‘stuck’, they may compare their data to the related literature, in order to sensitise them to issues potentially fruitful to look for. Constant comparison allows the full complexity of data to be recognised, enabling relationships between categories to be developed, and variation to be captured and accounted for (Willig, 2008).

Negative Case Analysis Having identified categories, it is important to look for ‘negative cases’. This allows the researcher to validate or adjust the emerging

theory, so as to enhance depth and its ability to capture variation and complexity (Willig, 2008).

Theoretical Sensitivity In GT, the researcher constantly interacts with the data by asking questions and modifying these questions in light of emerging data. Each emerging category, relationship, or idea prompts a new look at the data, in order to elaborate and modify emerging theory (Willig, 2008).

Diagramming A number of authors have advocated the use of diagramming as a way of aiding the analytic process and organising ideas (Strauss and Corbin, 1990, Birk and Mills, 2011). In this study, I found the use of diagramming helpful at all stages of the analytic process. A ‘tree’ diagram was created for each individual interview demonstrating the emerging conceptual and subcategories. Furthermore, a large diagram containing a ‘working model’ of the emerging grounded theory was created and updated following each interview. This enabled me to ‘keep track’ of, and visually represent, the conceptual and subcategories and their relationships, in addition to how they had developed. I did this by making notes on the large diagram of which categories had been collapsed together to produce each category, and which participants had contributed to each.

The Analytic Process: An Example

In line with GT, analysis began as soon as data was collected, and data analysis and data collection ran concurrently. As a result, each interview was analysed in isolation, and then compared with existing data, in order to integrate new data with existing data, and to continually build and refine theory. Thus, at any one point in the study there existed a ‘working grounded theory model’ of the emerging categories and theory. Following each interview, this working model was elaborated upon and refined. I will now discuss Chloe’s interview (interview six) to illustrate the entire analytic process. It is felt Chloe’s interview is the ideal choice to illustrate the process as saturation had not been reached by this point, but analysis and theory development was well under way.

Step One: Open Coding Chloe's interview was coded sentence by sentence which yielded a total of 165 open codes. Table 1 details some example meaning units, and the open codes allocated to them:

<i>Sentence (meaning unit)</i>	<i>Open code allocated</i>
'I spoke to the hospital there and they were so against it'	'hospital against pregnancy'
'I had a massive sense of guilt, that I just felt so guilty thinking like how can I bring someone in to the world when I can't even look after, I mean at the time I could barely look after myself sort of thing'	'feelings of guilt when unwell'
'They were good at saying you know don't take that then if that's a problem, just concentrate on this one'	'CF team flexible with treatment'
'He wants to help as well, you know little jobs, he likes to do little jobs, getting things from the fridge and pressing buttons and things'	'child likes helping with treatment'
'I've got a lot of support and that's a major major thing to have that support, otherwise I'd not have had any chance of doing it on my own'	'importance of social support'

Table 1. Meaning units and allocated open codes: Examples.

Step Two: Establishing Conceptual Categories By constantly comparing the open codes to one another, the 165 open codes were then grouped together into categories that were related in meaning. This process yielded a total of 17 conceptual categories. For example, the following open codes were grouped together: 'treatment neglected', 'doing physio', 'treatment done to stay well', 'too tired for treatment', 'treatment easier over the years', 'time for treatment', 'developing a routine for treatment'. These open codes were grouped together to form the conceptual category 'Treatment Adherence', because they were all felt to be related in meaning to Chloe's adherence to treatment. For an example of this process see Appendix E.

Step Three: Establishing Subcategories The next step was axial coding and the development of subcategories in order to enhance the explanatory power of the conceptual categories. A table was created for each interview during this process to make a note of the conceptual categories and emerging subcategories, and the relationships between them. This table also contained the meaning units and open codes from which the categories came. For an extract of the table created from the analysis of Chloe's interview see Appendix F. In creating the subcategories, the open codes were used as titles for the subcategories as a 'starting point'. Constant comparison of the data within the conceptual categories and of these subcategories to each other led to their refinement, and these were eventually combined and collapsed to form the final subcategories for Chloe's interview. For example, 'treatment neglected', 'too tired for treatment', and 'doing physio' were collapsed and relabelled to form the subcategory 'treatment disruption versus maintenance', as they all related to the extent of treatment disruption. The use of questioning in developing these subcategories was particularly helpful here. This process yielded a total of 59 subcategories. Table 2 details some example open codes, and the conceptual and subcategories they were allocated to.

<i>Open Code</i>	<i>Conceptual Category</i>	<i>Subcategory</i>
'health deterioration'	Physical Health	Health Status
'no time for treatment'	Treatment Adherence	The Importance of Time
'miracle baby'	Amazing Experience	Disbelief at Having a Child
'needing constant attention'	Child as the Focus	Constant Commitment to Caring
'importance of asking for help'	Social Support System	Use of Social Support

Table 2. Open codes and the categories they were allocated to: Examples.

The properties and dimensions of categories, and the relationships between them were also noted. For example, Chloe discussed how she utilised the support of her family in caring for her son, Nicholas, much more when she was feeling unwell. Thus, the extent of her use of social support (property of 'Use of Social Support')

appeared to vary along a dimension from a lot to a little (dimension of ‘Use of Social Support’), dependent on the extent of ill health (property of ‘Health Status’) from well to ill (dimension of ‘Health Status’).

Step Four: Returning to Previous Data The next step in the analysis involved reviewing interviews one to five in light of concepts that had emerged from Chloe’s interview, and coding each interview specifically for these. Thus, the process of selective coding began here. This enabled the validation (or disconfirmation) of categories emerging from Chloe’s interview, and the validation (or disconfirmation) of categories established in the five prior interviews. For example, a subcategory emerging from Chloe’s interview was that of ‘CF Teams Awareness of Mother’s New Needs’, whereby Chloe had discussed how she felt her CF team needed more of an awareness of her new needs as a mother, and specifically would have liked more contact with her CF team on becoming a mother. Therefore, I reviewed transcripts one to five for any evidence of this concept. Across the five interviews there were many instances of participants discussing this issue. At this point, these meaning units were captured under two subcategories on the existing working grounded theory model. These subcategories were ‘Discussions with CF teams’, where participants had discussed how they would like to talk to their CF teams about more than lung function, and ‘Emotional Support’ where participants discussed a desire for emotional support from their CF team. As a result, it was decided that these two subcategories, and the one from Chloe’s interview, would be collapsed in to one subcategory, because it was felt that all of these subcategories were pertaining to the same phenomenon, that of the desired input from the CF team on becoming a mother. Thus, these subcategories were collapsed together and relabelled ‘Adaptation to CF Team Input’, which then captured all related meaning units. Again, keeping a table of this process enabled a systematic approach and an audit trail to be kept. For an extract of this table see Appendix G.

Chloe’s interview was then reviewed in light of the dominant themes in the existing working model developed from interviews one to five. For example, a dominant theme in the existing working model that had not emerged as a subcategory in Chloe’s interview was ‘Partner as the Main Source of Support’. Chloe’s interview was re-coded for this and indeed, the implication from her

discussions was that her partner was the main source of support for her. A table was also kept of this process (Appendix H).

Step four allowed for emerging categories to be filled in and validated, and the exploration of negative cases. For example, in the previous five interviews, four participants explained they had been able to reintroduce their treatment within three months of becoming a mother. However, it took Chloe two years to do this. Chloe attributed this to being physically exhausted, and this led me to consider the role of fatigue in determining treatment adherence. This enabled a further relationship to be identified, and thus further complexity and variation to be accounted for.

Returning to each individual interview following each new interview and asking new questions enabled theoretical sensitivity throughout.

Step Five: Integrating the Data The next step involved integrating the conceptual and subcategories emerging from Chloe's interview, with those in the working grounded theory model developed from interviews one to five. This involved comparing the new categories emerging from Chloe's interview with the existing categories from the previous five to develop and validate the categories. As a result of this process, some categories that directly mirrored each other could be directly combined, such as those relating to treatment disruption. Some were collapsed, such as the subcategories discussed above. Other subcategories that appeared to be pertaining to the same phenomenon were also collapsed into another subcategory and re-labelled. For example the subcategory 'Partner shattered' from Chloe's interview was combined with 'Partner needs support' that had emerged from interviews three and five, and 'Parenting hard for the Partner' from interview two. These were collapsed together because they appeared to be related in meaning, in regards to the impact that becoming parents had had on their partners. The resulting subcategory was re-labelled 'Impact on the Partner'.

Step Six: Adjusting the Working Grounded Theory Model The working grounded theory model that had been developed from interviews one to five that I had drawn out on large A1 sheets of paper was then amended (Appendix I and J). Chloe's name was added to the conceptual category labels that she had contributed to, the new subcategories that had come from her interview were

added on, and the categories that had been collapsed with others removed and the amended titles added. Notes from step four were also added to the diagram. At this point, the grounded theory working model was made up of 19 conceptual categories and 131 subcategories. Updating the large working model diagram in this way enabled me to keep an audit trail of where each category had come from and how it had developed over time.

Step Seven: Noting Relationships Amongst Categories The relationships emerging amongst categories were also noted throughout this process. This list of relationships amongst categories and the interviews they had emerged from was also updated following each interview. A new relationship that emerged from Chloe's interview was that of tiredness being a cause of treatment disruption.

Step Eight: Updating Research Journal A journal was kept throughout the research which detailed all decisions made, such as those relating to the collapsing of categories, and the rationale for these. The process of analysing each individual interview and its integration was detailed in the research journal following each interview, in addition to any amendments to the working model to maintain an audit trail of the analysis.

Step Nine: Adapting the Interview Following each interview, new questions were raised based on emerging concepts. I made a note of these, to follow up with subsequent participants. After Chloe's interview, there were a number of concepts that were not fully understood at this point, such as why some treatment appeared easier to adhere to on becoming a mother than others. It was decided this would be followed up in interview seven with Kimberley. In this way, principles of 'theoretical sampling' were adhered to.

Final Selective Coding

Once all of the steps had been completed for each of the 11 interviews, there existed a total of 15 conceptual categories, and 175 subcategories. Whilst selective coding had been conducted throughout, it was at this point that the selective coding process took precedence. Strauss and Corbin (1998) suggested that during integration, the researcher should identify one core category capturing

the main theme of the research. In this case, three core categories were identified, that were related to and through one central process. The core categories were identified by laying out all of the conceptual categories, and arranging those together that appeared related in meaning. For example the conceptual categories of ‘Treatment Adherence’ and ‘Physical Health’ were related in that they were factors associated with CF more generally, and so were allocated to the core category ‘Living with CF’. One conceptual category, that of ‘Balancing Mother’s and Child’s Needs’, did not appear to fit in any one of the three core categories more so than the others, but appeared central and related to all three. It was therefore established that this category best represented a central process, linking all three core categories together.

At this point the grounded theory model was also refined. Excess categories were trimmed. For example, those categories that only one participant had contributed to, such as ‘friendship loss’ from Adele, were removed. Further constant comparison meant that some subcategories were collapsed and relabelled. For example, the subcategories ‘Partner Genetically Tested’, ‘Conscious Decision to Have a Baby’, and ‘Considering Options’, were thought to be related in meaning, in that they all referred to the thought processes prior to becoming a mother. Thus they were collapsed together and relabelled to form the subcategory ‘Giving the Decision a lot of Thought’. One category, ‘Child Development’ was broken down and its meaning units incorporated into other categories. This category illustrated how treatment adherence had become easier over time. However, when this category was reviewed, it was apparent that the meaning units within it were related to other subcategories. For example, it included the following meaning unit which was related to treatment adherence becoming easier over time:

‘The last few years have been much better because he’s been at nursery and then at school, you know I get all the time in the world for me now’ (Chloe)

It was felt this meaning unit would be better included in the subcategory ‘The Importance of Time’, to demonstrate variation across time. ‘Child Development’ also included meaning units relating to developing routine, and the child’s increasing understanding of their CF. Again, as with the meaning unit above, they

were moved to the relevant subcategories, and the category child development removed as a result.

Following this the grounded theory model was complete. As detailed further in the results chapter, it includes a central process, three core categories, 13 conceptual categories, and 70 subcategories.

Memo-Writing

The coding process is not ‘objective’ and there is a constant interplay between the researcher and the data (Strauss and Corbin, 1998). Therefore, it is important to bring one’s own experience and knowledge in a way that enhances creativity, as opposed to imposing bias. Bringing one’s own experience can make the researcher more sensitive to the data, and enable the recognition of problems and alternative explanations. It is important to remain aware of these, and engaging in memo writing aided the process of reflexivity. It also enabled my thoughts about emerging categories and their relationships to be recorded, to aid in the process of analysis. Memo-writing occurred throughout the entire research process. Figure 1 captures an extract of a memo that was written following the first five interviews:

Date: 18.6.2012: The Concept of Routine

Routine has been discussed heavily throughout the interviews, in a number of contexts. It seems to be mentioned in regards to the mother’s treatment, but also in regards to the child. I’m currently wondering-what is important about being in a routine? Are participants talking about their own routine for treatment or their child’s routine?

On reviewing the ‘routine’ meaning units from interviews one to five, it appears that they fall into two distinct categories. The first category appears to relate to the general importance of routine for getting treatment done. The second set of meaning units appear to relate to how participants have created a routine to get their treatment done, and they discuss creating a new routine around their child’s. Working their treatment around their child’s routine appears to give them more time to get their treatment done, which is why it appears helpful. Therefore the current category ‘routine’ can be broken into two-that of ‘the importance of routine’, and ‘working around the child’s routine’.

It appears this may be a reason for treatment getting easier over time, as participants discuss how getting into a routine, and particularly their child being in a routine, has developed as they have grown older.

Figure 1. Memo Extract

Quality Standards in Qualitative Research

There are several criteria available against which the standard of qualitative research can be judged. These criteria contribute to the legitimisation of qualitative research, and encourage better quality research and valid reviews of qualitative studies (Elliott et al., 1999). Throughout the research process, from design to analysis, a number of evaluation criteria were born in mind. These included Elliott et al.'s (1999) guidelines for reviewing qualitative research, the criteria laid out by Henwood and Pidgeon (1992) which are particularly informed by GT, in addition to the criteria for evaluation discussed by Strauss and Corbin (1998). A number of procedures were utilised to ensure the research was of high quality.

Supervision

Supervision with my academic supervisor with his extensive experience of both GT and CF was paramount in ensuring the quality of the research. Supervision occurred monthly throughout the research process, and generally took place in between each of the interviews. The systematic approach taken to data analysis, in addition to the use of diagrams, meant that my ideas could be communicated clearly, and supervision could be utilised in a variety of ways to ensure the research was quality controlled.

Supervision was utilised to ensure the validity of the coding process and the emerging categories and theory. The process of open, axial, and selectively coding each interview was discussed and reviewed. The emerging theory was also discussed in each meeting. Presenting the working grounded theory model in the format of a large diagram, as previously discussed, allowed the research supervisor to fully understand and comment on my ideas about the emerging categories and relationships between them.

Supervision was also utilised to discuss developing relationships amongst categories, and hypotheses generated by the theory. It was also utilised to discuss 'gaps' in the analysis, and areas that may be useful to explore with the next participant. In this way theoretical sampling, emphasised as a quality standard by Henwood and Pidgeon (1992) and Strauss and Corbin (1998), remained a priority throughout.

Supervision was also utilised to reflect more generally on the process of the research, and my feelings towards the participants' stories. Utilising supervision in this way enabled the promotion and maintenance of reflexivity, noted to be an important quality standard by Henwood and Pidgeon (1992) and Elliott et al. (1999). Minutes of each meeting were made in order to maintain an audit trail of the research, which Burns (1989) argued is important in maintaining methodological and procedural rigor.

I also attended a peer supervision group facilitated by an academic with extensive experience of conducting and reviewing qualitative research. This provided additional opportunities for the research process to be reflected and commented on, through discussions with peers and the academic facilitator of the group.

Credibility Checks

Credibility checks are a further way of maximising the standard of qualitative research. Elliot et al. (1999) discussed the different types of credibility checks that researchers may use to check the credibility of their categories, themes, and accounts. These can include checking their understanding with the original participants or those who are similar, and using multiple analysts, such as an analytical 'auditor'. All three of these credibility checks were utilised, and therefore other credibility checks such as comparing two or more qualitative perspectives were not utilised.

Returning to Participants In order to check the credibility of the categories and accounts emerging from the analysis, participants were sent a summary of the results. This summary included a description of each category and the relationships between them. Participants were asked to comment on whether they felt the categories accurately captured and reflected their experiences of being a mother. Eight participants replied and their feedback was as follows:

'It's really interesting to see that other women with CF have the same worries and concerns as me. There is a definite need for adolescent counselling in this area in regards to what to expect' (Adele)

'Fab! Fits very well with my view!' (Pippa)

'I loved reading the results. They've really captured my experiences of being a mother. I honestly can't think of anything that you have missed. I still look at both my girls and am blessed that I was able to have them' (Tamsin)

'They sum up my experience perfectly!' (Ellie)

'I think they are an accurate description of what motherhood and CF involves. It will be very helpful for other women with CF wanting to try for a baby, and give a real insight into how other women cope. I wish I had had this information when I became pregnant' (Chloe)

'I think the results summarise my experience well. On reflection, one of the things I didn't mention, though I think it comes out in the results, was how becoming a mother has helped me to understand myself better physically: I am better at recognising my own physical limits and staying within them...making sure I am prioritising rest...and seeking treatment early' (Kimberley)

'I found them really interesting to read and quite comforting in that I was surprised how many others must share my feelings, difficulties etc. There were also some points which I didn't say but on reading them felt a real affinity with' (Amy)

'The results all look good to me!' (Heidi)

Comments From Similar Others Emma Harris was eager to hear the results of the research, and was keen to review them and give her feedback as detailed below:

'On reading the results of the research, I was struck by how closely the themes covered reflect my own experiences, and also the topics that are regularly discussed on our online support group. Group discussions regularly reflect members' strong desire for motherhood, the careful planning that goes into it and the fulfilment and joy that it provides. Commitment to maintaining health and

extending life expectancy for the child's sake are also common themes, as is the value of a strong support network in order to achieve this. The lack of information available to women with CF who are considering parenthood is very representative of my own experience, as well as that of other members, and was the motivation behind setting up the support group and the CFmothers.com website. Perhaps the most striking feature of all for me was the identification of the central process being that of a balancing act between the needs of mother and child. A member of our group once described herself as having two children – one, her young son; the other, her CF – with each requiring her time, energy and commitment. The central balancing process identified in this research highlights perfectly these joint responsibilities of the CF mother'.

Auditor Check Auditor checks as discussed by Elliott et al. (1999) are also advocated by Strauss and Corbin (1998). In this case, a colleague with experience of conducting qualitative research at PhD level, and who is familiar with GT, checked the categories derived from the analysis. In order to do this he was provided with one page from each of the 11 transcripts, with the originally selected meaning units and their allocated open codes marked on the transcript in order to standardise the process. He was also provided with a list of the final core, conceptual, and subcategories, and asked to match the meaning units and their associated open codes to the correct categories. One page from each transcript was selected specifically to ensure he was presented with a diversity of data.

The auditor was able to correctly allocate all but one meaning unit to their associated categories. He explained the process was straightforward given the clear nature of the categories, although was time consuming. On the one occasion he struggled to decide between two categories to allocate a particular meaning unit to, he attributed this to being unfamiliar with CF.

Verification Elliott et al. (1999) discussed a further credibility check, that of a 'verification step' by the researcher, whereby the data is reviewed for discrepancies and overstatements. This was completed during the final stages of theory integration, and during the selection of quotations to utilise in the write up of the results here.

Reflexivity

As part of their criteria for evaluating qualitative research, Henwood and Pidgeon (1992) discussed the importance of ‘reflexivity’. They argued the role of the researcher should be acknowledged, given the object of enquiry is shaped by the research process. Similarly, Elliott et al. (1999) also talked about the importance of the researcher ‘owning one’s perspective’. Whilst I adhered to the principles of Strauss and Corbin (1998) throughout the research, it is important to note that the way in which researchers utilise their method of choice, and the questions they ask, will be influenced by their own background, which will shape the research process and ultimately the findings (Willig, 2008). Indeed, Strauss and Corbin (1998) acknowledged the process of coding is not objective, given the constant interplay between the researcher and the data. As previously noted, memo-writing and keeping a research journal enabled the principle of reflexivity to be integrated into the research process. However, important areas to note about myself as part of the process of reflexivity include the following:

Demographic Details I am a 28 year old white female working towards a doctorate in clinical psychology. I have experience of completing an IPA project, however was new to the GT methodology.

Personal Biases There were two main potential biases to be aware of in conducting the current study. Firstly, I am of childbearing age and also have a chronic illness. This meant there was the potential for me to be ‘similar’ to participants in certain ways. This may have led to certain biases, such as being motivated to see ‘resilience’ as opposed to ‘struggles’. This potential bias was confounded by a further bias, that of having a close female friend with CF. This may have made it difficult to deeply explore difficult aspects of the participants’ stories, such as those associated with ill health and life expectancy. Alternatively, it may have meant that I had a ‘fixed’ view of how CF affects someone’s life.

Both of these potential biases were considered before embarking on the research, and indeed it was reflected on whether they may make the research too emotionally difficult. However, I decided that having a chronic illness myself, and having a close friend with CF, would mean I had a personal vested interest in the project, and my energy and enthusiasm for it would be maintained over the three

years as a result. Indeed, this was the case, and I found that I was continually motivated to thoroughly understand participants' individual experiences, in order to present an accurate and complete picture, that would serve as useful for CF teams and female patients with CF. Furthermore, I feel having an existing understanding of CF and its treatment enabled me to be sensitive to participants' stories. For example, visual images readily came to my mind when participants described doing their nebulisers and clearance physiotherapy in front of their children. Furthermore, my own health condition is substantially different to CF in regards to symptoms and prognosis, and I am not at a stage in my life where motherhood is a consideration.

Clinical Interests My preferred client group to work with are those with chronic illness, and I have experience of working clinically with children and adults with diabetes, chronic pain, HIV, CF, and individuals having undergone amputations. My preferred theoretical orientations in regards to clinical work include person centred, systemic, and narrative approaches. Whilst before starting the research I expected the interviews to be dominated by CF related discussions, I was struck by how discussions often felt like those that could be had with any mother, such as discussions around having no time and feeling exhausted. I was interested in these discussions, and I feel this fits with my enjoyment of listening to people's stories outside of their illness, in addition to those that include them, in line with narrative approaches. Whilst it is important that the researcher's identity and standpoint remain secondary to objectivity, I feel these values of mine enabled me to achieve a balance between discussing issues around CF and those around being a mother, and exploring the relationship between them to fully understand participants' experiences.

Role of the Researcher The approach I adopted towards the data was in line with Strauss and Corbin's acknowledgement of the role of the researcher. Strauss and Corbin (1998) argued the researcher's role is to systematically gather and analyse data, maintaining a close relationship between data collection, analysis, and emerging theory. Researchers should allow theory to emerge from the data as opposed to imposing any preconceived ideas. They suggested it is up to the researcher to balance science with creativity. Science involves maintaining rigour

and grounding the analysis in the data. However creativity is also important, in asking questions, naming categories, and extracting an ‘innovative, integrated, and realistic scheme from masses of raw unorganised data’ (p13). They acknowledged research is not a truly objective process, and requires some interpretation. The use of supervision and memo-writing contributed to ongoing reflexivity and the consistent acknowledgment of my role in the process of data analysis, the results of which I will now present.

RESULTS

Overview

I will first provide a description of the participants. I will then summarise the data collected from the quantitative measures. Finally, I will present the grounded theory developed from the analysis, including a description of the emerging core, conceptual, and subcategories, and how they relate to one another.

The Sample

It is important to situate the sample as part of good quality qualitative research (Elliott et al., 1999). In addition to quality of life and psychological measures, information on participants' health status and demographic details were also collected.

Demographic Details

Table 3 details the health and treatment status of participants. For comparison purposes, the final row of the table details the mean FEV1% and BMI of 76 women with CF from the general CF population (mean age=35, Abbott et al., 2013).

<i>Participant</i>	<i>Age at Diagnosis</i>	<i>FEV1 %</i>	<i>BMI</i>	<i>Chest Clearance Physio.</i>	<i>Nebulisers</i>	<i>Enzymes</i>	<i>Vitamins</i>	<i>Inhaler</i>	<i>Anti-biotics (oral)</i>	<i>Diabetes</i>
Adele	6	68	27	✓	✓	✓	✓	✓	✓	✓
Pippa	3 months	78	23	✓	✓	✓	✓	✓	✓	✗
Tamsin	6 months	67	20	✗	✓	✓	✓	✓	✓	✗
Ellie	2	77	31	✓	✓	✗	✗	✗	✓	✓
Jessica	20	-	-	✓	✓	-	-	-	-	-
Chloe	14	42	21	✗	✓	✗	✗	✓	✓	✗
Kimberley	18 months	77	22	✓	✓	✓	✓	✗	✓	✓
Amy	4	27	21	✓	✓	✓	✓	✗	✓	✓
Joanna	Birth	75	21	✓	✓	✓	✓	✓	✓	✗
Heidi	3 months	68	22	✓	✓	✓	✓	✗	✓	✗
Rachel	8 months	103	-	✗	✓	✓	✓	-	✓	✓
Mean	-	68	23	-	-	-	-	-	-	-
Abbott et al. (2013)	-	51	21	-	-	-	-	-	-	-

Table 3. Health and Treatment Status of Participants (‘-’ indicates missing data’).

As can be seen from Table 3, in regards to health status, the participants in this study (mean age=30) appear to be in notably better health with regards to lung function than those described by Abbott et al. (2013). However, this may be due to the participants in the current study being on average 5 years younger. The mean BMI of the current participants is also higher than the mean BMI reported by Abbott et al. (2013). A number of participants in the current study have high BMIs which would explain the overall higher mean BMI. This may be due to the fact that these participants have carried babies, and as a result weigh more than the sample described by Abbott et al. (2013).

Table 4 details socio-demographic details of participants.

<i>Participant</i>	<i>Age</i>	<i>Children</i>	<i>Mode of Conception</i>	<i>Marital status</i>	<i>Educ. status</i>	<i>Occ. status</i>	<i>Partner's occ. status</i>
Adele	29	Freya, 18 months	IVF	Married	A-Levels	Paid part time	Paid full time
Pippa	31	Christopher, 4	IUI	Married	A-Levels	Homemaker	Self employed
Tamsin	41	Holly, 3, Lucy, 14	Natural, IUI.	Married	GCSEs	Paid full time	Paid full time
Ellie	30	Henry, 18 months	Natural	Married	GCSEs	Homemaker	Paid full time
Jessica	22	Jack, 2	Natural	Married	-	Homemaker	Self employed
Chloe	29	Nicholas, 5	Natural	Married	GCSEs	Homemaker	Paid full time
Kimberley	32	Alfie, 3	Natural	Married	Undergraduate	Homemaker	Self employed
Amy	32	Izzy, 2	Adoption	Married	Undergraduate	Paid part time	Paid full time
Joanna	28	Noah, 3, currently pregnant	Natural	Married	Undergraduate	Homemaker	Paid full time
Heidi	31	Ava, 7 months	Natural	Co-habiting	Undergraduate	Paid part time	Paid full time
Rachel	24	Thomas, 4, William, 14 months	Natural	Married	-	Homemaker	Paid full time

Table 4. Socio-demographic Details of Participants.

As can be seen from Table 4, the sample are relatively high achievers with regard to academic qualifications, with similar rates as reported by patient registries (e.g. CF Trust, 2013). Rates of employment are lower in this sample however, as compared to those reported by CF patient registries and by Besier and Goldbeck (2012). This is perhaps understandable, given participants' statuses as mothers. High rates of marriage, as seen in this sample, may also be unsurprising for this same reason.

Pen Portraits

The purpose of pen portraits is to introduce the reader to the sample and provide a more complete picture. Included in the pen portraits are more detailed background information, my impressions of participants formed during the interviews, and a brief summary of their personal story, with an emphasis on their unique contributions.

Adele

Adele is married to Paul who works full time. Prior to becoming a mother, Adele worked full time, and returned to work part time after having Freya. She described having a close circle of friends who she had met at a mother and baby group, in addition to a supportive family close by.

Adele openly discussed finding motherhood difficult, particularly when she was feeling ill. She said she originally questioned whether they had made the right decision having Freya, when she was made acutely aware of her limited life expectancy during a period of illness following Freya's birth. These feelings felt particularly difficult due to how wanted Freya had been. Whilst her treatment was significantly disrupted on first becoming a mother, she described being able to re-introduce her full regime within around two months. She discussed how things had become easier as Freya has grown up in every aspect of being a mother. Adele had had some negative experiences with her CF team, and was motivated to take part in the research in order to contribute to CF teams' understandings of life as a mother with CF.

Pippa

Pippa is married to James who works full time, although is self employed. She has two sisters who also have children, who she described as her best friends. She described spending time socialising with them and her parents.

Pippa explained how unexpectedly difficult she had found the first few months of being a mother, due to Christopher's difficult temperament. She described however that at six months things changed in regards to his character, and she came to love being a mother. She described how she had always been very in tune with her body and had always done treatment 'as and when necessary'. On initially becoming a mother this attitude remained, although she was not always able to do as much treatment as she would have liked. Over time however, she has developed a different attitude to her treatment, and is now fully adherent. She described this as being due to wanting to be in the best possible health for as long as possible for Christopher. I was struck by Pippa's bright and positive attitude, however she did discuss certain frustrations about finding some aspects of mothering hard, and expressed a desire to be like 'normal' mothers. Pippa was easy to engage and was eager to take part in the research and share her experiences, given her feeling there was too much focus on discussing pregnancy with her CF team, and not enough on what life as a mother would be like.

Tamsin

Tamsin is married to Ben who works full time. She had her first daughter with her first husband, and her second daughter with Ben. Her second daughter was not planned as she did not think she could have any more children, but was a 'lovely surprise'. Tamsin works full time, however two of the five days works from home.

Tamsin was the only participant I interviewed who works full time, and her experiences stood out as being different from the others. She discussed how her treatment was still disrupted on certain days, and attributed this to working long hours and not having enough time. She said she fully adheres to her treatment on the days she works from home and at the weekend when her husband is present to care for their children.

Tamsin had grown up being told by CF doctors that she would 'not see 18', and thus as an adolescent grew up enjoying life and not giving the future much

thought. However, when she reached 18 and felt relatively healthy, she began to question things she had been told by her CF team. Tamsin discussed a great sense of achievement at having being able to have two children, given she was always told this would not be the case. Tamsin was eager to take part in the research to raise awareness of the issue, and spoke of the dangers of automatically believing CF doctors.

Ellie

Ellie is married to Oliver who works full time. In discussing her experiences of being a mother, Ellie openly discussed how Henry was entirely her priority for the first few weeks, and her main concern was attending to his needs as opposed to her own. Her family offered her a lot of support in caring for Henry but initially she felt reluctant to use this as she felt she should do it alone. However, she gradually came to realise that her treatment was just as important as Henry, and found ways to reintroduce this. She discussed the amazing bond she feels with Henry, and at the time of interview was planning to have another child.

I was struck by how assertive Ellie had been with her CF team, such as refusing to give birth at the hospital where they were based, instead wanting to give birth at a hospital closer to home. She described herself as being 'feisty', and had the perception that many people with CF are like this, because having CF means you have to be strong and a 'fighter'.

Jessica

Jessica was 22 at the time of interview, and was diagnosed with CF aged 20, when she was six months pregnant. When she was 14 she was diagnosed with a severe form of asthma, and given a steroid inhaler that did not help. She said she did not give it much thought and got on with her life, as it didn't really stop her doing anything, although she was known as 'the girl with the loud cough' at school. However, on reaching the 6 month point in her pregnancy, she became severely ill and was admitted to hospital where she was quickly diagnosed with CF. Jessica explained how she and her husband, Rob, had then 'googled' CF and were devastated by what they read. However, Jessica described quickly accepting it, and getting into a treatment routine. She attributed this quick acceptance to her family's attitude of 'not moaning' and 'getting on with things', particularly health

problems, which were prominent in her family. Jessica described how the treatment routine she had developed during pregnancy was broken on becoming a mother, and for a period of time she neglected her treatment, which upset her. However, she described over time how things have improved, and discussed her desire for another child, although wanted to wait until she was in better health. Jessica's husband is self employed and was able to work from home, which Jessica said had been extremely helpful in coping with motherhood. Jessica was again easy to engage, and I was struck by her positive attitude, and quick acceptance and apparent adjustment to CF.

Chloe

Chloe is married to David who works full time. Chloe had had involvement with two different CF teams after transferring her care due to re-locating. Her experiences of the two teams were extremely different. Her child, Nicholas, was unplanned due to Chloe believing natural conception was not possible for women with CF. However, Nicholas was very much wanted and a 'happy surprise'.

Chloe described her treatment being disrupted on becoming a mother, with some or all of her treatment getting missed for a period of two years. This was a much longer period than described by the majority of other participants, who eventually re-introduced their full treatment regime within a few months. After two years Chloe became very ill, and felt like she had lost control of everything. Following this, Chloe realised the importance of adhering to her treatment, and demonstrated a commitment to it. Chloe talked about how much she enjoys being a mother, and how it has given her a real motivation to stay well and adhere to her treatment. Chloe appeared quite shy, however wanted to share her experiences to contribute to the lack of information available on motherhood and CF.

Kimberley

Kimberley is married to Richard who works full time. She described living in a close religious community, and having a close circle of friends and family around her, Richard, and their son, Alfie.

Kimberley explained how on becoming a mother she experienced very little treatment disruption, because her husband was able to work flexible hours. As a result, he was able to ensure he was around at particular times of the day, to

enable her time to do her treatment. Kimberley talked openly about the feelings of guilt she experiences as a result of feeling limited in the activities she can engage in, and how Alfie's life may look different to his friends. She also discussed feeling guilty at the thought of what the future may hold. Kimberley was eager to be involved in the research to share her experiences of being a mother. As did Pippa, she described a desire to know what life may look like as a mother with CF when she was considering having children. She felt that her CF team could not offer her this information, and as a result felt this kind of research was of paramount importance.

Amy

Amy is married to Mark, and they adopted their daughter, Izzy, when she was 14 months old. Izzy was two and a half at the time of the interview. Amy's husband works full time, and his job involves working shifts. Amy had worked full time up until adopting Izzy, and now works part time as a teacher. Amy described having a close and supportive family around her.

Amy discussed the process of adoption and how she felt it had been the best option for her. She talked about how surprised she had been to be successful in this, given stories she had heard about other women with CF trying to adopt. Amy described how Izzy quickly got used to CF being a part of life, and how she 'absorbed' it all. Amy often talked about feeling guilty for having time away from Izzy when she was ill. This was particularly so when they had only had Izzy for a few months, and Amy was concerned that time apart would damage the relationship they were starting to build. Whilst Amy's story was slightly different to the other participants given she had become a mother immediately to a slightly older child, she reported the same experiences of an initial period of treatment disruption as she adjusted to life as a mother, with treatment getting easier to do over time.

Amy was easy to engage throughout the interview, and was motivated to take part in the research given she felt her CF team were lacking in appropriate knowledge and information on CF and motherhood. She explained she would have appreciated this when she was considering her options in regards to having children.

Joanna

Joanna is married to Gareth who works full time. She described minimal use of social support on becoming a mother, although explained she had a close network around her if she needed to use it. She was six months pregnant with her second child at the time of the interview.

In discussing her treatment, Joanna explained she experienced little disruption on becoming a mother. She attributed this to her son, Noah, quickly getting into a sleeping routine, which enabled her time to do treatment when he was asleep. She discussed how important it was for her from the beginning to look after herself as well as her son, and the importance of getting the right balance. She discussed how her health had deteriorated during her pregnancy with Noah, and how it took her a long time to reach her pre-pregnancy lung function following Noah's birth. She said she had always wanted another child, but had waited until her lung function was higher before trying to get pregnant again. She discussed her plans for caring for the new baby, and said that as Noah was about to start nursery, she felt she would be able to care for both Noah, the new baby, and herself effectively. She acknowledged she had support available should her health deteriorate. Joanna was enthusiastic about taking part in the research, feeling that the more research that is done the better, so that younger women with CF can develop an understanding of how their life might change should they choose to have children.

Heidi

Heidi lives with her long term partner Simon. Simon works full time, and Heidi had recently returned to work part time. They described having lots of support from family available, which they had used a lot, particularly in the first few months.

Heidi had the youngest child out of all the participants, and was thus less able to talk about issues that may arise with toddlers or slightly older children. However, Heidi still described feeling that things had become easier over time, such as being in more of a routine and finding she has more time to herself. She also talked about her intentions in regards to her daughter, Ava, witnessing her treatment. She discussed plans to do her treatment in front of Ava, so that she grows up with it being 'normal'. Heidi was extremely enthusiastic about taking

part in the research, again being motivated to share her experiences after trying to research ‘CF and mothers’ in planning and preparing for motherhood, and realising there was very little information on the issue.

Rachel

Rachel is married to Steve who works full time, with his job involving shift work. Rachel’s story felt slightly different to the other participants. She explained how she had been brought up to be very independent, and that whilst her parents currently visited her twice a week, this was only for an hour or so, and she didn’t feel she could ask for their support in caring for her children. Rachel explained she would be reluctant to do this as she was used to being independent, but it also appeared that she did not feel able to, given that her parents ‘had their own problems’. Rachel appeared to be relatively isolated, and she described her husband as sometimes saying he was jealous of her being at home all day while he went out to work. She said she sometimes feels he does not understand how CF affects her.

Rachel was easy to engage and had strong opinions on a variety of issues, such as her decision to be open about her CF with her children from the beginning. I was struck by how assertive Rachel was with her CF team, such as ‘arguing’ with them for three years about wanting to have a port-a-cath fitted. Rachel was again motivated to take part in the research and share her experiences, due to feeling that CF teams need to understand what life is like for mothers with CF.

Quantitative Results

Following the interview, participants completed the CFQoL (Gee et al., 2000) and the HADS (Zigmond and Snaith, 1983).

CFQoL

The CFQoL (Gee et al., 2000) comprises nine domains, and a transformed score between 0 and 100 is established for each. A score of 100 indicates the most positive quality of life score possible, whereas a score of 50 or below indicates the individual may be experiencing some difficulties in that area. Table 5 summarises the participants CFQoL domain scores. For comparison purposes, the final row in

the table details the mean scores found by Abbott et al. (2013) from a sample of 76 female patients with CF (average age 35 years, average FEV1 51%).

<i>Participant</i>	<i>Physical Func.</i>	<i>Social Func.</i>	<i>Treat. Issues</i>	<i>Chest Symptoms</i>	<i>Emotion. Func.</i>	<i>Concerns for the Future</i>	<i>Interpers. Rels.</i>	<i>Body Image</i>	<i>Career Concerns</i>
Adele	70	90	40	75	83	33	34	100	15
Pippa	86	90	93	75	88	70	60	66	30
Tamsin	94	100	60	90	93	33	72	60	85
Ellie	90	100	93	95	100	70	88	100	50
Jessica	-	-	-	-	-	-	-	-	-
Chloe	78	75	33	30	78	23	66	80	30
Kimberley	94	80	60	70	85	60	60	93	80
Amy	50	55	53	20	45	10	26	86	55
Joanna	60	80	73	50	83	23	62	73	75
Heidi	86	80	73	80	80	20	54	80	80
Rachel	-	-	-	-	-	-	-	-	-
Mean	79	83	64	65	82	38	58	82	56
Abbott et al. (2013) mean	77	76	70	70	70	36	55	68	45

Table 5. CFQol Scores and Mean Comparisons ('-' indicates missing data).

As can be seen from Table 5, the average quality of life scores for this sample are relatively high, other than for 'concerns for the future'. The average scores on a number of the domains are higher than those reported by Abbott et al. (2013). This may be due to the sample in the current study having a higher lung function than the sample described by Abbott et al. (2013). However, research has often demonstrated that physical health parameters are only moderately related to overall quality of life scores in those with CF (e.g. Gee, Abbott, and Hart, 2005). Alternative reasons may be due to the younger age of this sample, as research has often found deterioration in quality of life over time (Abbott et al., 2013). A further reason may be that all but one participant was married, and all had achieved an important life goal of having children.

Low scores for many of the participants on 'concerns for the future' are possibly to be expected, given their statuses as mothers, and are similar to those in

the Abbott et al. (2013) sample. Other areas where problems may be evident include Amy's physical functioning scores, possibly to be expected given her FEV1 of 27%. Treatment appears particularly burdensome for Chloe, and chest symptoms problematic for Chloe, Amy, and Joanna. This may reflect Chloe and Amy's low FEV1%, and Joanna's pregnancy. Amy also reported difficulties in emotional functioning and interpersonal relationships, as did Adele. Many participants reported career concerns, however this appears typical for an adult CF population, as demonstrated by the scores reported by Abbott et al. (2013).

HADS

Each item on the HADS is scored on a scale of 0-3, yielding a score between 0 and 21 for anxiety and depression. Scores between 0 and 7 indicate a lack of anxiety or depression, a score of 8 to 10 indicates a 'borderline' presence, with a score of 11 or above indicating the presence of anxiety and depression. The results in Table 6 detail participants' HADS scores. For comparison purposes, the final row details the mean scores from a sample of 57 adults with CF (mean age 26 years, mean FEV1 65%) described by Havermans et al. (2008).

<i>Participant</i>	<i>Anxiety</i>	<i>Depression</i>
Adele	5	3
Pippa	1	1
Tamsin	4	1
Ellie	0	1
Jessica	-	-
Chloe	8	5
Kimberley	5	1
Amy	6	6
Joanna	5	4
Heidi	8	4
Rachel	-	-
Mean	5	3
Havermans et al. (2008)	6	4

Table 6. HADS Scores ('-' indicates missing data).

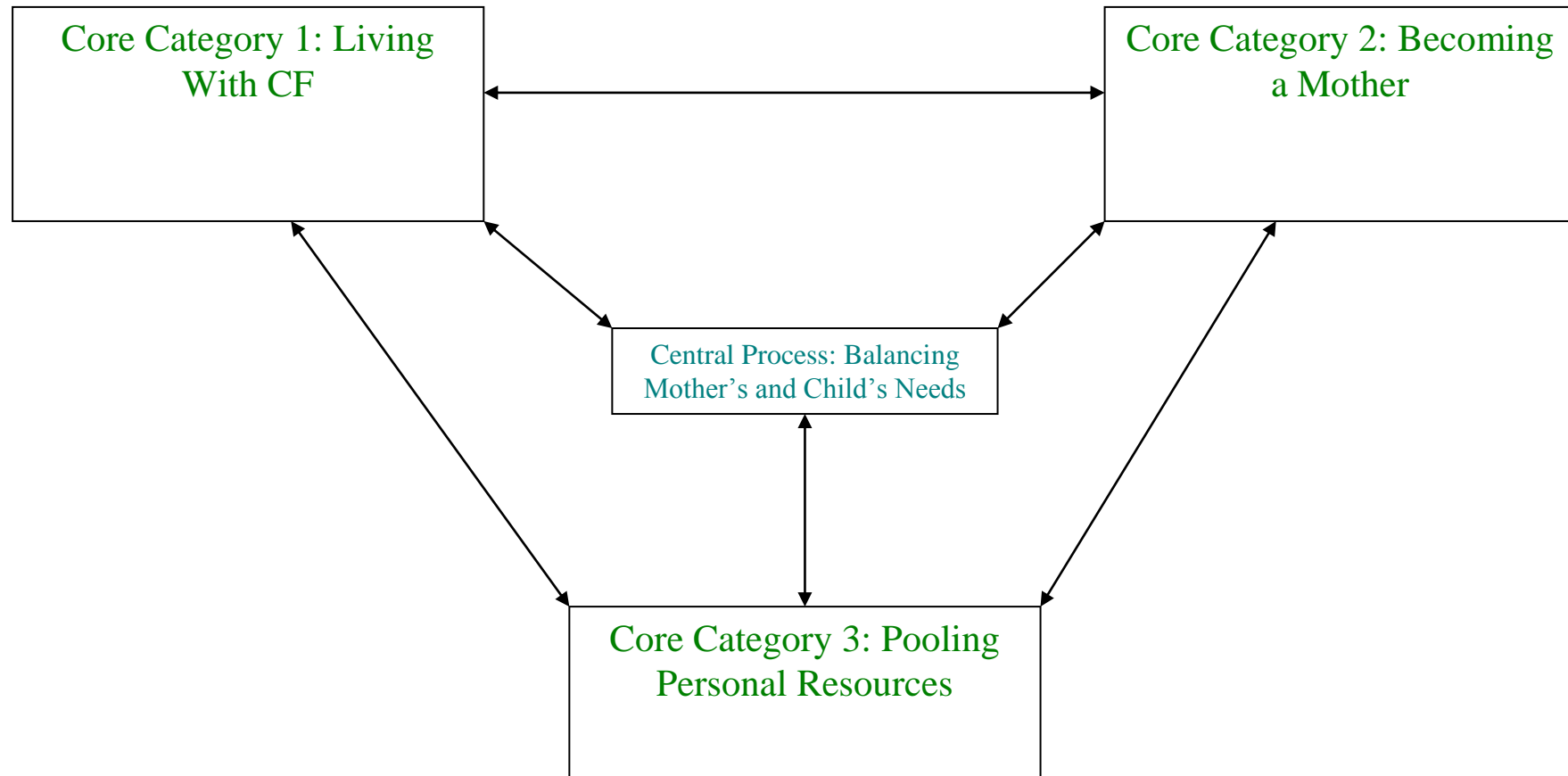
The mean scores observed in this sample are similar to those detailed by Havermans et al. (2008). There appears to be an absence of clinical anxiety and depression, other than a borderline presence of anxiety for Chloe and Heidi. However, eight is the lowest score in the 'borderline' range, and neither Chloe nor Heidi reported problems in the area of emotional functioning on the CFQoL.

Qualitative Results

I will now present the qualitative results using a series of diagrams and narrative descriptions of the categories. The grounded theory is presented in four figures. The first illustrates the theoretical formulation developed. This details how the three core categories relate to each other and a central process. The remaining figures detail the conceptual and subcategories contained within each of the three core categories.

The properties and dimensions of the categories and the relationships between them are woven into the narrative of the results. I will begin by describing the theoretical formulation developed. Figure 2 presents this theoretical formulation, including the core categories and their relationships to one another diagrammatically.

Figure 2. Theoretical formulation: The Relationship of the three core categories to one another and the central process.



Theoretical Formulation

The first core category, 'Living with CF' includes conceptual categories relating to the day to day issues involved in living with CF. These are issues characterising day to day life for anyone with CF, regardless of whether one is a mother or not, such as involvement with health services and the need for treatment. The second core category captures conceptual categories relating specifically to becoming a mother, such as having a child to care for.

These two core categories are not distinct or mutually exclusive however. Instead, they are closely related, mutually influencing one another. Factors associated with 'Living with CF' ultimately influence the process of 'Becoming a Mother'. For example, living with CF means that planning and preparing for motherhood is recommended. In addition to this, becoming a mother also influences living with CF, such as the experience of treatment disruption, and an impact on physical health.

The third core category, 'Pooling Personal Resources', details the resources that participants described drawing upon on becoming a mother. This core category is also closely related to 'Living with CF' and 'Becoming a Mother'. Managing CF and motherhood involves pooling a number of personal resources in order to manage the dual demands of living with CF and being a mother. Examples include utilising family support to enable treatment adherence, and the partner's support to help care for the child in order to manage the guilt often experienced at having time away from their children.

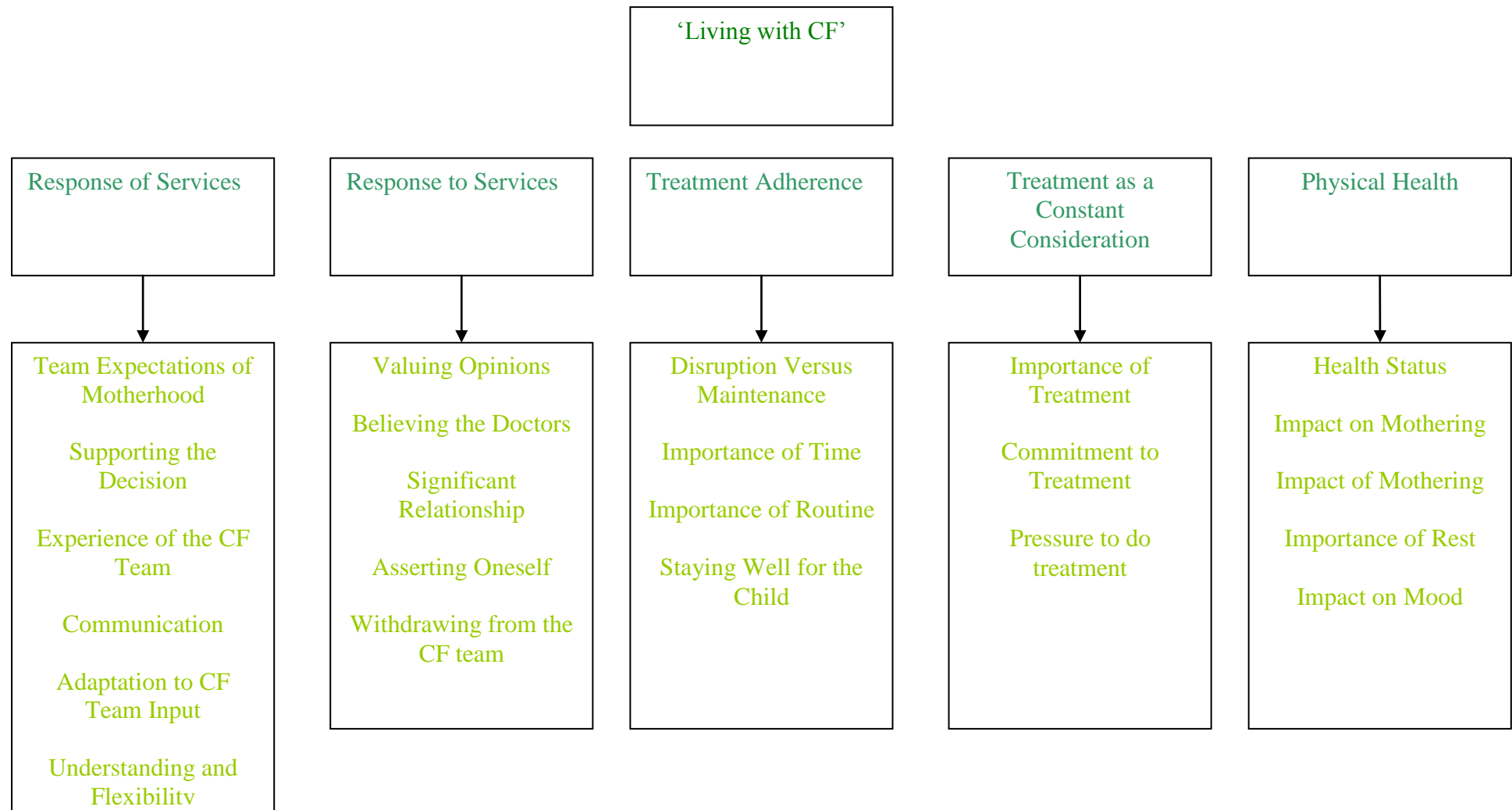
An important way in which all three core categories influence and relate to each other is captured by the central process labelled 'Balancing Mother's and Child's Needs', which I will describe in further detail later.

I will now describe the conceptual and subcategories contained within each of the core categories, in regards to their properties and dimensions, and the relationships between them, using illustrative quotations for each. The specific category to category relationships amongst the conceptual and subcategories will further illustrate the non-distinct nature of the core categories.

Core Category One: 'Living with CF'

Figure 3 on the next page illustrates the conceptual and subcategories contained within the core category 'Living with CF'.

Figure 3. Conceptual and subcategories included in 'Living with CF'



Conceptual Category: Response of Services

Sources: 11

Participants discussed the roles and responses of their CF teams both prior to, and on becoming a mother. The first four subcategories within this conceptual category relate to the period prior to becoming a mother, and the last two after becoming one.

Subcategory: Team Expectations of Motherhood.

Sources: 6

Participants discussed the extent to which they perceived their CF teams expected they may be contemplating having, or be able to have, children. Three participants felt their CF teams did not expect they would be able to have children, either naturally or through other means such as adoption. Whilst three participants had the experience of their CF teams raising the issue of children once they had reached young adulthood, three participants felt their CF team did not expect them to be contemplating having children...

'I'd been with my other half for five years and they never once said to me about trying to conceive or anything like that, it was like it was not even thought about that that's what we might be doing...there was no, not even a conversation about babies' (Adele)

Although it is possible that the attitudes of teams may be due to differences in the health status of individuals, two participants experienced different attitudes following a transfer in their care to a new team, suggesting the beliefs held by teams may also play a part.

Subcategory: Supporting the Decision

Sources: 11

A variety of experiences in regards to how supportive their CF teams were of their decision to have children were reported by participants. Seven participants at one point or another experienced a lack of support...

'We said we had wondered about surrogacy...and the reaction was almost a laugh, not very supportive certainly' (Amy)

'She (doctor) was very off, you could tell she didn't like what I was doing' (Tamsin)

Eight participants described experiences of supportive CF teams...

'They basically just said, we're very behind you' (Kimberley)

Two participants experienced differences in levels of support across two different teams, and two participants experienced different levels of support from doctors within the same team.

It appears that the extent of doctors' support was dependent on a number of factors. Two participants had the experience of doctors 'checking out' whether they felt they'd be able to cope with motherhood, and whether they had fully thought through their decision. Furthermore, all participants were subject to a number of health checks before doctors would support their decision, and a major consideration in the extent of doctors' support was health status. Whilst one doctor suggested she would support the decision no matter what health the participant was in, the rest who supported the decision suggested this was provided participants were in the correct health...

'He (doctor) said I have no problems with you having kids if you keep up your weight and your health and your lung function' (Joanna)

Subcategory: Experience of the CF Team

Sources: 7

Participants discussed their perception of how experienced their CF teams were in caring for women with CF who wanted to have children. Whilst three participants felt their teams were experienced, six reported feeling at one point or another that the team they were under had little experience. Three participants felt this was

problematic, leading to receiving little or inaccurate information, or a lack of appropriate care...

'It's not something they frequently deal with and I think all the doctors should pool their resources as opposed to each unit having two or three different pregnant women and not knowing what to do with them' (Adele)

Seven participants felt that prior experience of caring for mothers with CF influenced the extent to which their teams supported decisions or held expectations that female patients with CF would consider having children, linking this subcategory with those subcategories discussed above.

Subcategory: Communication

Sources: 5

Whilst one participant found the communication between her CF team and the obstetric team was effective, four felt it was significantly absent or inadequate. Participants felt this caused problems and that more was needed, mainly due to the lack of experience of the obstetric team in caring for women with CF...

'There's no advice for gynaecological departments looking after people (with CF) who are pregnant cos I was almost teaching the high risk gyny people you know about CF' (Heidi)

Subcategory: Adaptation to CF Team Input

Sources: 11

Participants discussed the extent to which they felt their CF care was appropriately adapted to the demands of motherhood, and the adaptations they felt were required. Three participants discussed the amount of contact they had with their CF team. They noted they had no extra contact with them after having children, and felt this would have been beneficial. Five participants also said they had particularly benefited from being seen at home by the team where possible, due to it being harder to attend clinic appointments.

Participants also discussed the content of their discussions with members of the team at clinic appointments. One participant noted a continued and sole focus on

medical issues, which she felt was unhelpful. Seven participants expressed a desire for discussions with the team about life as a mother, and issues outside of their health. The six participants who reported experiencing these conversations with their team had appreciated these. Some felt these general ‘lifestyle’ discussions are particularly important on becoming a mother to assist the CF team in effective treatment planning, which can be difficult given new commitments on becoming a mother...

‘Part of planning the best treatment for me is planning the treatment that as much as possible suits your, fits in with your lifestyle, and I think unless they (CF team) know about you, that’s very difficult to do isn’t it? I do think it’s very important (general life discussions) but I probably realised how, become more aware of how important it is since I’ve had Izzy to consider as well’ (Amy)

These conversations also appeared beneficial in providing emotional support. Six participants discussed levels of emotional support they received from their CF team after becoming a mother. Whilst three had received or been offered this, three participants were explicit in describing its absence from the team, though they desired it....

‘I definitely think there could have been more sort of emotional support, even just contact and a bit of how are you type thing’ (Adele)

The desire for this was as a result of the overwhelming nature of becoming a mother with CF and the amount participants felt they had to cope with. However, two participants did not want to talk to their CF team directly, but would like to be signposted to another service, or would not want to discuss these issues with their CF team at all.

This subcategory links to ‘Experience of the CF Team’ and ‘Health Status’, with one participant feeling that a lack of necessary adaptations in CF care was down to the team’s lack of experience, whilst another felt it was due to her being in good health. However, this relationship is not consistent as a number of

participants who were in poorer health on becoming a mother also had no increased contact with their team.

Subcategory: Understanding and Flexibility

Sources: 11

As shall be elaborated on in further subcategories, it was often difficult for participants to adhere fully to their treatment on becoming a mother, particularly in the early stages. Participants discussed their CF teams' understanding of this and their resulting flexibility with treatment goals. Teams demonstrated an understanding if participants were not managing to fit in their treatment during the newborn phase in particular...

'When he was a newborn I would explain to them everything that was going on but they just gave me really good encouragement and said "just try and do it, if you can't that's fine, just try and get the next one", obviously they understood how disrupted it was' (Jessica)

Three participants explained how their CF teams had suggested alternative ideas for their treatment, which ultimately enabled some extent of treatment adherence...

'They were really good at coming up with new techniques and ways that I could do it (physiotherapy) while I was looking after Ava...and the same with the nebuliser as well...they gave me breathing techniques that I could do so that I could still do that physio' (Heidi)

This subcategory links to the subcategory 'Health Status'. Three participants felt their CF team were understanding and flexible at hearing about their treatment disruption due to them being in good health...

'I never felt under pressure but I think because I am generally well, they were like it's alright if you let things slip for a little while...but I think maybe if I wasn't so well it might have been different' (Ellie)

Another way all but one CF team demonstrated understanding and flexibility was in allowing participants to do IVs at home instead of coming into hospital wherever possible...

'They were always very respectful of the fact that ultimately I wanted to stay with my child, so they were always happy to let me do them at home' (Kimberley)

Participants noted being able to do IVs at home as been particularly important on becoming a mother.

A final way CF teams demonstrated flexibility was being flexible with appointment days and times, which participants particularly appreciated on becoming a mother.

Conceptual Category: Response to Services

Sources: 10

This conceptual category captures the responses of participants to their CF teams in a variety of contexts.

Subcategory: Valuing Opinions

Sources: 6

Eight out of 11 participants described seeking the advice and support of their CF team before making any firm decisions to go ahead with pregnancy or having children by any other means, suggesting they valued their team's opinions. Indeed, six participants discussed explicitly how much they valued the opinions of their doctors, and gave it as their reason for approaching their CF team before making any firm decisions about having children and how they may go about it...

'There was no way I would have got pregnant without the support of my team...I kind of felt that if they weren't going to support me in this then perhaps it wasn't the right thing to do because I had every faith in that they're looking after me in the best possible way' (Heidi)

Subcategory: Believing the DoctorsSources: 5

Five participants described automatically believing their doctors' opinions, such as when they were told pregnancy would not be possible, reflecting the weight of their opinions...

'We had already decided that we wouldn't go through a natural pregnancy anyway, but I think that (doctor's opinion) would have definitely sealed it had we not' (Amy)

Subcategory: Significant RelationshipSources: 3

Three participants explicitly referred to the significant relationship they have with their CF team...

'They become kind of like part of your wider family almost as well' (Heidi)

This subcategory is related to 'Adaptation to CF Team Input', with some participants feeling that the added 'lifestyle' type discussions facilitate this important relationship. One participant also explained the significant relationship with her CF team as being a further reason for seeking their support and advice prior to getting pregnant.

Subcategory: Asserting OneselfSources: 5

Participants discussed the extent to which they felt able to assert themselves with their team during discussions about having children. One participant described growing up feeling unable to challenge what the doctors told her about issues such as pregnancy. However, despite the weight of doctors' opinions, five participants also talked about standing up to their doctors, when they felt they had been given incorrect advice, such as when they had been advised against pregnancy, in spite of being in good physical health and having a good support system...

*'I was just like I couldn't care what you say anyway, I'm going to do what I want'
(Rachel)*

Subcategory: Withdrawing from the CF team

Sources: 3

This subcategory illustrates the potential detrimental effects that can occur if participants perceive they are not being supported by their CF team. Thus this subcategory relates to 'Supporting the Decision'. When participants were exposed to a lack of support from a particular doctor or the whole team this resulted in some participants feeling 'shut down' and withdrawing from the team...

'I definitely stopped phoning, say if I wasn't well or something, I wouldn't phone them straight away or anything, I'd be quite distant...I didn't want to see them I was quite...because my consultant said it, just because it was his opinion, I assumed that it was the whole 12 members of the team's opinion as well' (Rachel)

Conceptual Category: Treatment Adherence

Sources: 11

This conceptual category relates to how treatment adherence was affected on becoming a mother. It contains subcategories detailing what happened to treatment, conditions influencing treatment adherence, and reasons for adhering to treatment.

Subcategory: Disruption versus Maintenance

Sources: 11

Participants discussed the extent to which treatment was disrupted on becoming a mother. Whilst two participants experienced no disruption, nine did, at least temporarily, with some or all of their treatment getting missed, with the first few months being particularly difficult...

'There were plenty of times that I missed by nebuliser because he was newborn, and my second IV, it's hard' (Jessica)

However, it appeared that some treatment was disrupted more than others, with physiotherapy and nebulisers being more disrupted than tablets....

'I never missed any of my tablets, but it's easy to miss your physio and your nebulisers' (Ellie)

However, for eight of those who experienced disruption, this was time limited, and treatment was eventually maintained...

'I ended up not doing my nebulisers, that was the first thing to sort of stop, but I only stopped for about maybe six weeks or so' (Adele)

Of the eight participants who were able to eventually reintroduce their full treatment regime, seven were able to do this within around three months. Only one participant still misses treatment on certain days, due to working full time.

The impact of treatment disruption on health is an important issue to consider. Indeed, four participants attributed a deterioration in their health to their treatment being disrupted, demonstrating a relationship to the subcategory 'Health Status'. As a result, this prompted efforts to maintain their treatment...

'I didn't do any of my treatments in that (first) 12 weeks, then I noticed I wasn't feeling 100%, and I had to start fitting things (treatment) in' (Rachel)

All but one participant acknowledged that treatment was eventually maintained and has become easier to adhere to over time. Reasons for treatment disruption, eventual treatment maintenance, and treatment getting easier over time will be given throughout later subcategories.

Subcategory: Importance of Time

Sources: 10

Time was commonly cited as a major influence on the extent of treatment adherence. Participants described having a lack of time to themselves on becoming a mother, particularly during the newborn phase, and eight participants

gave this as a reason for treatment disruption, demonstrating a relationship to the previous subcategory...

'Half an hour sitting (doing treatment) when you've got a newborn baby is pretty impossible to do...because you have no time, because you haven't got time to yourself to be able to do it' (Heidi)

Indeed, participants explained the reason that physiotherapy and nebulisers were harder to maintain than tablets was because of the amount of time needed to do them.

However, four participants noted that as their children have grown older they have more time to themselves, which is one reason for eventual treatment maintenance, and for treatment getting easier over time, again demonstrating a relationship to the previous subcategory...

'It's got better (as he's grown older) having more time to fit things in...treatment's not getting missed' (Ellie)

Indeed, the one participant who still struggles to fully adhere to treatment is the one for whom time is still a significant issue, due to working full time.

Subcategory: Importance of Routine

Sources: 10

Participants noted that they had an existing routine for their treatment, which was broken upon becoming a mother. This meant participants initially had to fit in treatment as and when they could. Three participants suggested this break in routine as being a further cause of treatment disruption, and all discussed the importance of re-establishing a new workable routine in order to adhere to their treatment, noting routine is particularly important for treatment on becoming a mother. Establishing a new routine came with time, and was a further reason for eventual treatment maintenance, illustrating a relationship to 'Disruption versus Maintenance'...

'You have to organise yourself and kind of work out a routine so that it fits in for you and for your little one' (Heidi)

'I got back on track (with treatment) when I got into a routine' (Adele)

This subcategory relates to 'Importance of Time', as six participants suggested the reason routine is helpful, is that it creates the time needed for treatment...

'If we get up at eight, everyone's washed, dressed, fed by nine, so I've got 10, 11, then 12 o'clock dinner time, so I've got two hours there that are free, fit my nebs in, fit whatever I need to do' (Rachel)

Subcategory: Staying Well for the Child

Sources: 11

Participants discussed a major reason for adhering to their treatment, a need and desire to stay well for their children, in the short term so that they could engage in mothering, and in the long term, to prolong life expectancy...

'If I'm not well, I can't take care of the baby' (Jessica)

'I felt a lot more aware of how precious life is and how my life is as much precious as hers because I wanted her to have me as long as physically possible, and I think that really came to light when she was born, oh my god, I need to be as fit as I can possibly be forever' (Adele)

This desire and need to stay well has resulted in overall increased compliance in the longer term for 10 participants, following initial treatment disruption...

'I've been a lot more stricter with myself so I have, and I've been more compliant so I have with treatment and especially in regards to physio. I used to be quite lax-a daisy in terms of doing physio so I did, but since having Noah I would say the treatment and physio have definitely increased...you know someone else needs you' (Joanna)

Conceptual Category: Treatment as a Constant Consideration

Sources: 11

This conceptual category captures the centrality of treatment in participants' lives, with it being something to constantly consider. It details beliefs and feelings about treatment, and the commitment participants demonstrate to treatment adherence.

Subcategory: Importance of Treatment

Sources: 9

Participants talked about how treatment was and is a priority, and more important than things such as household chores. Participants consistently acknowledged the importance of adhering to treatment...

'It was really important to me that I did my treatments, I probably went slightly overboard in the way I was so regimented about having to do everything' (Kimberley)

This subcategory is closely related to 'Health Status'. Participants discussed wanting to be as healthy as possible, which was why treatment felt so important...

'I just thought as of now I've got to make time for this...I will do the nebuliser because it's maintaining my health' (Pippa)

This subcategory also relates to 'Staying Well for the Child'. Participants described how treatment felt even more important on becoming a mother because they wanted to be as healthy as possible because of their desire and need to stay well for their children...

'Before I had Henry I wasn't great at doing my treatments anyway, so it (treatment) was even more of a priority if you like that it has to be done because I have to be here to look after Henry' (Ellie)

Subcategory: Commitment to Treatment

Sources: 11

Whilst the majority of participants experienced a period of treatment disruption, it was also evident in the interviews that participants demonstrated a continuing commitment to their treatment, attempting to do as much as they could under the circumstances. 10 participants discussed strategies such as adapting treatment times and the way they do treatment in an attempt to adhere...

'I'm in the car and I'm doing breathing exercises, you know I'm sitting playing with her and I'm doing breathing exercises' (Heidi)

Participants discussed how the commitment to their treatment has actually increased since becoming a mother, and again this subcategory also relates to 'Staying Well for the Child' and 'Health Status'. A priority was being well enough to look after their children...

'I had to take care of myself because I didn't want to be sick, I wanted to spend time with him, and be able to run around and play with him and stuff' (Jessica)

'I always made sure I fitted in my physio and my meds, making slots for that...it was always at the forefront of my mind that I wanted to be as well as I could' (Kimberley)

Only one participant demonstrated a slight lack of commitment to her treatment...

'Looking back I probably could have fit it in, I was just so, usually when you've got a minute to yourself I just didn't use that sensibly and do my treatment' (Chloe)

However, this quote appears to demonstrate that Chloe acknowledges the importance of treatment, and furthermore she went on to demonstrate a commitment to her treatment after two years, after experiencing deterioration in her health, again demonstrating a relationship to 'Health Status'.

Subcategory: Pressure to do TreatmentSources: 7

Participants discussed the extent of the pressure they placed on themselves to adhere to treatment, further illustrating their feelings around the importance of treatment and their commitment to it. Whilst two participants did not appear to place too much pressure on themselves to do treatment, four discussed feeling upset if they had not been or are unable to do their treatment, putting pressure on themselves to do it...

'I constantly tell myself you should be doing your treatment today, you should have made sure you've done it by this time' (Tamsin)

Two participants also reported feeling under pressure from the CF team....

'The physio and everyone saying you've got to do it you've got to do it, you've got to make the time and you've got to find the time to do it' (Ellie)

Thus, it may be that CF teams' understanding and flexibility in regards to treatment disruption is time limited.

Conceptual Category: Physical Health**Sources: 11**

This conceptual category relates to issues pertaining to physical health. It includes subcategories relating to health status and its relationship to mothering, how it may be managed, and the consequences of poor health.

Subcategory: Health StatusSources: 7

Participants discussed their health status on becoming a mother. Two participants who had experienced some health deterioration during pregnancy noticed a quick improvement in their health within a few months of becoming a mother. However five participants noted some deterioration, or worsening of symptoms, and a long recovery period...

'It took me about two and a half years to get my lungs back to pre-pregnancy'
(Joanna)

Whilst participants did not always attribute any ill health to becoming a mother per se, as previously noted four participants attributed one reason for deterioration in their health to missing treatment, demonstrating a relationship to 'Disruption Versus Maintenance'...

'If I didn't do that minimum (treatment) then I would see myself slipping...if I didn't do any nebulisers then I would really feel it the next day and the next few days' (Adele)

Participants expressed a desire to maintain good health because of their new responsibilities, and this has been acknowledged in 'Staying Well for the Child'. Indeed, this desire to be in good health is particularly important on becoming a mother, wanting to be in the best possible health for their children...

'You realise how much more important it is that you stay fit and healthy, it becomes even more important because you know it's not just you you're looking after' (Amy)

This desire to maintain a good health status and avoid deterioration, to be well enough to take care of the child is why treatment is so important, and why participants demonstrated a commitment to their treatment as discussed in previous subcategories.

Subcategory: Impact on Mothering

Sources: 9

Participants discussed the impact of their health status on their ability to carry out mothering activities: the more poorly they felt, the harder it felt being a mother. All participants felt their health sometimes limits them to an extent in their mothering activities, such as the kind of play they can engage in, and this often involved considering alternatives...

'She loves rough and tumble play, being thrown up in the air...that sort of thing I find that harder...so Izzy and I, we'll do lots of crafty things instead' (Amy)

This subcategory relates to treatment adherence. One participant explained that seeing the negative impact her health can have on mothering reinforces the importance of adhering to treatment.

Subcategory: Impact of Mothering

Sources: 9

Participants also discussed the impact that mothering has on their physical health. In discussing the first few months of becoming a mother, all participants expressed feeling sleep deprived, which they often felt had a negative impact on their health. Participants also described feeling physically exhausted as a result of being a mother...

'Things like pushing the pushchair far, that kind of thing, that made me a bit tired...and carrying him for long periods and things like that' (Pippa)

One participant explained how the impact of mothering on her physical health in regards to exhaustion became more apparent as the child grew older...

'When they start moving about, him being into everything I found that really hard and so exhausting' (Chloe)

This subcategory is related to 'Disruption Versus Maintenance'. Five participants discussed how tiredness was a further cause of treatment disruption...

'I was just so exhausted I just couldn't be bothered' (Chloe)

Subcategory: Importance of Rest

Sources: 6

Participants highlighted the importance of resting, as did their CF teams, suggesting this is a must in order to manage the impact that mothering can have

on health status, demonstrating a relationship to the subcategory discussed above. Rest appears to be important no matter the age of the child...

'Your body does need to just get a rest, a wee bit of respite, and then after that you feel refreshed and you can carry on' (Joanna)

Subcategory: Impact on Mood

Sources: 9

Participants discussed the impact that health status has on their mood. Difficult emotions such as guilt that participants experienced (discussed below) were more intense when they felt unwell. Four participants discussed how poor or fluctuating health caused upset and frustration...

'My first winter (of being a mother) was awful, and I was straight back on IVs, which I was quite upset about...my health was then very up and down so I got a bit frustrated' (Jessica)

Four participants discussed how health status impacts on mood via the impact it can have on mothering, demonstrating a relationship to this subcategory. Some participants discussed experiencing frustration when they couldn't engage in the type of play they wanted to, in addition to experiencing feelings of guilt...

'I feel a bit more limited...my energy...so there's sort of a daily guilt...that I'm not providing as fuller life for him than I would do if I didn't have CF' (Kimberley)

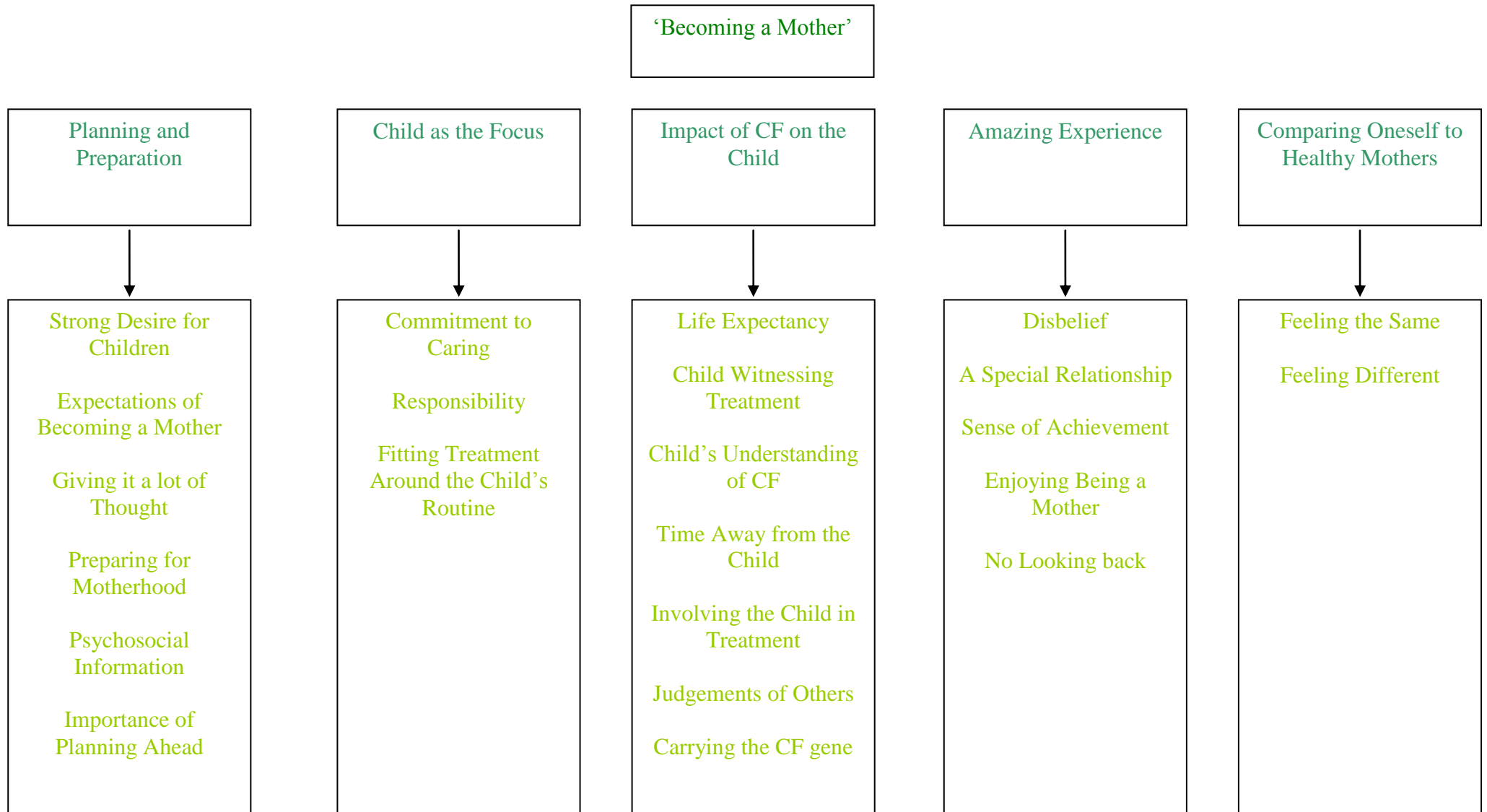
Three participants also discussed how health status impacts on mood via the impact that mothering has on health, demonstrating a relationship to this subcategory. Here Pippa reflects on feelings resulting from experiencing breathlessness pushing the pushchair...

'Those kinds of things frustrated me the most....I suppose anything that affects your health or makes you realise that you're not as healthy as you wish to be, they can be quite depressing' (Pippa)

Core Category Two: 'Becoming a Mother'

Figure 4 illustrates the conceptual and subcategories contained within the second core category, 'Becoming a Mother'.

Figure 4. Conceptual and subcategories included in 'Becoming a Mother'



Conceptual Category: Planning and Preparation

Sources: 11

This conceptual category relates to themes of planning and preparation evident throughout participants' experiences. The first five subcategories relate to the period prior to becoming a mother, and the final subcategory refers to processes on becoming one.

Subcategory: Strong Desire for Children

Sources: 11

Three participants underwent fertility treatments and one the long process of adoption, demonstrating their strong desires to have children. Indeed, all participants emphasised their long standing and strong desires to become mothers...

'I always wanted and always wished that I would have a baby' (Heidi)

Subcategory: Expectations of Becoming a Mother

Sources: 6

Whilst all participants discussed a great desire to have children, six participants discussed a lack of expectation they would ever have them due to having CF...

'I'd always wanted to be a mum, but it's something that I wasn't sure would ever happen having got cystic fibrosis, it was kind of would I be allowed to be a mum, would I be healthy enough to be a mum and did it happen...I never quite believed that it would ever happen' (Heidi)

'I thought it just wouldn't be an option and I didn't think I would be able to get pregnant anyway' (Chloe)

This subcategory also relates to 'Response of Services' as three participants said it was the messages they received from their CF teams that influenced their lack of expectation they'd ever have children...

'I always was left with this impression that it was a really unwise thing to do...so I'd always put to the back of my mind the idea of ever having a family' (Kimberley)

Subcategory: Giving the Decision a lot of Thought

Sources: 10

Participants discussed the amount of thought that had gone in to their decision to have children. Four participants had thought about children earlier than they may have done had they not had CF, due to issues associated with health and life expectancy...

'I probably started thinking about it in my early 20s...it was like a ticking time bomb, you think oh god the longer it goes the less chance I'm going to have, the less time I'm going to have with any child' (Pippa)

On getting to the point where participants had decided to have children, seven participants considered a range of options, such as having their partners genetically tested and considering IVF. Here Amy reflects on considering her options before deciding to adopt...

'My health had always been fairly stable but my lung function was I think I was aware was always relatively borderline for going through pregnancy...so we thought fairly briefly about surrogacy' (Amy)

Subcategory: Preparing for Motherhood

Sources: 8

Participants discussed the ways they prepared themselves prior to embarking on the journey to motherhood. Participants acknowledged the importance of planning for pregnancy so they could stop taking any potentially harmful medications. Participants also talked about the stages prior to this, in regards to the importance of getting as healthy as possible prior to pregnancy or the adoption process...

'Get yourself in tip-top, in best condition you can before you actually fall pregnant...you need to be very fit and healthy to be able to carry successfully'
(Joanna)

Preparing for motherhood involved liaising with CF teams and indeed establishing a good lung function and health status prior to pregnancy was often on the direct advice of the CF team. As noted in the 'Supporting the Decision' subcategory, doctors' support was often dependent upon establishing a certain health status. The following of this advice further demonstrates participants' valuing of doctors opinions.

For two participants, preparing for motherhood was not only about establishing good physical health, but also about ensuring the help of family and friends would also be available if necessary.

Two participants felt, however, that services placed too much emphasis on preparing for and getting through pregnancy, and not enough on preparations for and discussions around motherhood...

'A lot of the doctors go well yes you can get through a pregnancy and they don't begin to talk about, plan can you be a mum, can you look after a child' (Pippa)

As a result, it was hard to know what to expect, and the majority of participants said being a mother was harder than they expected it to be in regards to issues such as the lack of time they had to themselves, and the relentless care their children required, particularly in the newborn phase...

'It's probably a lot harder than I expected, time wise, having no time, and just having to constantly think what's going to be...organising things for her and organising my treatments...its double the workload' (Heidi)

These issues not being discussed by CF teams was compounded by a lack of information on the issue more generally.

Subcategory: Psychosocial Information

Sources: 9

Participants discussed how they felt that psychosocial information on motherhood and CF would have been helpful during the planning and preparation phase. Whilst discussions with CF teams involved receiving information on pregnancy and medical issues, participants noted a distinct lack of psychosocial information about motherhood, and a need for it in order to increase awareness of what being a mother with CF may be like, in increasing accurate expectations, and in helping to plan and prepare for this...

'The more research that is done the better, especially for the younger ones coming up and not knowing, not really knowing how it's going to work' (Joanna)

'There's not masses of information on people having children, so you're a bit stuck really' (Pippa)

Participants also felt this kind of experiential psychosocial information would be beneficial for CF teams to have, in order to increase their understanding and to inform discussions in the preparation stages...

'I always wanted to know at the time...a mum with CF...what does their day to day life look like and what things are different from them being a mum...it felt very impersonal I think when we talked about it, the decision to start a family with my team, I felt they couldn't offer me a lot of experience stuff which is what I wanted to hear' (Kimberley)

One participant had been given some medical information on motherhood and CF from her CF team during adolescence, which had contained information about women in America who had died during pregnancy, which she had found unhelpful. The CFMothers forum was referenced as being so helpful due to the lack of available experiential information.

Subcategory: Importance of Planning Ahead.Sources: 8

Participants discussed the importance of planning ahead and being organised on becoming a mother. This appeared to be a coping mechanism in itself, reducing anxiety about the amount they had to juggle. Participants acknowledged they have always needed to be organised due to having CF, but this is particularly important on becoming a mother...

'I think you find that you've got to be a lot more organised' (Amy)

This category relates to 'Treatment Adherence' and 'Importance of Time', as participants explained that being organised and planning their treatment was helpful in creating time to do it...

'If it's planned ahead and its organised then you've got more time, and if you've got time then you can make sure you get things done, and you make sure you fit your nebuliser in you can make sure you can fit in certain exercises for physio' (Heidi)

This planning ahead for treatment and being organised is further evidence of participants being committed to their treatment.

Conceptual Category: Child as the Focus**Sources: 11**

This conceptual category captures participants' descriptions of their children being central to way they live and organise their lives.

Subcategory: Commitment to CaringSources: 11

The commitment to caring for a child that is required and the amount of attention they need at any age was discussed throughout the interviews. This subcategory is strongly related to 'Disruption Versus Maintenance', with the attention their children required, particularly during the first few months, being a cause of treatment disruption...

'For the first two or three weeks, all I seemed to do was feed and express and it was just, I don't know, everything (treatment) went out of the window' (Ellie)

Four participants suggested the extent of their treatment disruption depended on the behaviour of the child. For example, Rachel reflected on why her treatment was disrupted with her first baby, but not with her second...

'With my second baby his temperament was different, he didn't have colic...I think the difference was the amount of attention the baby needed' (Rachel)

This subcategory also relates to 'Importance of Time', as three participants explained that the attention their children required led to treatment disruption by taking up their time.

The participants with slightly older children noted however, that as time has gone on, their children have become more independent and need less care and constant attention, giving them more time to themselves. The time point at which participants noted this varied, however it was one reason given for treatment getting easier over time, further demonstrating the relationship to 'Disruption versus Maintenance'...

'As time goes on and she needs less care, I could give myself more care' (Adele)

One way participants manage the constant attention their children require is to fit their treatment around the child's routine, doing it at times when the child is unlikely to need them. This was helpful during the first few months and continues to be so.

Subcategory: Fitting Treatment Around the Child's Routine

Sources: 11

This subcategory is related to the earlier subcategory, 'Importance of Routine'. Participants discussed the importance of re-establishing a new routine in order to

adhere to their treatment. This involved establishing a new treatment routine around their child's...

'It's about making a new one (routine) that focuses around the kids completely, and then the CF part fits into the kids' (Rachel)

Participants described how they came to fit treatment around their children's eating, napping, and bed times...

'I've tried to time them so for example if I was, say I'm doing three IVs a day, the morning one is hard...then I do another whilst she's having her afternoon nap and then one after she's gone to bed...and I'll do an evening physio and do it after she's gone to bed' (Amy)

Thus this subcategory strongly relates to the conceptual category 'Treatment Adherence'. Participants explained that their children being in a predictable sleep routine enabled treatment adherence because it created guaranteed slots of time to do treatment, demonstrating a relationship to 'Importance of Time'...

'It kind of gave me windows of opportunity to do treatments...I think one of the reasons I was able to do my treatments quite so well was because he kept having at least two hours of afternoon sleep...that is very helpful...I always had this guaranteed two hours' (Kimberley)

Participants described how their children's routines had developed over time. This was a further reason given for eventual maintenance and treatment getting easier over time for eight participants, further demonstrating a relationship to 'Disruption Versus Maintenance'...

'The first few weeks he didn't have much of a routine, that was quite hard, but as he got older he really got himself into a routine which helped me...that made it a lot easier' (Jessica)

Two participants also talked about fitting rest time around their children's routines as well as their treatments.

Subcategory: Responsibility

Sources: 8

Participants discussed the sense of responsibility they felt on becoming a mother, having someone else depending on them...

'The overwhelmingness of having a whole new person to look after, that you are responsible for keeping them alive' (Adele)

This subcategory relates to the subcategories 'Staying Well for the Child', 'Importance of Treatment', and 'Commitment to Treatment'. All participants described the reason they felt the need to stay well, and the resulting importance of and commitment to treatment, as being due to their sense of responsibility for their children...

'I absolutely to the letter do everything, I'd say that's purely as a result of having a child...it's the awareness you are now responsible for someone else, you owe it to them to keep yourself in good shape' (Kimberley)

Conceptual Category: Impact of CF on the Child

Sources: 11

This conceptual category relates to participants' thoughts on the impact that having a mother with CF may have on their children. It includes subcategories relating to the short and longer term implications of CF, in addition to the opinions of others. This potential impact has already been alluded to in 'Impact on Mothering' in the conceptual category of 'Physical Health'.

Subcategory: Life Expectancy

Sources: 9

Participants expressed a desire to be around for their children for a long time, but acknowledged this may not be the case, considering the potential impact of this...

'There is still always going to be that little shadow over your head of when will my time come...my older one is very aware...I got really bad flu and ended up in hospital for two weeks...she kind of got a little bit worried, a little bit worried and a little bit upset' (Tamsin)

Three participants expressed feeling guilty as a result of this...

'I really do feel guilty sometimes, erm and I think gosh I'm like putting my son through that, you know what's to come sort of in the future' (Chloe)

This subcategory relates to the subcategories relating to treatment. Participants acknowledged being committed to their treatment and feeling their treatment was important due to wanting to extend their life expectancy and be as well as possible for as long as possible for their children.

Subcategory: Child Witnessing Treatment

Sources: 10

Participants discussed the impact on their children of them witnessing their treatment routines. All participants said their children notice and show an interest in their treatment, which is reflected in things such as copying behaviour...

'One morning I turned round and Izzy was lying on my physio bed with a towel over her, giving herself percussion physio, just role playing with teddy, giving him his' (Amy)

Participants described wondering what their children think about their treatment, with it being more of a consideration as they grow older...

'I'm going on IVs on Monday, and when I last had IVs he was still little so he didn't notice...so it'll be interesting to see what he does, what he thinks' (Ellie)

Three participants explained their children get frustrated when they witness them doing their treatment...

'I think my treatment's become a competing thing for him. He sees me sitting down with my nebuliser and my mouthpiece and I think he wants me to talk and he wants me to play' (Kimberley)

However, participants also discussed feeling that having the child witness their treatment is helpful, feeling it minimises any potential negative impact of the treatment on their children. Some discussed how they actively chose to do their treatment in front of their children, as a way of making it 'normal'...

'We said from the outset we want to be very very open about things so I do physio in front of her...we wanted to be just this is what happens in our house and this is normal...we thought it may actually be more upsetting if I'm doing physio so Izzy's not allowed to come in, or its something secretive or hidden' (Amy)

Subcategory: Child's Understanding of CF

Sources: 10

Participants discussed their children's understanding of CF, including the need for treatment. This is something that has become more of an issue as the children have grown older, and the development of their understanding was often prompted by the children witnessing their mothers' treatment. Three participants described how their children often ask questions, such as why they need to do treatment. All participants explained how they want their children to have an understanding of their CF from a young age, so as to reduce any 'shock' later on...

'I don't want it to be a shock...I want him to know everything really, to understand it' (Chloe)

Participants described trying to explain CF to their children by explaining their symptoms and treatment, but that this was often difficult...

'He understands in terms of germs, he knows that I might have germs in my lungs and that my treatment helps to fight them...trying to explain it in a way that's not

too scary for him...but in a way that still makes him understand...it's just quite tricky' (Kimberley)

Participants talked about how they purposely let their children observe their treatment to enable them to develop an understanding, with the aim of reducing any negative impact. Here Heidi discusses her plans in relation to her daughter seeing her treatment...

'Hopefully (by watching treatment) she'll be gaining an understanding of what mummy's doing and why she's doing it, and if I'm open about it then hopefully she'll feel she can ask questions about it and say how she's feeling about it as well...if she didn't understand, she just knew I'd got cystic fibrosis, she might think well actually mummy's going to die now, and if she's seen me doing my treatment, she's seen how it all works, then she's not going to think like that' (Heidi)

Four participants also thought that their children having an understanding of their CF was also helpful for them, in enabling them to get their treatment done, demonstrating a relationship to 'Treatment Adherence'. This varied according to age however, with the children's understanding developing over time. This was a further reason given for treatment getting easier over time...

'When they get older, like my son now, he knows it's mummy's time and that's that, he'll go and play with his toys and we'll have play time after' (Jessica)

Whilst participants discussed a desire to have their children understand CF and reflected on how they have explained it to their children, this tended to focus on explaining their cough, germs, and the need for treatment, as opposed to discussing the longer term implications of CF, such as reduced life expectancy. Only one of the children (who was 14) appeared to have an understanding of this. Other participants had much younger children and this may be a reason for the lack of these discussions. However, only two participants made reference to plans to have these discussions in the future.

Subcategory: Time Away from the Child

Sources: 8

Participants discussed the impact of having to have time away from their children, due to being ill or needing to do treatment. Four participants expressed feeling guilty for the negative impact this may have on their children...

'I was in (hospital) for two weeks...I found that tremendously hard...you just feel, you feel really guilty that you're not there' (Amy)

This subcategory relates to 'Disruption Versus Maintenance' as not wanting to have time away from their children was a further cause of treatment disruption for two participants in the first few months.

These feelings of discomfort at having time away from their children varied across the years, and was different for different participants. Some felt more uncomfortable leaving a crying baby, however for others, the guilt intensified as their child grew older...

'He's much more communicative, I think it feels that bit harder when you hear someone saying "mummy stop doing that come and play with me", when you hear a voice saying those words it's much more emotive' (Kimberley)

The above quote suggests that for some women, whilst the logistics of treatment get easier as the child grows older such as having more time (as Kimberley acknowledged), it may be harder emotionally, due to the time away from the child it requires.

Whilst participants explained they did not like having time away from their children, they reasoned that it was necessary in order to stay well, demonstrating a further relationship to 'Treatment Adherence'. This subcategory also relates to the conceptual category of 'Physical Health'. One reason that poor physical health resulted in guilt was because it meant participants had to have time away from their children. Furthermore, not wanting to have time away from their children was a further reason to stay well and adhere to treatment.

This subcategory also relates to ‘Child’s Understanding of CF’. One of the reasons three participants wanted their children to have an understanding of their treatment was so that they understood why they needed to have time away from them...

‘It helps me to feel that I’ve explained to him that it’s not just that I don’t want to talk to him for half an hour or that I can’t be bothered to do something more interesting with him, and I think he understands that...he knows he’s not being neglected’ (Kimberley)

Subcategory: Involving the Child in Treatment

Sources: 8

Participants described ways they found to include their children in treatment, and they were sometimes able to do this when they were babies, such as breast feeding whilst doing nebulisers. However participants mainly discussed how they have been able to do this as their children have grown older. Not only did participants acknowledge this was helpful in adhering to treatment, but they also felt that by involving their children this minimised any negative impact resulting from having to have time away from them...

‘He even helps me get some of it ready...I make it in to a game, rather than make it into something morbid...it’s fun, as long as they’re with you and they’re doing something and they’re getting attention and that one to one time, they’re happy’ (Rachel)

Subcategory: Judgements of Others

Sources: 7

Participants discussed their awareness of the judgements of others in regards to the potential impact that having a mother with CF may have on a child. Some negative judgments of CF teams were implied in their lack of supporting the decision. However, two participants were explicitly exposed to negative views from other health care professionals. Here Rachel discusses an interaction with a health care professional who was not part of her CF team...

'She turned to me and said, no I think it's disgraceful that they're (women with CF) allowed kids, she didn't know I had CF...at this point I was 10 weeks pregnant and I just started crying' (Rachel)

Other participants discussed adoption services, and how they feel their judgments about CF are unfair...

'You can't rule everyone (with CF) out just because of two words...the door's closed before they even have a medical on you, and I don't think that's very fair' (Joanna)

Subcategory: Carrying the CF Gene

Sources: 2

Two participants acknowledged their children being a carrier of CF, and the implications this may have on their life...

'They're obviously going to be a carrier, and it would be good to know what gene they're carrying so it will save them having to go through genetic counselling when they're older' (Tamsin)

Conceptual Category: Amazing Experience

Sources: 11

All 11 participants contributed to this conceptual category. It includes subcategories relating to the positive feelings and experiences that being a mother has provided.

Subcategory: Disbelief

Sources: 6

Participants expressed disbelief at having actually become a mother...

'You just look at it and you can't, can't believe how lucky you are' (Amy)

Participants acknowledged this was due to messages they had received from doctors, and their own lack of expectation they would ever have children...

'Every day I think gosh he's a miracle, I can't believe I even you know managed to carry him...I didn't expect that I could, so I'm always grateful' (Chloe)

Subcategory: A Special Relationship

Sources: 4

Participants described the unique mother-child relationship, and the unconditional love from their children that they have enjoyed as part of being a mother...

'It's just the love that you get from him, and it's just the way he looks at me, he doesn't look at anybody else like he looks at me' (Ellie)

Subcategory: Sense of Achievement

Sources: 5

Participants described the sense of achievement they felt at having being able to have children given their CF...

'It was the morning after she was born and I remember sitting and looking at the cot and sobbing, and it was just oh my goodness she's here and she is mine, and wow I've made her, and I've done it, and she's perfectly healthy, and she's a little piece of me...despite everything and everything I go through, I've made another little person' (Heidi)

Subcategory: Enjoying Being a Mother

Sources: 9

Participants discussed how much they have enjoyed being a mother, and how it has been even more wonderful than they imagined it would be. Three participants discussed how the joy their children bring is a further reason they adhere to their treatment, demonstrating a relationship to 'Treatment Adherence'...

'Its just amazing, you know they bring so much joy to your life and it gives me a reason now to try harder, and you know I want to be around longer' (Chloe)

Subcategory: No Looking BackSources: 5

Participants discussed how positive the experience of becoming a mother has been for them, how they have no regrets, and cannot imagine life any other way...

'I live for my two girls, it's just, I can't imagine life without them and I can't imagine them having a life without me' (Tamsin)

Conceptual Category: Comparing Oneself to Healthy Mothers**Sources: 11**

This conceptual category captures the comparisons participants made between themselves and mothers without CF or another health condition.

Subcategory: Feeling DifferentSources: 10

Participants discussed ways in which they felt different to other mothers. This included issues relating to their health, time pressures, tiredness, and life expectancy. Whilst participants acknowledged motherhood is difficult for anyone, participants felt it is harder for those with CF...

'You're tired as a normal mum but with CF you're an extra bit tired, it's time consuming being a mum but then having CF as a mum, there's even more you have to do' (Joanna)

Some participants said they avoided thinking about the differences between themselves and other mothers because this caused annoyance and frustration, and indeed some participants did express frustration at this difference...

'I've had many a conversation with normal mums who say they're tired, and I think, yes so am I, but I also have to do X, Y, and Z treatment!' (Tamsin)

Three participants suggested healthy mothers may take things for granted whereas they appreciate every moment, feeling this was a positive difference.

This subcategory relates to the conceptual category 'Physical Health', as some participants felt guilty because of the impact their health has on mothering in comparison to other mothers, as noted by Kimberley in 'Impact on Mood'.

Two participants discussed wanting to be the same as other mothers and in many ways participants feel they are.

Subcategory: Feeling the Same

Sources: 11

Participants discussed how some of the changes and issues they have experienced as part of becoming a mother are similar to that of any other parent. For example, three participants likened the changes in their treatment to changes in lifestyle for any parent...

'My treatments...that was my day to day living and I have to change it, modify it, like any person would I imagine who has children' (Adele)

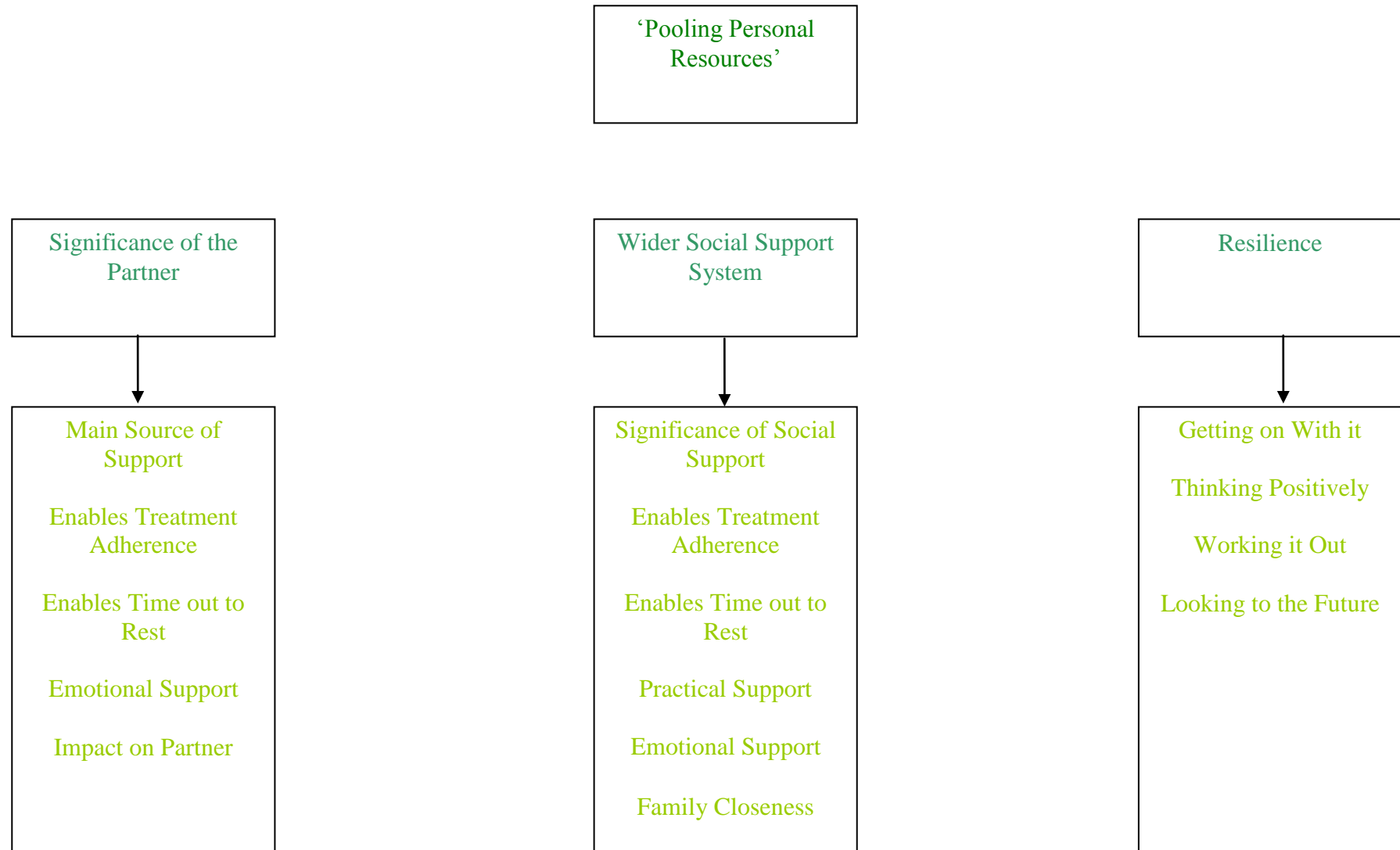
For some participants, comparing themselves in these ways appeared to be reassuring. Here Chloe, who struggled because she was tired all the time, was reassured by her doctor...

'She just explained that all mums feel like that, feel tired...she made me feel really good' (Chloe)

Core Category Three: Pooling Personal Resources

Figure 5 details the conceptual and subcategories contained within the third core category, 'Pooling Personal Resources'.

Figure 5. Conceptual and subcategories included in 'Pooling Personal Resources'



Conceptual Category: Significance of the Partner

Sources: 11

This conceptual category details how and why the Partner has played a significant role in participants' adjustment to motherhood, in addition to the impact it's had on him.

Subcategory: Main Source of Support

Sources: 10

Participants discussed how their partner has been the most significant source of support on becoming a mother. Here Jessica reflects on the first few weeks...

'Anything I needed, he was there, so he was literally my rock through the whole thing, that was amazing to have that...I didn't feel too overwhelmed, I think because my husband was the first point of call' (Jessica)

The support of the partner appears to continue to be important in coping with motherhood, no matter the age of the child.

This subcategory relates to 'Impact on Mothering', as it appears having the partner's support helps to manage this for some participants...

'He can do things like lift, when I'm not well, he can lift the kids in and out of the bath, he can carry the pram in and out of the car...if I was single and on my own I would really struggle' (Rachel)

Subcategory: Enables Treatment Adherence

Sources: 11

Participants discussed how having their partners care for their children enabled them to do their treatment. This appeared particularly important during the newborn phase...

'For a good few months...I had to rely on my other half to take her off me, just to have half an hour so I could just sit and do some treatments, or I could sit and do some physio' (Adele)

A number of participants' partners had flexible working hours, and some attributed this as one of the reasons why they were able to do any of their treatment at all in the first few months. Indeed, one of the participants who was able to maintain her treatment throughout attributed this to the flexibility of her husband's working hours.

It appears that the support of the partner continues to be important as the child grows older, particularly in the morning when treatment appears to be the most difficult...

'In the morning...Mark will often take Izzy out to play in the garden while I do a physio' (Amy)

This subcategory relates to 'Importance of Time'. Participants acknowledged having their partner care for their children, particularly during the newborn phase, allowed them time to themselves to do their treatment...

'I knew he was being taken care of, looked after, and I could go and have that time, do my medicine' (Jessica)

This subcategory also relates to 'Time Away from the Child'. Three participants explained having their partner care for their children manages the guilt they feel for having time away from them to do treatment...

'You feel like you're being cruel to the kids, you're leaving them all the time to go and do things for yourself, so at least if you're palming them off to their dad you don't feel as bad' (Rachel)

Subcategory: Enables Time out to Rest

Sources: 4

Participants also discussed how having the support of their partners in caring for their children also enables them time out to rest, which continues to be important no matter the age of the child...

'Days when I'm just a bit more tired than other days he'll make the suggestion of, I'll just take them out for a while...that's kind of nice because that could be a couple of hours just to have a sleep' (Tamsin)

This appears particularly important when participants are unwell, and in this way having the partner's support helps to manage the impact that mothering can have on health, demonstrating a relationship to this subcategory.

Subcategory: Emotional Support

Sources: 6

Participants also discussed the extent of emotional support received from their partners. Whilst one participant felt she did not get this from her husband, five did. Here Adele discusses the first week when she suddenly became aware of her own mortality...

'My husband Paul was really good, you know he was good at reassuring me and a brilliant source of, I suppose, support' (Adele)

Subcategory: Impact on the Partner

Sources: 10

Participants also discussed the impact that having children had on their partner, the child's father. They acknowledged that his life had also changed, and that he experienced a number of the same issues as them...

'He was shattered' (Chloe)

'He had to suddenly switch from one type of life to another' (Pippa)

Some participants said their partners also needed support, particularly when they are poorly or in hospital. It appears the wider support system becomes particularly significant here...

'I had to go in to hospital for treatments, then obviously you think, right OK, I'm going to need some help here, hubby can't manage it all on his own' (Tamsin)

Four participants discussed how when they are ill, their husbands take on more responsibility, which often leads to feelings of guilt...

'If I've had off days or that, my husband has got a lot, a lot then falls on him, and I know he'll be worrying about me...I think you feel very guilty about that' (Amy)

This subcategory also relates to 'Treatment Adherence', as some participants also said that a reason to do treatment was to be around for their partner for as long as possible, minimising the impact on him, in addition to their children.

Conceptual Category: Wider Support System

Sources: 11

This conceptual category relates to the wider social support system that participants drew upon on becoming a mother. It contains subcategories detailing the importance of and consequences of receiving social support. Two participants discussed the use of nurseries, however discussions mainly focused on family and friends.

Subcategory: Significance of Social Support

Sources: 11

Participants discussed the extent to which they had used and found social support helpful in coping with motherhood. Eight participants reported that the support of family and friends has been important...

'I've got a lot of support (from wider family) and that's a major major thing to have that support, otherwise I'd not have had any chance of doing it' (Chloe)

Three participants discussed how they had not utilised social support. The use, and significance of, social support may be influenced by its availability, or participants comfort in asking for it. 10 participants reported that help from family

was available to them if they wanted it, however over half reported they were reluctant to ask for it.

A clear relationship emerged with the subcategory 'Health Status', with participants reporting that the extent of their use of social support is influenced by their health status, utilising this more when they are ill...

'If I'm not well I have some friends that I met when I had Freya that step in and take her off my hands for a few hours, or she goes to my in-laws...I've got lots of sort of back up places for her to go' (Adele)

By utilising this social support, three participants described how the impact of poor health on mothering and the feelings associated with this are managed, demonstrating a relationship to this subcategory...

'When I've been at home and not felt very well it's chance for mum and dad, they take Izzy out...I know that she's having a lovely time...you're not worrying then that you not feeling very well is impacting more than it has to on her' (Amy)

Subcategory: Enables Treatment Adherence

Sources: 5

Whilst participants said their partners were their main source of support, some participants also utilised the help of family and friends in order to create time to do their treatment. It appears that this support was generally utilised when their partner was not around, for example when he was at work. It appears that this support was particularly helpful for some participants in the beginning...

'In the beginning they (family) would come over and help...they came over and would have Ava so that I could do my treatment' (Heidi)

This subcategory relates to 'Importance of Time', as two participants acknowledged that having family care for their children means they get time to themselves to do their treatment.

For some participants, having the family care for their children also helps to manage the difficult feelings often experienced as a result of having to have time away from their children, demonstrating a relationship to this subcategory...

'Although you're missing being at home and you do still feel worried and anxious and upset that you're not there, you know that you don't need, I knew that I didn't need to worry about Izzy' (Amy)

Whilst it appears that having wider social support continues to be helpful in enabling treatment adherence to some extent, it appears less significant over time, as a result of other factors occurring over time that make treatment easier, such as the child's increasing understanding and independence, their developing routine, and the ability to involve them in treatment.

Subcategory: Enables Time Out to Rest

Sources: 7

Participants discussed a further consequence of utilising wider social support, that of time out to rest...

'They (friends) were also really good about someone coming and sitting with him if I wanted to go to bed for an hour' (Kimberley)

This continues to be important no matter the age of the child, and is recognised as important in managing the impact that mothering has on physical health, demonstrating a relationship to this subcategory...

'I need more support...so that I don't exhaust myself looking after her and trying to fit everything in' (Heidi)

Subcategory: Practical Support

Sources: 3

Participants discussed how family and friends were also helpful in providing practical support. This included things such as cleaning and bringing food...

'My mum and dad were great when I first had Henry, they'd come round and they'd bring me meals and things so I wasn't having to worry too much about food' (Ellie)

This support was significant given that some participants reported difficulties with eating in the first few weeks.

Subcategory: Emotional Support

Sources: 3

Family and friends also provided emotional support for three participants. Here Ellie talks about a time when she was feeling anxious about everything she had to fit in on becoming a mother...

'The biggest thing they (family) said to me was look, just relax, I think I was getting myself more and more worked up, and once I was told look everything's fine, Henry's happy, I think that's what did it' (Ellie)

One participant suggested however that she would not access emotional support from her family, and would prefer to access it from her partner or from health professionals.

Subcategory: Family Closeness

Sources: 4

Participants discussed how they have become closer to their family as a result of becoming a mother. Whilst two participants felt this is part of motherhood more generally, two participants felt this is important due to issues associated with life expectancy...

'Somewhere in your mind you always know that you have a condition that could limit the expectancy of your life, and you want your child to have a network around them that is as inclusive and as loving of them as possible' (Kimberley)

Conceptual Category: Resilience

Sources: 11

As can be seen from the previous categories, participants described how being a mother with CF can be hard. However, throughout the interviews, there was also evidence of participants drawing on their own resilience, and in turn demonstrating resilience.

Subcategory: Getting on With it

Sources: 10

Participants described often attempting to adopt an attitude of not letting things beat them and ‘getting on with it’. Here, Pippa reflects on the first few months in regards to the relentless commitment to caring that was required as a result of her baby’s difficult temperament...

‘I just thought oh I can’t wait for this stage to end...you just get on with it...you get out and you just get on with it’ (Pippa)

Subcategory: Thinking Positively

Sources: 9

Participants discussed how they tried to draw on their own personal strength of thinking positively in times of difficulty. Here Adele reflects on the first week when she became aware of her own life expectancy and questioned her decision to have Freya as a result...

‘I just managed them (difficult feelings) by thinking, the only way is up...but that’s how I am in general, I’m quite sort of forward thinking and not one to dwell’ (Adele)

Subcategory: Working it Out

Sources: 7

Participants described how things have become easier over time, and how they have moved through a process of working out a way to manage being a mother with CF. Three participants talked about how being a mother has involved learning as you go along, and learning from experience...

'At the beginning with a newborn, you're new to it...you're learning at the same time...and now he's getting older...it's just a constant learning curve' (Jessica)

Subcategory: Looking to the Future

Sources: 6

Participants discussed their hopes for the future, and four were planning to have more children. Participants also discussed their hopes for the future in regards to their health and life expectancy, expressing desires to live as long as possible...

'I used to think I've only got to see them (my children) till they're 18 and now I think I want to help them when they're adults...and now I think oh no I want to be there because I want to be there to be a grandma' (Rachel)

These desires were further motivations for adhering to treatment, demonstrating a relationship with this category.

Two participants discussed how they tried not to think about the long term future for fears of what it may hold, and instead focus on the foreseeable future...

'I try not to think about you know the 'what ifs', quite probable things that will happen in the future and I sort of focus on little things. I want to be there to see her go to school and when I get there I'll think about when she goes to secondary school' (Adele)

Central Process: 'Balancing Mother's and Child's Needs'

Sources: 11

This category is slightly different to the other categories in that it describes a process that is related to, and central, to all other core categories, with specific relationships to certain subcategories. It is presented here in an attempt to draw out the process common to the core categories which have been described above,

and place them within the context of one overall process – the attempts by the participants to balance their own needs with the needs of their children.

As can be seen from the theoretical formulation in Figure 2, the process of balancing these needs is central in that it involves balancing the factors associated with ‘Living with CF’ such as treatment, with factors associated with ‘Becoming a Mother’, such as caring for a child. One way participants discussed doing this was by ‘Pooling Personal Resources’ such as utilising social support, which enabled the child to receive care and attention, but also allowed participants time to rest and adhere to their treatment in order to maintain their health, ultimately to be well enough to look after the child.

As described in previous subcategories, participants placed importance on, and demonstrated a commitment to, their treatment. However, they also acknowledged a commitment to caring for their children. Participants frequently described this as a balancing act, having two people to care for instead of one. It appeared that finding the right balance between meeting both their needs was a difficult task, particularly in the beginning...

‘Trying to balance a new baby and my health...it’s quite hard’ (Jessica)

This was even harder at times when the child needed most attention, as highlighted in the subcategory ‘Commitment to Caring’...

‘That was when it became quite hard I think, getting the balance, because he was sleeping less in the day, and he was doing more when he was awake’ (Kimberley)

It appeared that attempting to balance both their needs frequently led to physical exhaustion, further illustrating the impact that mothering can have on health. Not being able to find the right balance due to this (and/or other factors) often resulted in treatment disruption, demonstrating a relationship to ‘Disruption Versus Maintenance’...

‘I just couldn’t manage it, I couldn’t juggle it, it was just non existent, I could only do one or the other, I couldn’t do both...I had a go but basically every time I tried

I was just exhausting myself...I just accepted that something had to give, and I just put my child's needs before mine' (Rachel)

Participants acknowledged the importance of finding the right balance between looking after their children and themselves. Here Jessica gives her advice to future mothers with CF...

'Their natural instinct is going to be baby first...but as well, they'll realise very quickly that they need to also put themselves up with their baby as well' (Jessica)

This often involved putting themselves first, which often led to an 'internal conflict' but ultimately this was for the child's benefit...

'You have to look at the ramifications of everything you do, and if it means you have to put yourself first then so be it' (Pippa)

'You almost have to be a little bit selfish and say to yourself that, that's maybe the attitude I've taken, that I'm no good to Izzy if I'm poorly, and sometimes that will mean that, physio's a perfect example I think, she might not like it but I think you've just got to do it' (Amy)

In addition to the use of social support, participants discussed other strategies for being able to balance both their needs. This involved ensuring their children's core needs were met first, so that they were then comfortable about putting themselves first for a short while whilst they did treatment. It also appeared that establishing a new routine around their children's was also a way of ensuring both their needs were met, demonstrating a relationship to this subcategory...

'You get your child in a routine and then you fit your treatment around the child, so in a way you're putting your CF second, but you're not really' (Joanna)

Participants also acknowledged that including their children in treatment was also a way of ensuring that both their needs could be met, demonstrating a relationship

to the subcategory 'Involving the Child in Treatment'. Here Heidi acknowledges why adapting her physio to include her baby has been helpful...

'You can still be involved with your daughter and you can still have her and do what you need to do for her, but actually you can do things for you as well' (Heidi)

Some participants reported that the ability to balance both their needs came with time, due to factors previously discussed, and described feeling much happier once they felt they had achieved this balance...

'Round about 6 months I felt, I felt happy that I was getting everything done that I needed to...I was like that's good, I'm taking my pills and my nebuliser and my IVs, I'm covering all bases and I'm still taking the best care of my child as well...I'm taking care of myself and my baby's absolutely fine as well' (Jessica)

Summary

The psychosocial impact of having children on women with CF is multifaceted. On becoming a mother, women with CF need to develop strategies for balancing their own needs for treatment and rest, with their children's needs for care and attention. Participants described engaging in problem-focused coping such as altering their treatment routine, and emotion focused coping such as thinking positively. However, whilst things appear difficult at first, there is a general theme of many difficulties getting easier with time, such as a greater opportunity for free time to do treatment. This appears largely due to factors associated with the child's development, such as their increasing independence and developing routine. Other issues do not appear to get easier over time, however, such as feelings of guilt associated with reduced life expectancy.

The CF team have a major role to play in the process of becoming a mother, and participants felt strongly about the need for adapted care on becoming a mother. They also highlighted the importance of having the support of their CF team, and the importance of CF teams having an understanding of what life is like for mothers with CF.

DISCUSSION

Overview

I will now summarise the results and place them within the context of the existing literature. I will then go on to provide a critique, and discuss implications for clinical practice and future research.

Summary and Synthesis

Psychological, Emotional, and Social Impact

Some participants discussed the altered family dynamics as a result of becoming a mother, such as becoming closer to their family. For some this was simply part of having a baby, whereas for others it was a conscious effort to manage the awareness of their limited life expectancy. Participants often felt guilty due to the impact becoming parents had had on their partners, due to the large amounts of responsibility he often took on when they were feeling unwell.

Participants discussed many positive feelings. These included disbelief due to their lack of expectation they would ever have children, despite their strong desires to do so. They described their special relationships with their children, feelings of achievement, the enjoyment their children bring, expressing no regrets in regards to their decisions. These positive mothering experiences have been discussed by healthy mothers (e.g. Barclay et al., 1997, Darvill et al., 2010), and those with chronic illness (Sanders, 2008).

Participants discussed feelings of responsibility on becoming a mother, and fatigue was associated with the constant demands of child rearing. This has been described in studies with healthy (e.g. Nelson, 2003, Nystrom and Ohrling, 2004) and chronically ill mothers (e.g. Sparud-Lundin and Berg, 2011, Pakenham et al., 2012). Participants here discussed a lack of time to themselves, given the attention required by their children. This has been described by healthy mothers (e.g. McVeigh, 1997, Nystrom and Ohrling, 2004) and those with chronic conditions (Ingram and Hutchinson, 2000, Pakenham et al., 2012).

Participants often described feeling guilty and anxious due to the impact their health has on mothering, such as limiting their energy. These feelings were described as being particularly intense when they felt unwell. These feelings have

been found in research with mothers with other chronic illnesses (e.g. van Mens-Verhulst et al., 2004, Nelms, 2005), and are in line with predictions by Gotz and Gotz (2001) and Lemke (1992). Here, poor health also led to upset and frustration, as did observing the impact that mothering activities had on their health, as described by mothers with other chronic illnesses (e.g. Ingram and Hutchinson, 2000, Sparud-Lundin and Berg, 2011).

Participants reflected on the impact that having a mother with CF may have on their children. They often felt guilty due to their shortened life expectancy, as discussed by mothers with other chronic illnesses (e.g. Ingram and Hutchinson, 2000, Vallido et al., 2010). This finding is in line with suggestions by Edenborough et al. (2008) and Duncan-Skingle and Pankhurst (2001), that mothers with CF may experience difficult feelings around this issue. These findings are in contrast to those found by Frankl and Hjelte (2004), who found that parents with CF expressed no concerns that their condition had any impact on their children.

In this study, some participants also reflected on the potential impact of their children witnessing their treatment, with an awareness of their children's frustration at not having their mothers' full attention at these times. However, overall, participants felt it was helpful for children to witness their treatment, and to have a good understanding of their CF, in order to minimise any negative impact, such as 'shock' later on, and to 'normalise' their treatment. This is notably different to reports by some chronically ill mothers, who have often reported trying to 'hide' their illness and treatment, in order to protect their children (e.g. Wilson, 2007, Vallido et al., 2010). Other mothers with chronic illnesses have described feeling disclosure would be positive, in helping to prepare their children for their death (e.g. Ingram and Hutchinson, 1999, 2000). Participants in this study also appeared to view disclosure positively. They did not express fears around 'burdening the child' or causing 'emotional devastation' by disclosing their CF, as described in other research (e.g. Nelms, 2005). Neither did they appear to experience an 'emotional burden' around disclosure of their CF as suggested by a number of authors in the field (Duncan-Skingle and Pankhurst, 2001, Edenborough et al., 2008). However, some reported finding it difficult to explain their CF in 'child friendly' terms. It appeared having their children observe their treatment was a helpful way of explaining and developing their

children's understanding. It must be noted however, that whilst some participants said they wanted their child to 'know everything', participants appeared to focus on explaining the 'short term' impact of CF, such as the presence of their cough and the need for treatment, as opposed to the longer term implications of CF. This may be due to an avoidance of the anxiety this would cause, or due to the young ages of their children. Alternatively, given it was mainly the studies with mothers with HIV where discussions around disclosure were dominant, the different findings may be due to CF being different to HIV in regards to the stigma attached.

Participants discussed the time away from their children they often needed to have, which often led to guilt. This has been discussed by other chronically ill mothers (Vallido et al., 2010, Murphy et al., 2011). Some also acknowledged their children's genetic carrier status.

A number of different experiences were described in this study in comparison to mothers with other chronic illnesses, in addition to that around disclosure. Participants did not express concerns they couldn't 'protect' their children, as found by van Mens-Verhulst et al. (2004) and Sparud-Lundin and Berg (2011). This may be due to those mothers having asthma and diabetes, illnesses prone to 'acute attacks' of symptoms. Neither did participants acknowledge fears their children would experience stigma, as discussed by mothers in the study by Ingram and Hutchinson (2000). This may be due to the specific stigma associated with HIV as acknowledged earlier. However, participants did acknowledge the judgements of others regarding their fitness as mothers.

A further difference was that, whilst participants acknowledged their shortened life expectancy, they did not express concerns about their children's care after they had passed, as discussed by some chronically ill mothers (e.g. Vallido et al., 2010, Murphy et al., 2011). This may be due to participants' available support systems.

Furthermore, neither did participants express feeling they did not meet the societal expectation of the 'ideal' mother, or appear to put pressure on themselves to achieve it, as discussed by other chronically ill mothers (Malacrida, 2009, Payne and McPherson, 2010). In line with findings by Frankl and Hjelte (2004), they did not appear to feel CF prevented them from being good parents.

Whilst in many ways participants described feeling similar to ‘healthy’ mothers, they also described a number of different experiences. They generally described feeling that it is harder being a mother with CF. This experience of feeling ‘different’ to healthy mothers is in contrast to findings by Frankl and Hjelte (2004), who found parents with CF felt no different. Participants in this study described ‘not taking anything for granted’ as being a major positive difference.

Here, participants did not discuss feeling alone or isolated, in contrast to many healthy mothers (e.g. Nystrom and Ohrling, 2004, Wilkins, 2006). This may be due to the majority of participants here describing consistently supportive husbands, often described as being absent by healthy mothers (e.g. Barlow and Cairns, 1997, Darvill et al., 2010). This may be due to the supportive role, and significant contribution to coping, that partners of those with CF often adopt more generally (Delelis, Christophe, Leroy, Vanneste, and Wallaert, 2008). Indeed, participants in the study by Darvill et al. (2010) reported that a lack of support from their husbands contributed to feelings of isolation. The majority of participants also described access to family support, which may also contribute to reduced feelings of isolation. Alternatively, it may be that participants do experience isolation, but are less distressed by it, or that they have previously adjusted to feeling isolated. Neither were changes to their marital relationships dominant during discussions as they have been with healthy mothers (e.g. Barclay et al., 1997, Nelson, 2003). This again may be due to the supportive role often adopted by the partner of an adult with CF more generally.

In contrast to healthy mothers in a number of studies (e.g. Barclay et al., 1997, Wilkins, 2006), there was limited evidence here of participants criticising themselves or feeling incompetent as mothers. This may suggest the participants in this study are ‘atypical’, in regards to their levels of confidence in themselves as mothers. The absence of a lack of confidence may be due to the support the mothers in this study reported, levels of which have been found to be associated with levels of confidence (Cutrona and Troutman, 1986).

Whilst participants acknowledged their lives had changed and discussed limited time available for themselves, their stories didn’t appear to contain themes of ‘loss’ or grieving for their former lives and freedom, as discussed by some healthy mothers (Barclay et al., 1997, Nystrom and Ohrling, 2004). It may be that

participants did experience loss and grief, but were less distressed by this, due to fulfilling an important life goal of having children. Whilst participants discussed a lack of time to themselves, they focused on the impact this had on their treatment, as opposed to their social life. Neither did they discuss feeling they had lost control of their lives or feeling highly stressed as discussed by some healthy mothers (e.g. Nystrom and Ohrling, 2004, Darvill et al., 2010). Again, as a result, the potentially resilient nature of the participants in this study is indicated.

Finally, neither did participants discuss a loss of personal identity or altered self concept as discussed by some healthy mothers (e.g. Barlow and Cairns, 1997, Nelson, 2003). However, participants did describe being more adherent to treatment, due to the significance they placed on the mothering role and their new responsibilities.

Self Care and Treatment Adherence

On initially becoming a mother, participants said it was difficult to adhere to treatment, supporting concerns discussed by participants in the pregnancy decision making study by Simcox et al. (2009). Whilst a minority of participants experienced little disruption, the majority did, with some or all of their treatment being neglected. This supports predictions by a number of authors in the field (e.g. Edenborough et al., 2008, McArdle, 2011). The missing of treatment often led to feelings of upset, due to many putting pressure on themselves to adhere. Reasons given for treatment disruption included fatigue, a broken routine, and a lack of time due to the amount of attention demanded by the baby. Treatment disruption due to putting their children's needs above their own has been described by other chronically ill mothers (e.g. Payne and McPherson, 2010, Sparud-Lundin and Berg, 2011). The amount of attention their children required was also found to influence adherence, with 'good' babies allowing increased amounts. Healthy mothers have also described the impact the infant's temperament has on the experience (Barclay et al., 1997, Wilkins, 2006), and the break in routine on becoming a mother (Oakley, 1986).

Some participants discussed a consistent commitment to their treatment, attempting to do as much as they could under the circumstances. Treatment often took place when their children were sleeping, or involved the utilisation of social support. For the majority of participants, their full treatment regime was not

reintroduced until two to three months post-partum. Participants discussed a number of reasons for their eventual treatment maintenance. These included their children's developing routines, increasing amounts of time to themselves, and their children's increasing independence and understanding. Healthy mothers have also reported being a mother feels easier with time as their child becomes less dependent (e.g. Wilkins, 2006, Darvill et al., 2010).

Overall, participants described increased adherence since having children. Participants sometimes felt guilty for putting their own needs above their children's, as described by mothers with diabetes (Sparud-Lundin and Berg, 2011), and healthy mothers (Currie, 2009). However, they consistently acknowledged the importance of attending to their own needs, in order to maintain their health for their children, due to the sense of responsibility they felt. They explained treatment adherence was particularly important to them on becoming a mother. Staying well was described as being important in the short term so they could fulfil the mothering role, and in the long term to be around for their children as long as possible. Increased adherence for these reasons have been discussed by mothers with other chronic conditions (e.g. Ingram and Hutchinson, 2000, Sparud-Lundin and Berg, 2011).

Finding the balance between attending to their own and their children's needs was described as being difficult, as acknowledged by mothers with other chronic conditions (Sparud-Lundin and Berg, 2011, Pakenham et al., 2012). This finding is in line with the suggestion by Tuchman and Gisone (2010) that mothers with CF may feel overwhelmed in attempting to achieve this balance. However, participants described consistently striving to achieve this, also described by mothers with diabetes (Rasmussen et al., 2007). Again, this was ultimately described as being for the child's benefit. This mirrors findings with healthy mothers, who have also discussed the importance of balancing their own and their children's needs for the maintenance of their well being, and the ability to care for their children (Currie, 2009, Barlow and Cairns, 1997).

The constant enjoyment their children bring to their lives was also discussed as a consistent motivator to maintain their health and adhere to treatment. This mirrors findings with mothers with other chronic illnesses (e.g. van Mens-Verhulst et al., 2004, Wilson, 2007, Sanders, 2008). Indeed, Edenborough et al. (2008) hypothesised that treatment adherence may be positively affected on

becoming a mother, with the child acting as a powerful motivator to stay well. Becoming aware of one's own mortality and the importance of looking after oneself on becoming a mother has also been discussed by healthy mothers (Nelson, 2003)

Some differences were found in this study as compared to mothers with other chronic conditions, however, in regards to self care and treatment adherence. Participants did not discuss pushing themselves beyond their limits as discussed by some chronically ill mothers (Malacrida, 2009, Murphy et al., 2011). Indeed, it was reported by participants that they purposefully replaced physical activities with slower paced ones. This lack of pushing themselves may be due to the importance participants placed on maintaining their health, and a lack of pressure they placed on themselves to be the 'ideal' mother. Furthermore, participants described close support systems, meaning they perhaps did not *need* to push themselves beyond their limits.

Many of the factors influencing adherence to treatment in this study have been well documented in the literature. Indeed, factors influencing adherence have been found to include time (Abbott and Gee, 1998, Llorente et al., 2008), energy levels (Abbott and Gee, 1998) routine (George, Rand-Giovannett, Eakin, Borrelli, and Zettler et al., 2010), and perceived importance of treatment (Llorente et al., 2008). The results also support studies demonstrating higher levels of adherence to oral medication than to physiotherapy (e.g. Llorente et al., 2008).

Coping and Adjustment

Participants had thought extensively about the best way to have a baby to minimise as much as possible any negative impact on themselves or their children, as also discussed by mothers with HIV (Sanders, 2008). They had prepared themselves as much as possible so that they could best cope with motherhood, by establishing good health and support systems prior to pregnancy or the adoption process. Studies with healthy mothers have also found themes of attempting to prepare for motherhood (Barlow and Cairns, 1997, Wilkins, 2006). In discussing the importance of information and preparation, participants referenced the usefulness of the CFMothers forum, similarly to healthy mothers who have discussed actively seeking out other mothers for informational support (e.g. Barclay et al., 1997, Darvill et al., 2010).

The use of social support was discussed as being extremely important here in coping with motherhood. This mirrors the importance of support for those living with CF more generally (Delelis et al., 2008). Here, the partner was described as the most significant source of support, mirroring studies with mothers with other chronic conditions (e.g. Sparud-Lundin and Berg, 2011, Pakenham et al., 2012). The importance of having the partner's support for both child care and emotional support has also been discussed by healthy mothers (e.g. Nystrom and Ohrling, 2004, Currie, 2009). Here, the partner's support was important in enabling time out to rest, thus helping to manage the impact that mothering can have on their health, and enabling treatment adherence. The important role of the husband in preventing health deterioration has been suggested by Edenborough et al. (2008) and Tuchman and Gisone (2010). Partners also offered emotional support, and helped to minimise the impact of health on mothering by doing things participants found harder, such as carrying and lifting their children. The importance of the partner's support for child care and engaging in parenting activities they found more difficult has been discussed by other chronically ill mothers (e.g. Payne and McPherson, 2010, Sparud-Lundin and Berg, 2011). In this study, support from the partner was also discussed as being important for child care as it reduced the guilt they felt at having to have time away from their children.

Participants discussed the large amount of responsibility their partners often had, which often led to feelings of guilt. This was discussed by mothers in the studies by Sparud-Lundin and Berg (2011) and Pakenham et al. (2012). However, in contrast to the study by Rasmussen et al. (2007), participants did not appear to find their reliance on their partners frustrating. This may be due to their acknowledgment of the importance of their partner's support for their own and their children's well being, or because they had adjusted to utilising his support prior to becoming a mother.

Participants also discussed the role of their family and friends, whose support appeared particularly important in the partner's absence. The importance of seeking support in balancing the mother with CF's dual commitments has been suggested by a number of authors (e.g. Edenborough et al., 2008, Tuchman and Gisone, 2010). Participants reported using this support more when they were ill, and this enabled the impact that poor health sometimes had on mothering to be managed. The relationship between use of support and health status has been

found in studies with mothers with other chronic conditions (e.g. Wilson, 2007, Pakenham et al., 2012), and in the general CF population (Delelis et al., 2008). Some participants reported feeling reluctant to ask for help however, feeling they should do it themselves. This potential reluctance was hypothesised by Wexler et al. (2007), and has been reported in studies with healthy mothers (Barclay et al., 1997, Currie, 2009).

Family and friends also contributed to participants being able to take time out to rest, again helping to manage the impact that mothering has on their health. Making time to rest has been described as a major coping strategy for managing fatigue by mothers with other chronic conditions (e.g. van Mens-Verhulst et al., 2004, Payne and McPherson, 2010). Healthy mothers in the study by Currie (2009) also discussed the importance of taking time out from their children, to maintain their own well being. Indeed, Edenborough et al. (2008) argued that mothers with CF should use support in order to do this. Participants here also used the support of their family to enable treatment adherence, as discussed by mothers with MS (Payne and McPherson, 2010). The importance of support from the wider support system in enabling treatment adherence appears to be less significant over time however, with other factors making adherence easier, such as the child's developing routine. Wider social support was also referenced as being important for practical and emotional issues. This has also been discussed by mothers with other chronic conditions (e.g. Nelms, 2005, Pakenham et al., 2012).

In contrast to some studies with chronically ill mothers however (e.g. Ingram and Hutchinson, 2000, van Mens-Verhulst et al., 2004), participants here did not discuss utilising their children's support. This may be due to the young ages of the majority of their children, their strong adult support systems, being on average in good health, and utilising other coping mechanisms.

There are some differences in the use of support described by the participants here as compared to healthy mothers. Participants described utilising support to enable them to maintain their physical health, through time out to rest and do their treatment. They did not discuss utilising support to reduce their stress and isolation, or to restore their sense of self as discussed by some healthy mothers (McVeigh, 1997, Currie, 2009, Darvill et al., 2010). This difference could be due to the relative lack of isolation participants discussed in this study, and the importance they placed on their treatment.

In this study, participants also described drawing on their own resilience in coping with motherhood, as discussed by some healthy mothers (Barclay et al., 1997). This included adopting particular attitudes and thinking positively. Participants also demonstrated high levels of optimism with regards to the future, often associated with increased health related quality of life scores, as apparent in this sample (Abbott, Hart, Morton, Gee, and Conway, 2008). Participants also discussed finding their own ways to cope, which involved constant learning, trial and error, and eventually ‘working it out’. The importance of learning new skills has also been discussed by healthy mothers (e.g. Barclay et al., 1997, Wilkins, 2006). The resilience demonstrated by this sample mirrors the resilience found in the general CF population (Hofer et al., 2012).

A number of other proactive strategies were discussed by participants in adjusting to and coping with motherhood. These included fitting their treatment around their children’s routines, in line with suggestions by Yankasas and Fernald (1999) and Edenborough et al. (2008), that mothers with CF may modify and adjust their treatment regimes. Participants also noted the importance of being organised and planning ahead, which gave them more time to manage their dual commitments. Mothers with other chronic conditions have also discussed altering their lifestyle, how they organise their time, and the importance of planning ahead (van Mens-Verhulst et al., 2004, Payne and McPherson, 2010). Healthy mothers have also described developing new routines, and the importance of being organised in enabling time to get everything done (Wilkins, 2006, Currie, 2009).

A strategy discussed here, that has not been discussed by mothers with other chronic conditions, was involving their children in treatment. Edenborough et al. (2008) hypothesised this may be helpful for the mother’s adherence and the child’s understanding. The difference may be due to the treatment of CF being more amenable to this strategy than treatments for other conditions.

Participants also discussed engaging in less exhausting activities such as arts and crafts, as opposed to play that involves physical exertion. This strategy has also been discussed by mothers with asthma and MS (van Mens-Verhulst et al., 2004, Payne and McPherson, 2010).

The processes discussed by the participants in this study mirror a number of processes described in models of coping and adjustment to chronic illness. Leventhal and colleagues (1980, 1997) suggested that individuals are motivated to

re-establish the status quo (i.e. a state of health) when faced with a problem. Here, there was evidence of participants attempting to do this. This involved finding ways to balance their own needs with their children's, in order to maintain their health. There was also evidence of participants interpreting and 'assigning meaning', such as when they noted a deterioration in their health. Participants generally felt this was due to the disruption in their treatment. Leventhal and colleagues suggested that assigning meaning enables the individual to begin to consider coping strategies. Here this involved participants developing coping strategies that enabled treatment adherence, in order to maintain their health. Leventhal and colleagues also suggested that coping is influenced by an individual's emotional state resulting from their interpretation of the problem. Here participants often expressed feelings of upset and frustration at their poor health and/or the impact it had on mothering. As a result, participants were motivated to find ways to cope with the problems they faced, such as having a lack of time to themselves, that enabled the care of both themselves and their baby. Participants appeared to appraise their coping strategies as effective, and thus continued with them, as hypothesised by Leventhal and colleagues. Furthermore, as hypothesised by Leventhal and colleagues, these processes were ongoing and dynamic.

Participants also described similar processes to those discussed by Taylor (1983). These included a 'search for meaning' as previously discussed, and a 'search for mastery'. This included maintaining a positive attitude, seeking information, and complying with treatment, strategies discussed by Taylor (1983). There was also evidence of participants engaging in self enhancement by comparing themselves favourably to healthy mothers. There also existed evidence of 'illusions' (positive interpretations of reality), such as optimism for the future.

As proposed by Folkman and Lazarus' stress and coping model (1984, 1988), there was evidence of participants engaging in appraisal. This involved considering what they had at stake on becoming a mother, such as missing treatment and deteriorating health, and what they could do to manage this. Participants appeared to interpret much of their situation as being controllable and, as hypothesised by Folkman and Lazarus, thus engaged in problem focused coping. This involved strategies such as fitting their treatment around their children's routine, and involving their children in treatment. Emotion focused

coping, such as thinking positively, was often engaged in to cope with less controllable issues, such as feelings of guilt associated with reduced life expectancy, again as hypothesised by Folkman and Lazarus. As hypothesised by Folkman and Lazarus, there also appeared to be a reciprocal relationship between emotion and coping. Emotions appeared to influence coping (e.g. anxiety around health deterioration resulted in finding ways to do treatment), and coping appeared to influence emotions. For example, participants reported feeling happier when they had achieved the 'correct' balance between meeting their own and their children's needs.

Overall, participants appeared to be coping, and have adjusted well, to becoming a mother. This may be due to participants engaging in a number of psychological and coping processes thought to be necessary for effective adaptation and coping by the various models discussed. These included assigning meaning (Leventhal and colleagues, 1980, 1997), the development of 'illusions' (Taylor, 1983), and utilising coping strategies that fit with the situation (Folkman and Lazarus, 1984, 1988). Furthermore, the participants and their families appeared to demonstrate a number of processes thought to be significant for family adjustment, such as effective communication and the ability to establish effective organisational patterns (Walsh, 2006).

The model developed here makes a number of additional contributions. It acknowledges the impact on the system, such as the child, partner, and wider family. This has been noted to be absent from the models discussed, and important when considering coping and adaptation to chronic illness (Rolland, 1987). The model developed in this study also acknowledges the importance of contextual factors, such as access to resources. These have been noted to be important, and often missing, by existing models in the literature (Biesecker and Erby, 2008). Finally, the model here also explicitly illustrates the remarkable resilience that those with chronic illness are able to demonstrate and draw upon. The importance of acknowledging resilience has been noted by a number of authors (e.g. Biesecker and Erby, 2008, Trivedi et al., 2011).

Experience of CF Teams

In discussing their experiences of becoming a mother, all participants spontaneously made reference to their CF teams. The majority had approached

their teams before making firm decisions about motherhood, and many said how much they valued their opinions, as also reported by mothers with MS (Payne and McPherson, 2010).

Participants reported mixed experiences in regards to how supportive their teams were of their decisions. Dependent on establishing a good health status, the majority of doctors were supportive. However, when a lack of support was perceived, this often resulted in participants withdrawing from their team. A lack of support in reproductive choices from medical teams has been reported by other chronically ill mothers, often with the consequence of withdrawing from their team (e.g. Wilson, 2007, Sanders, 2008).

In preparing for motherhood, some participants noted that discussions with their teams focused on the impact of pregnancy, and motherhood was often neglected during discussions. If it was, this was in the context of the potential for health deterioration. Participants reported a desire for psychosocial information, which they felt their teams could not offer them. This mirrors findings from studies of mothers with MS (Pakenham et al., 2012). It is also in line with reproductive research with female CF patients (Johannesson et al., 1998, Simcox et al., 2009, Tuchman et al., 2010). This lack of information made it hard to prepare, similar to dissatisfaction with ante-natal classes often reported by healthy mothers (Barclay et al., 1997).

During pregnancy, some participants noted poor communication between their CF and obstetric teams. A lack of communication between specialities has been discussed by mothers with diabetes (Sparud-Lundin and Berg, 2011).

On becoming a mother, participants described feeling that a number of adaptations to their CF care were required. This included increased contact and emotional support, being seen at home, and the need for lifestyle discussions to facilitate treatment planning. Participants appreciated their teams' understanding if they had neglected their treatment, and resulting flexibility with treatment. This involved being given alternative chest physiotherapy regimes, and being able to complete IVs at home. These findings are in contrast to those described by Frankl and Hjelte (2004), who found that parents with CF reported requiring no extra support from their CF team on becoming parents. Women with diabetes have also expressed the need for adaptation to their medical care after having children (Sparud-Lundin and Berg, 2011).

Strengths and Weaknesses of the Research

Strengths

Contribution to the Literature This study is the first to qualitatively explore the experiences of mothers with CF, with direct implications for CF care. Having a service user involved throughout the research process further enabled the research to be conducted in a way that would prove to be clinically useful.

Sample 11 participants were interviewed in this study, and some of the criteria for theoretical saturation as discussed by Strauss and Corbin (1998) were met. Data was collected until categories were well established and validated, and no new ones were emerging.

Greenhalgh (2010) discussed the importance of interviewing participants with a range of experiences within the phenomenon being studied. Given their diverse geographical locations, participants had a range of experiences of motherhood in relation to their CF teams' involvement. The sample here was also wide ranging in regards to the way in which they conceived their children. Method of conception is important to consider, given differences found in the experience of fertile and infertile couples (Sandleowski, 1995). McMahon et al. (2009) also found those mothers who had conceived via ART were less likely to be depressed, and have more positive experiences of motherhood, than mothers who had conceived naturally. Adoptive parents have also been found to experience unique feelings such as fears of difficulties with biological parents, in addition to more joy and less depression on becoming parents than biological parents (Levy-Shiff, Bar, and Har-Even, 1990, Koepke, Anglin, Austin, and Delesalle, 1991, Fontenot, 2007). However, in this study, there did not appear to be any differences in the experiences of those who had conceived naturally and those who had not.

Participants were also wide ranging with regards to their age. Age is an important issue to consider, given the differing experiences of younger mothers. As compared to older mothers, younger mothers often experience reduced self esteem and increased depression (Herrmann, Cleve, and Levison, 2001, Bunting and McAuley, 2004).

Methodological Rigour Extreme rigour was involved in the data collection and analysis process. I was able to interview 11 participants at a rate of once every three weeks. This approach meant that GT principles could be fully adhered to, and I had adequate time to analyse the data in great detail over the course of seven months. This systematic and consistent way of working also meant that I was able to adjust the interview schedule accordingly for each participant. This enabled me to further explore in detail, and validate or disconfirm, emerging categories, to develop and refine the theory throughout the research process.

Quality Checks Working to the time-frame described above meant I was able to complete a number of credibility checks described by Elliott et al. (1999). Importantly, I was able to return to the participants, and a ‘similar other’ for feedback on the results. In attempting to achieve quality control, Greenhalgh (2010) also discussed the importance of thinking critically about one’s analysis. In this instance, this involved the exploration of negative cases in theory development, as discussed by Strauss and Corbin (1998). An additional quality check that may have been useful however, would have been to analyse using an additional qualitative method, such as IPA.

Limitations

Sampling Strategy The sampling strategy in this study was purposeful. Recruiting from a national online forum meant that participants from a range of geographical locations, and thus a range of CF centres, could be interviewed. However, given the participants interviewed were those who first volunteered, it may be argued that the sample was a ‘convenience’ sample. Greenhalgh (2010) warned against this, suggesting researchers should seek out participants who vary in their experiences. However, the final set of participants varied on a number of bases in addition to location. These included age, number of children, nature of conception, educational achievements, occupational status, and health status.

As a result of recruiting through the CFMothers forum, the final sample may have been ‘biased’ or ‘atypical’. Studies of infertile and chronically ill women who use online forums have found they are used to seek informational and emotional support (Himmel, Meyer, Kochen, and Michelmann, 2005, Seale, Ziebland, and Charteris-Black, 2006). This may suggest that the sample in this

study have an 'approach' as opposed to 'avoidance' style of coping, and are proactive in their 'problem solving'. This contrasts with some women with CF who actively avoid reproductive information (e.g. Simcox et al., 2009). The participants' forum member status may also imply they are sociable, confident, skilled communicators, and have good general knowledge of CF. Finally, all participants were motivated and excited to take part and contribute to the lack of information available, suggesting they may have had particular and 'biased' experiences in relation to CF and motherhood.

Sample Whilst there were a number of strengths to the sample in this study, there were also a number of limitations. The sample appear 'atypical' in their high levels of adherence. This may be due to their parental status, or possessing characteristics often associated with increased adherence, such as social support, satisfactory marital relationships, optimism, good health, being of female gender, having good knowledge of the disease, and being concerned about their CF (Abbott and Gee, 1998, Sawyer, Winefield, and Greville, 2001). There was also a lack of avoidance or denial in this sample, often associated with non-adherence. This may be due to the majority of participants being in generally good health. Indeed, it has been suggested that those who regard their health as severe may be more likely to avoid their treatment (Abbott and Gee, 1998).

Generally, participants were high achievers and financially comfortable. It may be that the results apply less well to those of a lower SES. Low SES has been found to be a predictor of PND (Beck, 2001), associated with more mothering psychosocial stress (Sperlich et al., 2011), and a very different experience of motherhood (DeLashmutt, 2007). Indeed, van Mens-Verhulst et al. (2004) found that lower income women with asthma experienced a more negative impact on their health when they became mothers than did higher income women. In addition, the majority of mothers in this study did not work outside the home, or worked part time. This is important to consider, given some studies have found that mothers who do not work are at lower risk of depression (e.g. Sperlich et al., 2011).

Furthermore, all but one participant in this study were married. This is important to consider, given differences found in the experience of married and single mothers. Copeland and Harbaugh (2010) found that single mothers scored

significantly lower than married mothers on measures of self esteem and sense of mastery. They also reported increased depression, reduced support, and increased isolation. Murphy et al. (2011) found that married mothers with HIV experienced less fatigue and a reduced impact of their HIV on mothering. Single marital status has also been found to be a predictor of PND (Beck, 2001). Marital status is particularly important to consider in those with CF. Having a partner has been found to be associated with higher life satisfaction, psychological adjustment, better health, and the development of effective coping strategies in adults with CF (Delelis et al., 2008, Besier, Schmitz, and Goldbeck, 2009). As a result, the results described here may apply less well to mothers with CF who are single, or who have less supportive partners and less satisfactory relationships. Indeed, low marital satisfaction has been found to be a consistent predictor of PND in the general population (Beck, 2001). Participants also described effective and close extended support systems. These have noted to be important for adjustment to motherhood (van Mens-Verhulst et al., 2004, Homewood et al., 2009), and for increasing adherence to treatment (Walsh, 2006).

On average participants were in good health, meaning the results may apply less well to mothers with more severe CF. Indeed, many studies of mothers with chronic illnesses have reported differing experiences dependent on health status in regards to the impact the condition has on mothering (Nelms, 2005, Murphy et al., 2011), how the illness is managed (van Mens-Verhulst et al., 2004), and how much their mother identity is threatened (Wilson, 2007). Thus, the coping strategies described here may not be 'enough' for those where the mother has more advanced CF. However, Amy, who has an FEV1 of 27%, discussed the same coping strategies as those discussed by the healthier mothers.

There was a lack of evidence of depression in this sample. The results may therefore apply less well to mothers with CF who experience PND. Finally, the majority of pregnancies were planned, and all children were wanted. The results may apply less well to mothers with CF who did not plan or want children. Indeed, unplanned pregnancy is a further risk factor for PND (Beck, 2001).

However, whilst the results may apply less well to women with CF who are less financially comfortable, single, in poorer health, and who did not plan their pregnancies, the results highlight women with CF who may find motherhood harder, and may require additional support. Furthermore, it is important to note

that the aim of qualitative research is not to develop an ‘average’ view of a patient population (Greenhalgh, 2010), or to develop ‘generalisable’ theory (Strauss and Corbin, 1998).

A final limitation in regards to the sample is its size. The principle of ‘theoretical saturation’ was not *fully* achieved. Variations in regards to the categories’ properties and dimensions continued to emerge, even in the final interviews. However, Charmaz (1990) argued that theoretical saturation is a goal rather than a reality.

Researcher Bias Authors such as Henwood and Pidgeon (1992), Elliott et al. (1999), and Greenhalgh (2010), argued researchers should describe in detail their own perspectives so that the results can be interpreted accordingly. I made a continuous effort throughout the research to remain aware of my own biases. These included my own pre-existing knowledge of CF, my emotional ties to the project, and my own experience of chronic illness. Whilst I acknowledge that researcher bias can never be abolished, I feel I was able to remain aware of my biases and their potential impact as much as possible, through reflective diaries and discussions with my thesis supervisor. Overall, I feel these personal biases enabled me to be sensitive to participants’ stories, facilitated rapport building and in depth exploration, in addition to rigour during analysis. Indeed, Greenhalgh (2010) even suggested that researchers could be ‘congratulated’ for having ‘personal involvement’ with participants.

Access to Information A difficulty with data collection methods such as interviews, is that the information accessed depends on participants’ awareness of it. Even then, these narrative accounts are the participants’ perceptions (Charmaz, 2006). Alternatively, the participants may not have been willing to share all their thoughts with me. Whilst participants appeared open and comfortable in discussing their experiences, these possibilities cannot be ignored.

Grounded Theory Willig (2006) suggested that GT may be less suitable for psychological, as opposed to sociological, research. She argued that when applied to questions relating to experience, GT becomes a method for ‘systematic

categorisation', which results in a *description* of experience as opposed to an *explanatory* theory.

Clinical Implications

Relationship with the CF Team

It is important that CF teams develop and maintain effective relationships with their patients, being as supportive as possible. Participants in this study noted the negative impact on the relationship and their care when they felt unsupported by their team in their decisions to have children. Participants discussed a desire to have 'lifestyle' discussions and have their role as mother acknowledged, in facilitating this relationship and treatment planning. A number of studies have concluded the importance of medical teams being supportive, trusting, empathic, positive, and respectful of patients' decisions regarding motherhood. This is so that female patients can broach any concerns they have, and to do otherwise may risk the relationship and the mother's health (e.g. Rasmussen et al., 2007, Edenborough et al., 2008, Payne and McPherson, 2010). Edenborough and Morton (2010) suggested that care must be taken to avoid damaging the relationship that may jeopardise CF care when discussing pregnancy and motherhood. The relationship is also important in order for information to be fully absorbed (Wilkins, 2006).

Opening up Discussions

A number of participants in this study felt their CF teams did not expect them to be considering children, with little experience of discussions relating to motherhood. Participants indicated they would have appreciated their CF team raising these issues with them. Indeed, a number of authors have pointed towards the importance of CF teams raising issues of reproductive health with patients and their parents in early adolescence, repeating these discussions over time. This would enable CF teams to respond to patients' needs, reduce shock and distress in adulthood, encourage openness and honesty, and enable appropriate preparation and planning (Simcox et al., 2009, Edenborough and Morton, 2010, Havermans et al., 2011, Gage, 2012). Discussions should include physiological and psychosocial information (Simcox et al., 2009, Gage, 2012). It may be however, that

professionals require training to raise these issues (Havermans et al., 2011). Issues associated with reproductive health should be raised and discussed in a sensitive way, within the context of a supportive relationship, given the difficult emotional reactions that can be experienced by patients. Culture is also important to consider, and information should be available in multiple forms (Havermans et al., 2011).

Information Giving

Participants noted a general lack of information on CF and motherhood, particularly with regard to psychosocial issues, which they felt would have been helpful in planning and preparing for motherhood. This research serves as a foundation for information that could be delivered to female patients and their partners. Prior to pregnancy, CF teams are in a prime position to deliver this information. During pregnancy, and afterwards, obstetric teams are also well placed to provide further information. Edenborough and Morton (2010) suggested it is vital that female patients with CF are fully informed about motherhood.

A number of studies with mothers with chronic conditions have also concluded the importance of providing women with information about motherhood, both before, during, and after pregnancy as a form of support (Ingram and Hutchinson, 2000, Gulik and Kim, 2004). A number of authors have noted the importance of practical and psychosocial information for all mothers for increasing accurate expectations and enhancing adjustment to motherhood (e.g. Currie, 2009, Darvill et al., 2010). However, it is important to bear in mind that different women may vary in their preferences for the amount, content, and timing of information dependent on their coping style.

Needs Assessment

Participants discussed the adaptations they felt were required to their CF care on becoming a mother. A re-assessment of the needs of the new mother should be undertaken to establish these and how they could best be met. Assessments should cover mood, sources of stress, availability of support, family circumstances, and any other areas of difficulty. A number of authors have pointed towards the importance of assessing the mother's psychosocial needs to develop

individualised interventions where appropriate (Gulik and Kim, 2004, Edenborough et al., 2008).

Managing Health and Treatment

A major issue participants discussed in this study was treatment disruption on initially becoming a mother. The strategies participants described utilising in balancing their own and their children's needs provides useful guidance to health care professionals. However, it is important that CF teams remain constantly aware of the mother's new role and wherever possible help her to manage her dual commitments. This would include visiting her, and allowing her to do IVs, at home where ever possible, and planning outpatient appointments carefully, in an attempt to relieve the burdens of CF related treatment. Participants also appreciated their teams adjusting their physiotherapy regimes. Indeed, Edenborough et al. (2008) recommended physiotherapists visit the new mother at home, to develop new treatment routines around their new commitments. These authors also recommended treatment be regularly reviewed in order to reduce any burden resulting from treatment.

A number of studies with mothers with chronic conditions have concluded the importance of medical teams understanding the complexities of mothering with a chronic illness, and working flexibly with her to help her manage this (van Mens-Verhulst et al., 2004, Payne and McPherson, 2010).

Facilitating Support

A major coping strategy discussed in this study was that of social support. If the mother's social support is limited, health care professionals are in a good position to help the new mother access this. This may involve helping the mother to problem solve, and develop her communication skills to facilitate the request of support (van Mens-Verhulst et al., 2004, Copeland and Harbaugh, 2010). It may also involve putting them in touch with peers.

It is also important that new mothers receive professional support. Here participants discussed the practical support they required, such as that relating to housework, cooking, and childcare. Edenborough et al. (2008) suggested new mothers utilise home care support. A number of authors have noted the importance of professionals offering practical and round the clock support to help

mothers with chronic illness negotiate their new role, relieve treatment burden, and enable respite (Murphy et al., 2011, Sparud-Lundin and Berg, 2011, Pakenham et al., 2012).

Some participants discussed the desire for emotional support on becoming a mother, and Edenborough et al. (2008) highlighted the potential need for this. A number of researchers have concluded that mothers with chronic illness should be offered opportunities to discuss any difficulties and distress, and if appropriate, be referred to an appropriate specialist team member or service (e.g. van Mens-Verhulst et al., 2004, Vallido et al., 2010). The theory developed in this study serves as a framework for the kind of emotional support the mother with CF may require, such as coping with guilt.

It is important that the mother's family also receives appropriate support (Rasmussen et al., 2007, Edenborough et al., 2008, Walsh, 2006). Walsh (2006) argued the needs of the 'well' partner should not be neglected.

Direction to the CFMothers Forum

In seeking information and support, participants discussed the value of the CFMothers forum. This mirrors findings that other mothers are a significant source of informational and emotional support (e.g. Nelson, 2003, Darvill et al., 2010). Female patients with CF would benefit from being directed to the CFMothers forum, with its wealth of experiential knowledge in regards to pregnancy, adoption, surrogacy, and motherhood. Indeed, a number of authors have suggested that health care professionals should play an active role in facilitating contact between mothers. This has been suggested to be beneficial in regards to reducing isolation, validating struggles, and facilitating the sharing of expert knowledge (e.g. McVeigh, 1997, Barclay et al., 1997, van Mens-Verhulst et al., 2004). Darvill et al. (2010) specifically recommended the use of web based forums, ideal for those with CF. Indeed, Rasmussen et al. (2007) found that during the transition to motherhood, women with diabetes utilised forums to form meaningful relationships with similar others, to access information and support quickly, and to discuss sensitive information anonymously.

Communication and Education

A number of participants in this study felt their obstetric team lacked the necessary knowledge to manage their pregnancies, and noted poor communication between their medical teams. Edenborough and Morton (2010) suggested a CF specialist nurse co-ordinates the care of women with CF who are pregnant, and liaises with the different specialities. Midwives are well placed to prepare women for the realities of motherhood and can act as additional sources of support for the new mother. However, they must have an understanding of CF, and therefore it is important that the two teams liaise closely. A number of authors have noted the importance of collaboration and communication between all those involved in the care of mothers with chronic illness (Gulik and Kim, 2004, Sparud-Lundin and Berg, 2011).

Edenborough and Morton (2010) argued the obstetric team should ideally have experience of managing pregnant women with CF. CF teams are in a good position to offer periodic training to obstetric teams.

Following Guidelines

Participants discussed the inconsistency they experienced within and across CF teams in regards to the information, support, and advice they received in regards to their decisions about motherhood. It is important female patients are given consistent and accurate information and advice in order to reduce distress and confusion. Edenborough et al. (2008) have published an excellent set of guidelines for managing women with CF, both before, during, and after pregnancy, which address both medical and psychosocial issues.

Future Research

Expanding the Theory

The theory developed in this study offers a tentative framework for understanding the impact becoming a mother has on women with CF, and warrants further investigation and expansion. Understanding the experiences of mothers with chronic illness is important for the development of effective interventions to ease the stresses experienced (Sparud-Lundin and Berg, 2011, Pakenham et al., 2012). Repeating this research with a broader, more

heterogeneous sample, would allow for the further development of categories in regards to their properties and dimensions. This would enhance the explanatory power of the substantive theory developed here. The theory can also be tested for its ability to account for variation, and can be amended and elaborated. Exploration of the similarities and differences between this sample, and those who are single, of poorer health, and of a lower SES, would further inform the care of these women. Future studies may also explore the changing needs of these women as the disease progresses and their child develops. Alternatively, given the limitations associated with GT, alternative methods such as IPA could be utilised to explore the same phenomenon.

Informational Needs

Participants here acknowledged the lack of information relating to motherhood available and given to them, and expressed a desire for this. Guidelines in relation to this are lacking (Havermans et al., 2011). A qualitative study exploring the specific informational needs and desires of female patients with CF, including the desired timing and delivery of this information, would be a further fruitful area of exploration.

Impact on the Partner

Participants acknowledged the impact becoming parents had on their partners. Authors such as Edenborough et al. (2008) have highlighted the support the partner of a mother with CF may require. Delelis et al. (2008) noted that partners of those with CF are also required to adjust at times of ill-health and the transition to parenthood. A useful area for future investigation would be the partner's experience, to establish his support needs. A number of authors have noted that partners of mothers with chronic illness have frequently been neglected in the research (Payne and McPherson, 2010, Pakenham et al., 2012), and that fathers can often be ignored by health care professionals (de Montigny et al., 2012).

Impact on the Child

Participants in this study reflected on the potential impact that having a mother with CF may have on their children. There is very little research in this area, and it warrants further investigation in order to develop interventions to support these

children. Existing research has concluded that parental MS and HIV has a negative impact on children's adjustment (Bogosian, Moss-Morris, and Hadwin, 2010, Murphy, Marelich, and Herbeck, 2012).

Fathers with CF

With advances in ART, it is increasingly possible for males with CF to become fathers. Whilst mothers and fathers experience similar parenting experiences, there also appear to be significant differences (Nystrom and Ohrling, 2004). In regards to chronic illness, it is important to understand fathers' experiences, in order to understand the experience from both genders, to inform appropriate care (van Mens-Verhulst et al., 2004, Pakenham et al., 2012).

CONCLUSIONS

With regards to the initial aims of the research, and the research question, the following conclusions can be drawn:

1. A number of complex and interrelating psychosocial processes are experienced by women with CF when they have children. A number of coping and adjustment processes take place as a result.
2. Many of the results observed have been hypothesised by those working in the field. However, the theory developed in this study presents a rich account of the impact of motherhood, and highlights relationships among the processes experienced.
3. A number of novel findings were also evident. Some of these included the following:
 - Complete treatment disruption is not inevitable. Some participants experienced little disruption, and for all but one participant, this was time limited.
 - The utilisation of social support was not the only way of coping described by mothers with CF. There was much evidence of other forms of ‘problem-solving’, in addition to drawing on their own resilience.
 - Participants did not describe experiencing an ‘emotional burden’ around the issue of disclosing their CF to their child, as hypothesised by many authors in the field.
4. Participants discussed the significance of their CF teams’ involvement throughout the experience. They reflected on the impact and importance of having their support in their decisions to have children. This support, and a number of adjustments to their CF care, was also described as being important once they had become mothers, and continues to be important.
5. It was important to participants that their CF teams had an understanding of motherhood and CF, so they could provide them with this information when they were making decisions about having children, and when planning for motherhood.

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APPENDICES

Appendix A: Ethical Approval

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UNIVERSITY OF LEEDS

Miss Sophie Louise Cammidge
Psychologist in Clinical Training
Clinical Psychology Department
Charles Thackrah Building
101 Clarendon Road
University of Leeds
LEEDS LS2 9LJ

15 February 2012

Dear Sophie

Re ref no: HSLTLM/11/011

Title: What is the psychosocial impact of having a baby on the mother with cystic fibrosis and how does she manage this?

I am pleased to inform you that the above research application has been reviewed by the Leeds Institute of Health Sciences and Leeds Institute of Genetics, Health and Therapeutics and Leeds Institute of Molecular Medicine (LIHS/LIGHT/LIMM) joint ethics committee and following receipt of the amendments requested, I can confirm a favourable ethical opinion on the basis described in the application form, protocol and supporting documentation as submitted at date of this letter.

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval. This includes recruitment methodology and all changes must be ethically approved prior to implementation. Please contact the Faculty Research Ethics and Governance Administrator for further information (fmhuniethics@leeds.ac.uk)

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I wish you every success with the project.

Yours sincerely

A handwritten signature in cursive script that reads "Laura Stroud".

Professor Alastair Hay/Mrs Laura Stroud/Dr David Jayne
Chairs, LIHS/LIGHT/LIMM Joint REC



Participant Information Sheet

Title of the research; What is the Impact of Becoming a Mother on Women with Cystic Fibrosis?

You are being invited to take part in a research study. The researcher is myself, Sophie Cammidge, and I am conducting this research as part of my Doctorate in Clinical Psychology. Before you decide whether you wish to take part, it is important you understand why the research is being conducted and what your participation would involve. Please take time to read the following information carefully. If there is anything that you would like more information on then please do not hesitate to contact me. My contact details are at the bottom of this sheet.

Thank you for taking the time to read this.

What is the purpose of this research?

To date, there is very little research and information available on the experiences of mothers with CF, in addition to the impact that becoming a mother may have. The literature suggests that this information is desired by patients and professionals alike. As a result, the aim of this research is to explore the impact that becoming a mother has on women with CF, and how they go about managing this. The information will be utilised to inform CF teams of the potential issues that mothers with CF may face and require support with. The results may also provide useful information for women with CF who are contemplating having children.

Why have I been chosen?

I would like to speak to mothers with CF who live in the UK and have children aged 5 and under. The reason for this is so that the women we speak to will have had similar experiences of maternity services, and are more likely to remember what it was like becoming a mother. The reason for including only women who live in the UK is because the results will be used to inform NHS services.

Do I have to take part?

It is entirely your decision as to whether or not you would like to take part and you have as long as you wish to do so. If you do decide to take part, you can withdraw from the study prior to, during, or following your interview without having to give a reason. Alternatively, you could decide to take part, but ask that I do not use parts of your interview in the analysis, or do not use direct quotations from your interview when the results are written up.

What will happen if I decide to take part?

If you decide you wish to take part you will be asked to read and sign a consent form. You will then be interviewed over the telephone, on a day and time chosen by you. It is estimated that the interviews will last approximately 45 minutes to an hour. You will be asked a number of questions relating to your experiences of becoming a mother, and the impact this had and how you coped with this. Following the interview, you will be asked to complete two questionnaires which should take around 30 minutes to complete. These will be posted to you in a stamped addressed envelope for you to return to myself whenever is convenient for you.

Will my taking part in the research remain confidential?

All information collected from you as part of the research will be kept entirely secure and confidential. The interviews will be audio-taped and transcribed, however they will be anonymised and kept securely and safely. No quotes which may enable identification of individuals will be used when writing up the results.

What will happen to the results of the study?

The results will be written up as part of my doctoral thesis to be kept in the library at the University of Leeds. The results will also be written up for submission to a medical journal. This is so as to enhance the communication of the results to all those whom the research may be of interest to, such as professionals working in the field.

What do I need to do next?

If you would like to ask any further questions about the research, or if you would like to take part, then please feel free to contact myself using the following contact details;

Sophie Cammidge

Leeds Institute of Health Sciences
Charles Thackrah Building
University of Leeds
101 Clarendon Road,
Leeds
LS2 9LJ

Tel: 07885 482 767

Email: umslc@leeds.ac.uk

Thank you for taking the time to read this information.

If you would like to make a complaint about this research, please contact the Department of Clinical Psychology Administration Team at Leeds University who will make arrangements for you to do this. Please find contact details below;

Leeds Institute of Health Sciences
Charles Thackrah Building
University of Leeds
101 Clarendon Road,
Leeds
LS2 9LJ

Tell: 0113 343 0829 Email: Lydia.stead@leeds.ac.uk or Debby.williams@leeds.ac.uk



**Exploring the Impact of Becoming a Mother on Women
with Cystic Fibrosis.**

Consent Form

**Please initial
box**

- I have read and understand the information sheet
- I have had the opportunity to consider the information and to ask questions about the above study, and am satisfied with the answers to my questions.
- I understand that all information collected in the study will be held in confidence and that if it is presented or published, all my personal details will be removed.
- I understand that my participation is voluntary and that I am free to withdraw from the study at any point without having to give any reason, and without my care or legal rights being affected.
- I agree to the interview being audio recorded.
- I agree that anonymised extracts from my interview can be used as part of the write up.
- I agree to take part in the research.

Name of participant: _____ *Signature:* _____

Date: _____

Name of researcher: _____ *Signature:* _____

Date: _____

Appendix D: Initial Interview Schedule: Topic Guide

To start off, I was wondering if you had given motherhood much thought, prior to becoming one?

How, if at all, did your life change when you became a mother?

How was it looking after a new born baby?

What thoughts did you have? How did you feel? What happened to your self care regime? Did your relationships change?

Prompts: why do you think this was? Did these occur/this happen at some points more than others? How did this impact you? How did you manage this?

Have any of these issues changed as your child has grown older?

Prompts: why do you think these changes occurred? When did they change? How did you manage this?

How have your CF team been throughout the process?

Is being a mother what you expected it would be?

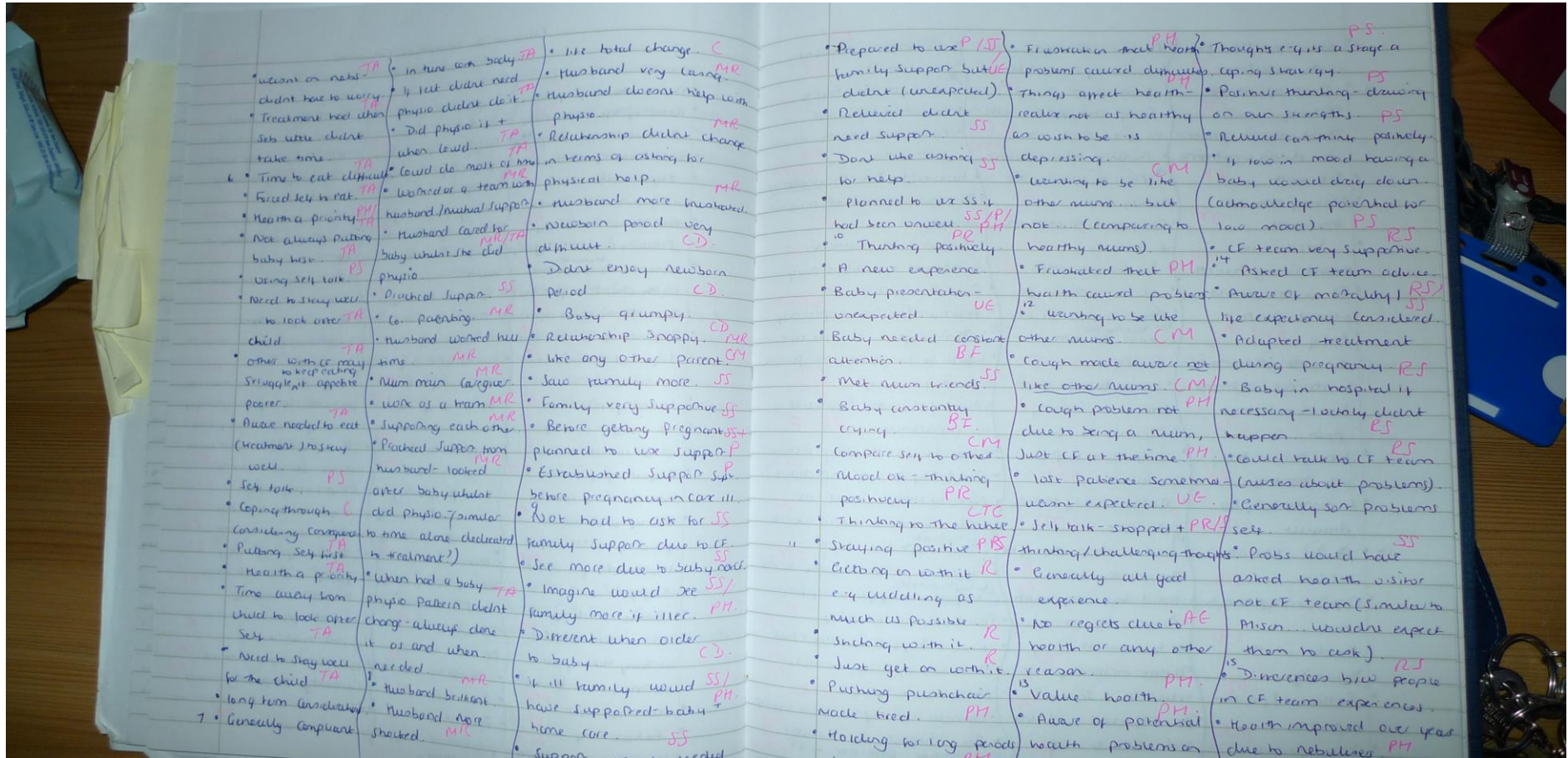
How do you see things progressing in the future?

What advice would you give to a mother to be who has CF?

Finally, is there anything you would like to add that you feel is important that we have not covered today?

Thank you very much for your time.

Appendix E: Figure 6: Step 2: Organising Open Codes



Appendix F: Step 3: Extract of Conceptual Category Table for Chloe

<i>Conceptual Category</i>	<i>Properties and Dimensions</i>	<i>Subcategories; structure (what, when, why) and quotes (page and line number)</i>	<i>Subcategories; process (who, how, actions and interactions) and consequences</i>	<i>Memos About Relationships</i>
Treatment Adherence	<p>Extent of treatment disruption (a lot to a little)</p> <p>Desire to stay alive for the child (strong to indifferent)</p> <p>Extent of routine (fixed to loose)</p>	<p>Treatment disruption versus treatment maintenance; neglected self due to looking after him and tiredness 5.168, other times able to do it e.g. IVs 5.174, neglected self 6.193, couldn't be bothered 8.260,</p> <p>Need to stay well for child; do treatment so can fulfil mothering and carry on 7.227, want to keep myself well for him 24.830,</p> <p>Child development; easier as older because he's been at nursery and then at school 12.434, more time and more understanding 13.442, 13.446, 13.463, more independent 13.466, doesn't moan 14.475,</p> <p>Routine important for treatment: 25.901, helped to adhere 26.904, and being in a routine is actively helpful in doing treatment 26.907.</p> <p>Significance of Time: The significance of time; treatment easy when have time to do it e.g. when he is at school or in bed 15. 523, now older have all the time in the world 13.422</p>	<p>Subcategory 'Health Status' could potentially go here as poor health is a consequence of missing treatment and improved health is a consequence of treatment maintenance.</p>	<p>Tiredness (sleep deprivation or physical exhaustion) cause of treatment disruption 5.170, 8.260, 8.290, as well as baby needing constant attention 5.169.</p> <p>Treatment disruption and baby needs attention; as grown up and needs less attention it is easier to do treatment 13.470.</p> <p>Child Development and Time for Treatment: older the child is the more time have, and thus easier to do treatment 13.442.</p>
Child as the Focus	<p>Extent of child's routine (fixed to loose)</p> <p>Amount of attention demanded by the child (a lot to a little)</p>	<p>Fitting treatment around child's routine; this is actively helpful, 9.321, not in a routine before but child has put her in a routine and that has helped 26.909, 26.920.</p> <p>Needing constant attention; when he needed most attention treatment was harder, 14.486, constant work 23.806, 23.809.</p> <p>Responsibility; you've brought them into the world so you have to look after them 23.812.</p>	<p>Consequence of fitting treatment around the child's routine is treatment maintenance. Captured in conceptual category 'treatment adherence'. Acknowledge in relationships.</p>	<p>Sense of responsibility leads to need to stay well for the child: 23.817.</p> <p>Fitting treatment around the child's routine enables treatment adherence: 9.321.</p>

Table 7. Extract of conceptual and subcategory development table.

Appendix G: Step 4: Extract of Table from Reanalysis of Interviews 1-5 in Light of Chloe's

Significant conceptual/subcategory or relationship found in interview 6 (Chloe)	Name of category/relationship	Details from individual interviews.
Subcategory	'Time needed to rest'	<p>1: If unwell book her in to nursery for more days so can look after self at home, 3.106, 4.129, hubby good if need 'time out' and need to rest if unwell 14.492.</p> <p>2: not mentioned.</p> <p>3: Hubby takes out to give time out to relax, page 15-relevant meaning unit currently captured in 'significance of hubby-enables TA'.</p> <p>4: Importance of resting 31.1100.</p> <p>5: not mentioned.</p>

Table 8: Extract of reanalysis of interviews 1-5.

Appendix H: Step 4: Extract of Table from Reanalysis of Chloe's Interview in
light of Existing Working Model

Dominant conceptual/subcategory/relationship captured in working model from interview 1-5 not mentioned by Chloe	Name of category/relationship	Details from interview 6 (Chloe)
Subcategory	Husband as the main source of support	<p>Chloe does not 'explicitly' say her husband was her main source of support as others have. However, this is implied as he is the first person she mentions in discussing her support system, and he dominates discussions around her use of support e.g. 4.133.</p> <p>Decision: Include Chloe in this subcategory.</p>

Table 9. Extract of reanalysis of interview 6.

Appendix J: Figure 8: Close up: Working Grounded Theory Model

Working

Treatment adherence.

← hardest thing for some but not for 7.

The importance of routine.

(Routines in TAP3, treatment dependent on child, 3, routine 1, routine important for treatment 4, importance of getting child into a routine 4, routine concept (category 4, clearly in 5 and 6) 7, 8 9 10 11.

Treatment disruption Vs treatment maintenance.

(5, 6, 4, 3, treatment from sacrifices 1, treatment no prob 2, flexibility of treatment 1, eating 3) This category includes variation across time, extent of disruption, and what treatment is (e.g. med vs physio). 7 (not as much as thought). 8, 9 10 11

Need to Stay Well for the Child.

(6, need to stay alive. 4, 3, need to stay well for the child 1, 2 - quotes from 1 in other 'hard to stay well' subcategories e.g. in sacrifices, responsibility to care for the child 2, 5) → reflects increased adherence, in 1 - realisation 'hard to stay alive'. 7 8 9 10 11

Child development.

(6, 5, treatment easier as older due to routine + more time 4, 'child development' 1 - routine, more time etc 3 is 522). 7 - noted in some accept - in 6 on research, it after 7 - illustrates link 5 to attention and treatment concept 8

Role of husband

(Husband needed 3, hubby support 2, - also discussed in significance of husband 3 and 55 important for treatment mentioned in 55 (concept category). 7 8 9 10 11

Want to be as well as possible

← hardest thing for some but not for 7.

put in TA.

time needed for treatment or how of time a cause of treat disrupt

link with (continuous) Overlapping + quality (captured) with (continuous) link of or parallel