Breaking the Cycle: The Transition to Motherhood with Anorexia Nervosa

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Thesis submitted in partial fulfilment of the requirements of Staffordshire and Keele Universities for the jointly awarded degree of Doctorate in Clinical Psychology

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CANDIDATE DECLARATION

Title of degree programme	Doctorate in Clinical Psychology
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Declaration and signature of candidate
I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work. I confirm that the decision to submit this thesis is my own. I confirm that except where explicitly stated, the work has not been submitted for another academic award. I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis. Signed: Gemma Worthington Date: 10/08/2014

Acknowledgements

I would like to thank the people who have supported me throughout my research journey. My academic supervisor, Dr Alison Tweed has guided me throughout this process, providing invaluable advice and knowledge whilst allowing me to develop into a more confident researcher. Recruiting women to participate in this study was not an easy task. I am grateful to Dr Kierron Worley for helping me to recruit participants and ensuring that my research was not forgotten by the teams I was working with.

This research has been part of a larger journey for me and I have changed both as a researcher and clinician. My placement supervisor Dr Peter Jones introduced me to a new, systemic way of working which ignited my curiosity and exposed me to new perspectives. The research process was personally and professionally demanding and at times I have experienced difficulties. I am indebted to my personal tutor Dr Ken McFadyen for believing in me and for helping me to find my voice again. I would also like to thank my family and friends for being accepting and tolerant throughout this process.

Most importantly I would like to thank the eight fearless and honest women who participated in this study, without whom this thesis would not have been possible. I am privileged to have had the opportunity to work with them and hope that by sharing their stories I can help others to understand their experiences.

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Thesis Abstract

For women with anorexia nervosa, control and routine are important in managing distress and maintaining a sense of self in challenging situations. The transition to motherhood is characterised by change and uncertainty. Women may struggle to integrate the demands of anorexia alongside the challenges of motherhood. The aim of this thesis was to review the literature regarding the experiences of pregnancy and motherhood for women with eating disorders and develop a grounded theory of the transition to motherhood for women with anorexia nervosa.

The literature regarding experiences of pregnancy and motherhood with an eating disorder was reviewed. The findings suggested a trend for remission of eating disorder symptoms in pregnancy followed by relapse during the postpartum period. Women with eating disorders were most likely to experience depression and anxiety during the later stages of pregnancy and postpartum. The review highlighted how eating disorders impacted on women's ability to embrace motherhood and bond with their children. There was a paucity of research exploring the lived experience of motherhood for women with specific eating difficulties, most notably anorexia. A grounded theory was informed by the experiences of eight mothers with anorexia. A core process of breaking the cycle highlighted how women were attempting to make lasting positive changes. They achieved this by protecting their children from anorexia, exploring new perspectives, setting a good example to their children and battling temptation to succumb to anorexia. This study provides a unique insight into the experiences of mothers with anorexia. In the final chapter the research process is reflected upon. It is hoped that these findings will influence clinical practice and help professionals to better understand women's experiences.

Thesis abstract word count: 275

Total thesis word count: 22,116 (including abstracts, tables and figures)

How do women with eating disorders experience pregnancy and motherhood?

Abstract: **195 words**
Manuscript: **6,506 words (excluding abstract, tables and figures)**

Journal Guidelines

The International Journal of Eating Disorders aims to advance scientific knowledge needed for understanding, treating and preventing eating disorders. The Journal accepts review articles that explore the status of a given research area and propose new directions for research and practice. Reviews should be a maximum of 7,000 words in length, excluding abstract, references, tables and figures. The Journal permits an abstract of up to 250 words and up to 100 academic references. There is no limit to the number of figures and tables but these should be appropriate to the material covered. Centred upper case headings are reserved for Methods, Results and Discussion sections of the manuscript. Subordinate headings are typed flush left and underlined in upper and lower case letters.

Referencing follows the Vancouver method of reference citation. References are numbered consecutively in the order in which they are first mentioned in the text. References are identified in text, tables and legends by Arabic numbers. All references cited are listed numerically at the end of the paper. When there are seven or more authors, the first six are listed followed by et al. after the name of the sixth author. Individuals are referred to as “people with anorexia nervosa” or “participants with eating disorders”.

Abstract

Objective: This review aims to critically appraise recent literature (2008-present) regarding psychological experiences of pregnancy and motherhood for women who experience eating disorders.

Method: A literature search of Web of Knowledge, EBSCO, NHS databases and Google Scholar databases was conducted to identify relevant studies. The main findings are presented followed by clinical recommendations and research implications. Seventeen articles met the study criteria and a range of outcome measures were used to explore psychological experiences of pregnancy and motherhood.

Results: The findings revealed a general trend for remission of eating disorder symptoms in pregnancy followed by relapse during the postpartum period. Women who experienced eating disorders reported depression, anxiety and weight concerns, particularly during the later stages of pregnancy and postpartum.

Discussion: Eating disorders impacted on the ability to embrace a new identity as a mother. Whilst the review was limited by small sample sizes and a wide range of outcome measures, it highlights the need to explore the best ways to support and engage mothers who experience eating disorders. Future research could focus on the lived experience of becoming a mother whilst experiencing specific eating difficulties, to help design sensitive and timely support services.

MOTHERHOOD WITH AN EATING DISORDER: A REVIEW OF THE PREGNANCY AND MOTHERHOOD EXPERIENCES OF WOMEN LIVING WITH EATING DISORDERS

Eating disorders

All individuals who experience eating disorders report concerns about weight gain, although the conditions present in different ways. Some presentations involve eating too much, others eating too little, and some involve behaviours intended to rid the body of excess calories[1]. Often the individual equates appearance with self-esteem, further fuelling the eating disorder as they strive harder to achieve an appearance that they believe will demonstrate their worth as a person. However as weight loss becomes a reality, eating difficulties can spiral out of control[2].

Eating disorders are categorised into one of four types; anorexia nervosa, bulimia nervosa, binge eating disorder and eating disorder not otherwise specified (EDNOS). There is some overlap between the categories. Anorexia nervosa is characterised by extreme fear of weight gain coupled with eating less and exercising more, which continues even when the individual reaches an unsafe weight. In bulimia nervosa individuals use binge eating and inappropriate weight control strategies such as excessive exercise to manage their weight. Binge eating disorder involves repeating cycles of dieting and binge eating[1]. EDNOS accounts for eating difficulties which do not meet the above criteria. Figures suggest that 10% of individuals with eating difficulties experience anorexia nervosa, 40% bulimia nervosa and the remainder either binge eating disorder or EDNOS[3].

Around 6% of adults in the UK display signs of an eating disorder[4]. Contributory factors include low self-esteem, family difficulties and abuse[5]. Eating disorders are most likely to develop during adolescence and early adulthood. 75% of those affected are female[1, 4]. Eating disorders may persist during adult life as a means of coping with stress or restoring control in chaotic situations.

Pregnancy and early motherhood

Pregnancy and early motherhood can be challenging events in the life cycle and are connected to feelings of uncertainty[6, 7], decreased relationship satisfaction[8] and reduced social contact[9, 10]. Fatigue is common[11] and women may require additional support during this period[6]. Some women experience psychological difficulties[6, 12] and a small number develop postpartum depression, which may impact negatively on maternal adjustment[13-14]. Past experiences of family relationships may affect how women care for their own children. For example, women who have experienced trauma or illness in their families of origin may be more anxious about the health of their own children[15]. Motherhood is a significant transition in the life cycle[16] and the changes a family makes to accommodate a new baby should not be underestimated[17].

As pregnancy progresses women experience changes to their weight and shape. During the early stages of pregnancy women are more likely to perceive a foetus as part of them. However as pregnancy progresses they begin to view their unborn child as a separate physical being[9, 18]. Weight gain during pregnancy is a common concern[19]. Many women experience significant pressure to quickly lose the weight they have gained[20-21]. Whilst many pregnant women experience anxiety related to their changing shape, some are particularly vulnerable and may attempt to lose weight using diet and exercise[22]. For women who experience eating disorders, weight and shape concerns are more pronounced and their strict adherence to diet and exercise regimes is likely to compromise their health[20]. Women living with eating disorders are likely to experience additional challenges and more information about these difficulties will help professionals to support them effectively.

Pregnancy and motherhood for mothers who experience eating disorders

Discovering a pregnancy can trigger the start of a difficult period for women living with eating disorders. Women who experience eating disorders are advised to plan a pregnancy with caution[6] due to increased risks of premature labour[23], caesarean delivery and miscarriage[24]. Whilst it is unusual for these women to

become pregnant due to the impact of an eating disorder upon fertility[25-26], around 12,000 women in the UK do become pregnant each year[21, 27]. Some symptoms of pregnancy, such as nausea and fatigue, are similar to eating disorder symptoms, so woman may not realise they are pregnant until a much later stage[28].

Women who experience eating disorders respond to pregnancy in different ways. Some report that a strong desire to protect their unborn child reduces the frequency and severity of their eating disorder behaviours[12, 23, 29] and gives their life a different purpose[30]. However others continue to restrict, purge and exercise during pregnancy[31-32]. Some women experience an initial reduction in their eating disorder symptoms only for these to return later in pregnancy and postpartum[26, 32-34] as they approach maximum pregnancy weight[21, 35]. Women who use strict diet and exercise routines to maintain a low body weight report many concerns about the impact of their pregnancy on their body[21]. Whilst some women use this opportunity to seek treatment, others rely on these behaviours to maintain a sense of control[36] and manage the overwhelming changes of motherhood. Greater clarity on women's experiences of pregnancy and motherhood with eating disorders would enable professionals to support women more appropriately.

Attachment quality and the influence of the family system

Studies exploring the influence of beliefs and family relationships on eating difficulties highlight the importance of good quality attachments. The ways in which family members interact may be connected to the development and maintenance of eating difficulties[15]. It may be more helpful to view eating difficulties as part of a trans-generational cycle rather than attempting to locate the problem within an individual. A systemic approach might suggest that eating difficulties function as a way of controlling patterns of interaction between different members of a family[17, 37]. Over time a cycle may form, placing younger family members at increased risk of developing eating difficulties if they witness these interactions during their formative years[38]. Mothers who witness and are influenced by these patterns of interaction in their families of origin may develop unrealistic expectations about eating behaviours and struggle to feed their children[15, 39]. Research suggests that children who are fed inappropriately display

a range of maladaptive behaviours including a lack of interest in interaction with their mother[40].

Attachment theory suggests that children form their first attachments to their caregivers; most often to the mother[17]. Within a secure attachment, a child is certain of their mother's availability in times of distress[41]. Insecure attachments are characterised by high levels of dependency, parental intrusiveness and difficulty expressing negative emotions[15, 17]. Research suggests that insecure attachments are common in families who experience eating disorders[42-43.] Mothers who experience eating difficulties may be more dismissive of their children[42]. It is possible that attachment problems precede eating difficulties rather than emerging as a consequence[44]. This highlights the need to look beyond cause and effect and focus on how eating difficulties develop and are maintained over time. More information about the transition to motherhood with eating disorders, connected to existing psychological theory, may offer a greater understanding of women's experiences.

Interventions for women

Two recent literature reviews have explored pregnancy and motherhood for women who experience eating disorders[45-46]. One literature review summarising what it known about eating disorders during pregnancy was published in 2008[45]. This review suggests that whilst women in the general population feel positive about weight and shape changes during pregnancy, women who experience eating disorders may feel differently. Some report an absence of symptoms during pregnancy followed by a relapse during the post partum period. Women with a history of eating disorders report greater use of laxatives and vomiting, higher exercise levels and greater weight concerns during pregnancy and postpartum. This review concludes that whilst evidence of the impact of eating disorders during pregnancy is currently limited, women who are at risk may benefit from screening and the offer of an appropriate intervention.

A second review published in 2008[46] focused on the impact of eating disorders during the postpartum period. Within this review, the main concerns of

new mothers living with eating disorders were connected to feeding and forming an attachment with their baby, and adjusting to a new identity as a mother. This review suggests that as these women have greater body image concerns, they may also be more likely to experience more eating disorder symptoms and psychological difficulties during the postpartum period. Women who experience these difficulties may be less able to form a secure attachment with their baby. The authors recommend a multidisciplinary approach to supporting new mothers who experience eating disorders, including screening during pregnancy and tailored, proactive support during the postpartum period.

Together these reviews found pregnancy was an overwhelming experience[45] and that women feel guilty for compromising their child's health by using eating disorder behaviours[46]. Women who influence their children's eating by limiting food may predispose children to developing their own eating difficulties[45-46]. Whilst health professionals are well placed to support women during pregnancy[45-46,] women are reluctant to disclose their difficulties[26] and their motivation to engage in treatment fluctuates[47] resulting in high drop-out rates from services[48-49].

Current public policy recommends that women who experience eating disorders are monitored throughout their pregnancies[50] and offered the opportunity of hospitalisation if their symptoms become more severe[21]. Although women are unlikely to seek help[51], health professionals can still encourage positive change and reduce the likelihood of postnatal depression by signposting women to appropriate support services[29, 52-53]. Women who experience eating disorders may be unlikely to discuss their difficulties due to fear that professional involvement might have a detrimental impact on their families. A more collaborative approach might help women to discuss their difficulties and make informed treatment decisions for themselves and their children.

Rationale for this review

Due to developments in fertility treatments, women who experience eating disorders are more likely to become pregnant and have children[45-46]. However

little is known about the psychological impact of pregnancy and motherhood[46]. Existing research has relied on retrospective data from small clinical samples, making the findings difficult to generalise[45-46]. More research is needed to develop a greater understanding of women's experiences and the type of support they might need[45].

The most recent literature reviews were conducted in 2008. However this is a new area of research and studies have been published since which further explore this area. It is important to continue exploring the area in order to provide health professionals with the most accurate, up to date knowledge so they can practise effectively and keep women's experiences at the heart of new research and interventions.

Review aims

Since the publication of the 2008 reviews, further studies have been published in this area. This paper aims to provide a broad review of the research published since 2008. The review question is "what are the experiences of pregnancy and motherhood for women who experience eating disorders?" It will explore the experiences of both pregnancy and postpartum for women living with eating disorders as no previous review has collated findings from the entire period.

The studies will include women with a range of eating disorder diagnoses, as past research has been biased towards women with diagnoses of anorexia nervosa and bulimia nervosa[1, 46]. It is hoped that this review will combine studies with larger samples and a range of methodologies. Past research has recommended greater awareness of eating disorders and motherhood. Existing research, whilst sparse, is beginning to explore the experiences of motherhood for women with eating disorders. This review will summarise findings related to this topic, identify areas for future research and make recommendations for clinical practice.

METHODS

Search strategy

This literature review involved the application of one search term to a variety of databases. Whilst the findings were not statistically analysed, the review was conducted systematically. The findings were organised and synthesised to provide an overview of the existing research findings related to this topic. A prior search of the literature indicated that this topic was relevant within the fields of psychology, medicine, social work and nursing. Two hosts, Web of Science and EBSCO were chosen to give broad access to multiple social sciences and humanities databases (CINAHL, Psych Info, Pub Med, Medline, Web of Knowledge and Proquest). A search was also conducted of NHS databases, the Cochrane Library, grey literature (including student theses, presentations and recommendations) and Google Scholar.

The search question was “what are the experiences of pregnancy and motherhood for women who experience eating disorders?” The search term based on the question was “(pregnan* OR bab* OR child* OR birth) AND ("anorexia nervosa" OR anorexi*) AND ("bulimia nervosa" OR bulimi*) AND (“binge eating”) AND ("eating disorder*" OR "disordered eating") AND (mother* OR parent*)”. Abstracts were screened for relevance to the research question using inclusion and exclusion criteria (see Table 1).

Table 1: Inclusion and exclusion criteria for the literature review

Inclusion criteria	**Exclusion criteria**
Original article published in an English language journal	Unrelated to the research question i.e. medical studies
Publication date 2008 or later	Aged below eighteen years
Female participants aged eighteen years and over	Does not include women with an eating disorder
Includes women with an eating disorder (anorexia nervosa, bulimia nervosa, binge eating disorder, EDNOS)	Does not examine pregnancy, postpartum or motherhood
Explores pregnancy, postpartum and/or motherhood	
Explores *psychological experiences* of pregnancy, postpartum and/or motherhood for women with eating disorders	

RESULTS

Search strategy

72 abstracts were retrieved from the Web of Science (1970-2013) out of a possible 316 generated by the search term. The remaining 244 were excluded due to not being published in English (N = 51) or publication year prior to 2008 (N = 193). Of the 72 abstracts, a further 60 were excluded due to sampling women under the age of eighteen who experience eating disorders (N = 27), not related to pregnancy, postpartum or motherhood (N = 21) or not exploring psychological experiences of this period (N = 12). 12 articles met the search criteria.

80 abstracts were retrieved from EBSCO (1970-2013) out of a possible 449 generated by the search term. The remaining 369 were excluded due to not being published in English (N = 67) or publication year prior to 2008 (N = 302). Of the 80 abstracts, a further 69 were excluded due to sampling women under the age of eighteen who experience eating disorders (N = 25), not related to pregnancy, postpartum or motherhood (N = 28) or not exploring psychological experiences of this period (N = 16). 11 articles met the search criteria.

A search of NHS databases and the Cochrane Library did not return any new results. In an attempt to eliminate publication bias, a search of Google Scholar gave 562 results, including abstracts and student dissertations. Sixteen original articles met the search criteria. Of these five had not been identified in previous database searches.

After duplicates were excluded, 17 articles met the search criteria. These were reviewed using a data extraction sheet to identify key information and findings (see Appendix A)

Research aims and design of the studies

Ten studies focused on pregnancy for women who experience eating disorders[54-57, 27, 58-62], five focused on motherhood for women who experience

eating disorders[63-66, 29] and two examined both pregnancy and early motherhood for women who experience eating disorders[19, 67].

The studies varied in their aims but included measurements of anxiety and depression[63, 67] attitudes to pregnancy[54], attachment difficulties[64], attitudes towards weight gain[56], disordered eating cognitions[27] and adaptation to motherhood[19, 29]. A range of eating disorders were studied, most commonly binge eating disorder[55, 62] and bulimia nervosa[65-66] but also anorexia nervosa[59] and EDNOS[56].

Six studies used a prospective cohort design[27, 54, 63-64, 66-67], five used a questionnaire design, with some using data collected as part of a wider cohort study[29, 55-56, 58, 62], three used qualitative techniques[19, 61, 65] and three used case study designs[57, 59-60].

Participants and settings

Table 2 provides study details. Sample size ranged from one[59-60] to 41,157[58], though not all these participants had experience of eating disorders as some were drawn from large cohort studies and included control groups. Where reported, participant ages ranged from 17 years[19] to 44 years[65].

Table 2: Study samples, methods, outcome measures and main findings listed in date order

Author, date and study country	Sample size, age and population	Method/duration	Outcome measures	Findings	Limitations
Micali, Simonoff and Treasure (2011) UK	N = 409 (total cohort of 10,887 women) Mean age not reported Pregnant women attending prenatal clinics	Prospective cohort study 12 weeks gestation to 8 months postpartum	CCEI (anxiety) EPDS (depression) EDE-Q (eating disorder symptoms)	Women with previous episodes of depression were at most risk of eating difficulties at eight months	Findings based on self report data
Easter, Treasure and Micali (2011)	N = 452 (cohort of 14, 663 pregnant women) Mean age not	Prospective cohort study Self-report questionnaires at 12	Socio-demographic data Time taken to conceive, feelings about pregnancy	Unplanned pregnancies more common in anorexia nervosa group compared to	Data collected during early 1990s All women were able to conceive therefore possible

Author, date and study country	**Sample size, age and population**	**Method/duration**	**Outcome measures**	**Findings**	**Limitations**
UK	reported Pregnant women attending prenatal clinics	and 18 weeks gestation		general population All eating disorder groups felt more negative about pregnancy	that eating disorders were less severe.
Tierney, Fox and Butterfield (2011) UK	N = 8 Age range: 17-37 years Pregnant women with eating disorder history	Qualitative study – framework analysis One interview during pregnancy or postpartum	Interview data Baseline demographic data	Divided loyalties between putting child first and demands of eating disorder	Potential researcher biases could not be identified
Micali, Simonoff and Stahl	N = 441 (cohort of 10,902 women in	Prospective cohort study	Feeding difficulties Child temperament	Pre-existing eating disorders impacted	Women self identified as having

Author, date and study country	**Sample size, age and population**	**Method/duration**	**Outcome measures**	**Findings**	**Limitations**
(2011) UK	general population Mean age of total sample: 29 years Pregnant women attending prenatal clinics	Measures completed between 18 weeks gestation and 8 months postpartum	DDS (child developmental status) CCEI (anxiety) EPDS (depression) EDE (weight and shape concerns	on ability to feed infants and increased the likelihood of postpartum anxiety and depression	an eating disorder
Berg, Torgersen and Von Holle (2011) Norway	N = 1887 (cohort of 45, 644 pregnant women) Mean age of total sample: 29.9 years Pregnant women	Quantitative study Questionnaires completed at 18 weeks gestation	DSM-IV (measuring eating disorder symptoms) HSC, SWL, RSES and RSS (psychological difficulties) Adverse life events	Remission of binge eating disorder in pregnancy most likely when women placed less emphasis on pregnancy weight gain	All findings based on self report Low response rate

Author, date and study country	**Sample size, age and population**	**Method/duration**	**Outcome measures**	**Findings**	**Limitations**
	recruited to the MoBa cohort study		Health behaviours Social support		
Reba-Harrelson, Von Holle and Hamer (2010) Norway	N = 749 (cohort of 13,006 women) Total sample range: 25 to 34 years Pregnant women recruited to the MoBa cohort study	Prospective cohort study From 17 weeks gestation to 36 months postpartum	DSM-IV (eating disorder symptoms) CFQ (maternal feeding) CBC (child eating problems and psychological status)	Mothers with eating disorders reported more restrictive feeding styles and children with more eating problems	Small sample size of women with AN (n = 17)
Swann et al. (2009)	N = 2,187 (cohort of 35,929 pregnant women)	Quantitative study Questionnaires completed at 18	Author developed questionnaires measuring binge eating, purging and	Women with eating disorders more worried about pregnancy related	Self report data This population has higher socio-

Author, date and study country	**Sample size, age and population**	**Method/duration**	**Outcome measures**	**Findings**	**Limitations**
Norway	Mean age of total sample: 29.9 years Pregnant women recruited to the MoBa cohort study	weeks gestation	concern and weight gain during pregnancy	weight gain	economic status than general population
Madsen, Horder and Stoving (2009) Denmark	N = 5 Age range: 20-32 years Women registered with specialist eating disorder unit	Case reports Early pregnancy up to one year postpartum	Demographic and observational data from obstetric appointments	All women minimised the impact of their eating disorder on their pregnancy	Little detail about data collection and ethical approvals
Manzato, Zanetti and Gualandi	N = 1	Case study	Demographic and observational data	Mother had difficulty bonding	Short follow up period of one

Author, date and study country	Sample size, age and population	Method/duration	Outcome measures	Findings	Limitations
(2009) Italy	Aged 19 years Obstetrics clinic outpatient	Between 33 weeks gestation and one month postpartum	from obstetric appointments	with her new-born	month postpartum
Mazer-Poline and Fornari (2009) USA	N = 1 Aged 29 years Obstetrics clinic outpatient	Case study Between 33 weeks gestation and birth	Demographic and observational data from obstetric appointments	In the final trimester the woman's mental health had deteriorated with high risk to mother and foetus	Ethical process unclear and little information about postpartum
Soares et al. (2009) Brazil	N = 123 (out of 712 women in the sample) Mean age of total	Questionnaire study Measures completed during second trimester of	EDE-Q (measure assess ED symptoms) PRIME-MD (current anxiety and depression)	Binge eating during pregnancy was associated with binge eating before pregnancy and	Findings are specific to women attending primary care units in Brazil

Author, date and study country	**Sample size, age and population**	**Method/duration**	**Outcome measures**	**Findings**	**Limitations**
	sample: 24.7 years Primary care units in Southern Brazil	pregnancy		current feelings of anxiety	
Stapleton, Fielder and Kirkam (2009) UK	N = 16 Age range 23-44 years Pregnant women and new mothers in Northern England	Qualitative – thematic analysis One interview during pregnancy or postpartum	Interview data Baseline demographic data	Mothers' responsibility for modelling appropriate eating behaviours conflicted with their eating disorder Social activities were stressful	Homogeneous sample of Caucasian women
Lai and Tang	N = 91	Prospective cohort study	Mother Treatment Scale (parenting	Parenting abilities associated with	Participants reported only mild

Author, date and study country	Sample size, age and population	Method/duration	Outcome measures	Findings	Limitations
(2008) Hong Kong	Mean age of total sample: 30.9 years Chinese women in Hong Kong	One prenatal interview then twice up to a year postpartum	behaviour) EDI-2 (bulimic symptoms) GHQ (maternal distress) MPAS (affectional bond with foetus during pregnancy)	level of maternal attachment and bulimic symptoms	bulimic symptoms
Koubaa, Hallstrom and Hirschberg (2008) Sweden	N = 44 (plus 67 control group of women without eating disorder) Mean age of women with eating disorder: 29 years	Quantitative study Questionnaires completed at 3 months postpartum	MAMA (body image) Somatic symptoms Marital relationships Attitude to pregnancy	Mothers with eating disorder before pregnancy reported greater postpartum adjustment difficulties 50% had had contact	No established cut off points for measuring maternal maladjustment; defined by the authors

Author, date and study country	Sample size, age and population	Method/duration	Outcome measures	Findings	Limitations
	Women attending prenatal outpatient clinics			with mental health services postpartum	
Crow et al. (2008) USA	N = 42 (out of 385 women with eating disorders) Mean age of total sample: 27.3 years Pregnant women with eating disorders attending prenatal clinics	Prospective cohort study Outcome measures completed over 18 month period at 6 month intervals	EDE (weight concern, shape concern and restraint)	Restraint, shape concerns, weight concerns, binge eating and purging diminished during pregnancy but returned to baseline levels postpartum	Self report data
Berg, Bulik and	N = 96 (cohort of	Quantitative study	DSM-IV (to measure	Bulimia nervosa in	Information comes

Author, date and study country	**Sample size, age and population**	**Method/duration**	**Outcome measures**	**Findings**	**Limitations**
Von Holle (2008) Norway	41, 157 pregnant women) Mean age not reported Pregnant women recruited to the MoBa cohort study	Questionnaire measures, unclear when these were completed	eating disorder symptoms) HSC, SWL, RSES, RSS (psychological difficulties) Adverse life events Health behaviours Social support	pregnancy associated with anxiety, low mood and low self-esteem Remission associated with greater self-esteem and life satisfaction	from third trimester only
Shaffer, Hunter and Anderson (2008) USA/Canada	N = 10 Age range: 26-39 years Women attending	Qualitative study – thematic analysis One interview during pregnancy	Interview data Baseline demographic data	Women ate to cope with distorted body image Struggle to prevent loss of control	Small sample of Caucasian women

Author, date and study country	Sample size, age and population	Method/duration	Outcome measures	Findings	Limitations
	Canadian antenatal centre			Fear of the postpartum period	

EPDS, Edinburgh Postnatal Depression Scale[68]; CCEI, Crown Crisp Experiential Inventory[69]; EDE, Eating Disorders Examination[70]; DDS, Denver Developmental Scale[71]; SWL, Satisfaction with Life scale[72]; HSC, Hopkins Symptom Checklist[73]; EDI-2, Eating Disorder Inventory 2[74]; GHQ, General Health Questionnaire[75]; MAMA, Maternal Adjustment and Maternal Attitude Questionnaire[76]; RSES, Rosenberg Self Esteem Scale[77]; PRIME-MD, Primary Care Evaluation of Mental Disorders[78]; CBC, Child Behaviour Checklist[79]; CFQ, Child Feeding Questionnaire[80]; MPAS, Maternal Prenatal Attachment Scale[81]; EDE-Q, Eating Disorders Examination Questionnaire[82]; PID, Parental Image Differential[83]; RSS, Relationship Satisfaction Scale[84].

Quality assessment

A hierarchy of evidence[85] was used to review the identified literature. The highest quality studies were those which used cohort and longitudinal designs, followed by qualitative methodologies and case reports. This literature review does not rank highly using this framework because there are no randomised controlled trials and few quantitative methodologies. This was understandable given that the search question focused on the *experiences* of pregnancy and motherhood for women living with eating disorders. The studies were assessed for quality using guidance from the Critical Appraisal Skills Programme[86] and evaluative criteria for qualitative research projects[87].

All of the studies identified relevant issues for further exploration. The cohort studies all identified specific populations (pregnant women), risk factors (binging and purging), possible outcomes (depression and anxiety) and harmful effects (eating disorders in pregnancy). The longitudinal studies used a naturalistic approach to the research, which was justified as they aimed to explore the occurrence of eating disorders before, during and after pregnancy. Two qualitative studies explained the relevance of the research and the need to study subjective experiences in greater depth[61, 65].

The best quality studies gave enough detail about their recruitment and selection processes to justify their choice of methodology. The best examples demonstrated how the sample was demographically similar to the British population[67] and how recruitment difficulties were overcome[19]. Not all studies provided these details, raising questions about the appropriateness of their selection criteria. Most did not discuss consent or confidentiality. The case studies[57, 59-60] did not detail recruitment and selection processes at all so it was impossible to tell how these participants had been identified.

Data collection methods varied depending on the chosen methodology. Exploratory studies used semi structured interview techniques, whilst larger cohort studies used standardised questionnaires. Most studies collected descriptive data including ages and length of pregnancy, although few differentiated between

different eating disorder types. The best qualitative study gave details of the topic guide[61]. Case studies provided large amounts of factual information but allowed the least psychological interpretation. An example of this is the case of a nineteen year old woman with anorexia nervosa[59] where the authors present observations and medical information but do not offer their hypotheses regarding the factors which might have contributed to her difficulties. Most qualitative studies provided some details about the researchers' clinical backgrounds[65]. However it may have been helpful for the researchers to suggest how their experiences impacted on data interpretation[87].

The range of psychological outcome measures was extremely varied. Many findings were based on self-report data but some standardised measures were used alongside diagnostic criteria[58]. Not all studies provided details of the psychometric properties of their measures. Additional psychometric detail is provided in Appendix B. The Eating Disorders Examination[70] and Eating Disorders Examination Questionnaire (EDE)[82] were commonly used. Both have established reliability and validity amongst women who experience eating disorders. The Chinese version of the EDE had "good" internal reliability[66]. There was good inter-rater reliabilities for the EDE subscales of purging, eating concerns and weight concerns (between .90 and .99), indicating that this is a stable and objective measure[27]. Other internally reliable measures included the General Health Questionnaire (GHQ; .87 to .93[75]) and the Maternal Prenatal Attachment Scale (MPAS; .82 to .84[81]). The Maternal Attitudes and Maternal Adjustment questionnaire (MAMA)[76] was high in test re-test reliability and compared favourably with similar measures[29]. Whilst some studies alluded to potential confounding factors[63], the best examples adjusted their models to accommodate them[54-55] or considered how they might be addressed in future research[66]. The best qualitative examples used relevant quotations to illustrate their findings[61]. More information about the development of codes and categories might have been helpful[87].

Lack of follow up information made it difficult to draw long term conclusions[56-57]. Two studies used longer follow up periods of three and four years postpartum[27, 64]. Two included more than one data collection point[27, 66]

which enhances the reliability of the findings. However most studies followed women for less than twelve months postpartum[66- 67] providing less evidence regarding the impact of eating disorders in early motherhood, during which there may be significant changes.

Overall the findings appear plausible, particularly when confounding factors were accounted for[54-55] and when data were collected at more than one time point[27, 66] using appropriate outcome measures[58]. The best studies made cautious interpretations[64], offered practical suggestions for reducing distress[61] and related their findings back to policy and guidelines[65]. It was easier to generalise the findings of studies which gave demographic information about their participants[54] or were conducted in the UK, where this review was based[63, 67]. Whilst most studies attempted to connect their findings to previous research, it was common for this to be the first time that some of these issues had been explored. For the qualitative studies there was not enough information in the form of audit trails and reflexivity to determine the comprehensiveness of data collection and interpretation[87].

Assessment of eating disorder status

This review included women who experienced eating disorders even if they did not form the majority of the study samples. Most studies provided details about their eligibility criteria. Two used variants of the Eating Disorder Examination[70] to confirm an eating disorder[62, 66] but most used self-developed questionnaire items based on DSM-IV criteria[55-56, 58, 63-64, 67]. The qualitative studies recruited women who self defined their eating disorder; one corroborated this with a doctor's diagnosis[61], another deemed women eligible if their symptoms impacted on their functioning[19]. Other methods included diagnostic interviews[29] and medical records[59-60]. Most studies distinguished between eating disorder subtypes and current and historic eating disorders which helped to highlight different experiences and identify gaps in the literature.

Other features of the study samples

Where data were available there were significant levels of attrition; one study experienced a 75% attrition rate in participants over twelve months[66]. Whilst it is difficult to draw definitive conclusions about this, it appears retaining women with experience of eating disorders is not an easy task.

Some studies recruited women from wider cohort studies, exploring specific aspects of the sample to obtain the data they needed[27, 54]. Where reported, women were recruited using hospital records[60] postal questionnaires[19], recruitment flyers[65], via other health professionals[61] and during ultrasound appointments[56, 64].

Most studies took place in the UK (N = 5), Norway (N = 4) and North America (N = 3). There were also studies from Brazil[62] and Hong Kong[66] and a case study of a young Arabian woman living in Italy[59]. These highlight how eating disorder beliefs may be influenced by culture, community and family upbringing.

Key findings

A large amount of information was contained in these articles. A basic content analysis was performed[88] to identify key themes. Firstly a list of key codes was generated by reading through all of the findings. This continued until no further codes could be identified. Overlapping codes were combined and broad codes were broken down into multiple categories, ensuring that all of the information was included. This resulted in five key themes. A colleague checked the analysis and agreed with the key codes and final themes. These themes and examples of contributing codes are shown in Table 3.

Table 3: Example of content analysis with themes and contributory codes

Theme	Weight and shape concerns	Remission and relapse	Mood/adjustment difficulties	Balancing eating disorder and child	Attachment difficulties
Contributing codes	Worrying about weight gain Afraid baby will be overweight Concerned about changing body shape	Symptoms remit in early pregnancy Unable to stop using eating disorder behaviours Improving during pregnancy but worsening postpartum	Mental battle to avoid losing control Higher levels of depression and anxiety Adjustment problems after birth	The benefits of having an eating disorder Strong desire to look after child Balancing needs of self and the child	Uncomfortable socialising with other mothers Feeding problems impacting food choices for mother and baby

Key findings were organised into themes of weight and shape concerns, patterns of remission and relapse, mood disorders and adjustment difficulties, balancing eating disorder and motherhood, and feeding and attachment difficulties, which will now be discussed in more detail.

Twelve studies explored women's feelings about weight gain during pregnancy and early motherhood. Women who experienced eating disorders had more severe concerns about weight gain which occupied more of their time. They were more likely to engage in restrictive eating patterns. Women with most concerns about pregnancy-related weight gain also reported more binge eating symptoms[55]. Women with eating disorder symptoms reported that during the later stages of pregnancy they became most fearful of not losing weight they had gained[62]. In a sample of 702 women in a primary care service in Brazil, 5.6% reported excessive weight and shape concerns, and in the same sample, 31% of women with binge eating disorder reported anxiety during their pregnancy[62]. At eight months postpartum, women who experienced depression and eating disorder symptoms during pregnancy reported the most symptoms of anxiety compared to women with a history of eating disorder symptoms and depression[67].

Previous research indicated that women who experience eating disorders report a remission in their symptoms during pregnancy, followed by a relapse during postpartum. This pattern was also found in the current review and was most pronounced amongst women with anorexia nervosa[27] and binge eating disorder[55], indicating that amongst women who experience eating disorders, there are different pregnancy experiences. In one study[27] women were most vulnerable to relapse during the postpartum period, although the length of the postpartum period is not specified. This seems reasonable given that during this time women who experience eating disorders are also more vulnerable to anxiety regarding their weight and shape.

Depressive symptoms were common throughout pregnancy and early motherhood. One study found that at 18 weeks gestation there were depressive symptoms in 14-40% of women with past or current experience of eating disorders[67]. Women living with eating disorders were more likely to associate

motherhood with personal sacrifice compared to women in the general population[54]. This is a period of increased risk for women who experience eating disorders and warrants further attention. The nature of the relationship between low mood and eating disorders in pregnancy is unclear, although some evidence suggests that previous depressive episodes increase the risk of eating difficulties during pregnancy[55]. Women who experience eating disorders reported more anxiety and depression at 32 weeks gestation compared to healthy controls[63] and lower self-esteem and reduced relationship satisfaction[55, 58] suggesting that this is indeed a significant issue for women.

Women who experience eating disorders may have difficulty adjusting to motherhood. Half of these women had made contact with mental health services since the birth of their child compared to 10% of controls[29]. One case study of a new mother with an eating disorder[59] highlighted the possible presence of significant attachment difficulties from the first month of postpartum. A sample of 91 Chinese mothers who experienced symptoms of bulimia nervosa revealed that whilst these women felt attached to their unborn child, they eventually became more restrictive in their parenting styles. It has been suggested that mothers who are preoccupied with weight loss may be unable to respond sensitively to their child's needs[66].

Women who experience eating disorders had difficulty balancing their desire to care for their child with the need to engage in eating disorder behaviours. One woman was motivated to change but unwilling to be hospitalised for treatment[60], whilst another reported concerns that her unborn child might be overweight[59]. When women were unable to refrain from using eating disorder behaviours during pregnancy, they attempted to reduce the frequency with which they engaged in these behaviours[57]. Others described pregnancy as a battle for control over one's body[61] and whilst some were able to reduce their eating disorder behaviours during pregnancy, others could not forego this sense of control[19]. Many reported that pregnancy was a positive experience which offered them the opportunity to make lasting changes for themselves and their children[19]. Women who have lived with an eating disorder for a long time may feel more

ambivalent during pregnancy. This can be an opportunity for health professionals to help these women prepare for motherhood.

The experience of eating disorders impacted on women's ability to form attachments to children. Mothers who experienced bulimia nervosa and binge eating disorder were more restrictive in their parenting styles and reported more behavioural difficulties in their children[64]. These mothers also experienced greater discomfort when they socialised with friends and fed their child in public. Some women struggled most when they were unable to leave their child alone so they could restrict and purge[65].

DISCUSSION

Main findings

The literature review aimed to explore the experiences of pregnancy and postpartum for women living with eating disorders, using research published since 2008. It was hoped that this review would update the current evidence base and direct future research. The findings suggested that eating disorders impact significantly on women's pregnancy and postpartum experiences. Women remained concerned about their changing body weight and shape throughout this period. There was a trend for eating disorder symptoms to remit during pregnancy then relapse during postpartum. Women experienced depression and anxiety throughout pregnancy and postpartum and were more likely to have sought help from mental health services.

The postpartum period in particular was associated with increased vulnerability. Women struggled to balance the demands of their eating disorder with their child's needs. This had implications for the attachments they formed with their children. The cross cultural mix of studies makes these results applicable to a wider range of women. The findings suggest that the transition to motherhood with an eating disorder is a challenging experience and women may require more support during this time. However a wide range of methodologies and incomplete psychometric details means it is difficult to draw further conclusions about the findings.

Limitations

The search term was applied to multiple databases, the grey literature and an internet search and was deemed exhaustive. Whilst seventeen articles is not particularly representative this review summarises what is currently known and directs future research accordingly. The search term and criteria were designed to capture a range of relevant literature but might have been improved using other pregnancy related words such as 'antenatal'. The decision to include only full text, English articles published in academic journals might have eliminated otherwise

appropriate articles. The findings do not give any information about the later stages of motherhood when children begin to communicate verbally and are old enough to attend school. It is possible that women may then experience different challenges and anxieties. As psychological status was not established consistently across the study samples using similar outcome measures, there is an unclear baseline which impacts on the significance of any reported improvements. Most studies did not report detailed inclusion and exclusion criteria. Where details were reported, the studies recruited women whose eating difficulties did not prevent them from participating. Women with more severe eating disorders might present differently.

These findings highlight the increased incidence of psychological difficulties amongst women with eating disorders. However this may reflect a simplistic view of depression and anxiety given that they are not unitary concepts. When measuring psychological experiences of pregnancy and motherhood for women with eating disorders, future studies could be more explicit about what is being measured. The use of small sample sizes, particularly for women with anorexia nervosa, limits the extent to which these findings can be generalised. Most studies used self report measures which are practically useful but perhaps less valid and allow limited conclusions. The views of partners and other family members were not sought although these findings suggest that supportive partners may aid the transition to motherhood with an eating disorder[19].

The terms ‘anorexia nervosa’ and ‘bulimia nervosa’ were used instead of ‘anorexia’ and ‘bulimia’. The term ‘anorexia nervosa’ translates to ‘nervous loss of appetite’[89]. This highlights the fear of weight gain and poor body image that accompanies eating difficulties. ‘Anorexia nervosa’ offers a more complete perspective than the term ‘anorexia’, meaning ‘loss of appetite’. Whilst both terms are commonly used amongst professionals and individuals with eating disorders, ‘anorexia’ can accompany other health problem including cancer[90]. Whilst ‘anorexia nervosa’ is more reflective of the difficulties many women experience, some women may identify more closely with the shortened term of ‘anorexia’ as it may seem less pathologising. The decision to use ‘anorexia nervosa’ might have discouraged women from sharing all of their experiences.

Theoretical links

The findings of this literature review connect to past research in the areas of attachment and systemic theory. Research suggests that insecure attachments are common within families who experience eating disorders[42-43] because mothers are unable to respond sensitively to their child's needs and may hold unrealistic expectations about their children's behaviour[15, 39, 42]. The current findings highlighted that women who experience eating disorders may indeed struggle to adjust to the demands of motherhood. Their preoccupation with weight loss may prevent them meeting their child's needs. Women reported feeling uncomfortable when they fed their children in public and struggled to strike a balance between meeting their child's needs and engaging in eating disorder behaviours. Mothers with bulimia nervosa and binge eating disorder reported more behavioural difficulties in their children. This may have implications for the attachments women form with their children, particularly if they have difficulty recognising their child's need for security and predictability. It would be helpful for professionals to have a greater appreciation of the implication of attachment difficulties for women with eating disorders and their children.

Other findings connected with literature related to motherhood and the family life cycle. The findings highlighted that these women experienced the transition to motherhood as difficult and overwhelming. They were likely to engage in restrictive eating patterns and were fearful of not losing weight they had gained during their pregnancies. In systemic theory, pregnancy and motherhood are key transitions in the family life cycle characterised by new routines and a change in role[17] and moving from one stage to the next can be challenging if there are existing vulnerabilities such as eating difficulties. Depressive symptoms were frequently found throughout pregnancy and early motherhood. Some women living with eating disorders were more likely to associate motherhood with personal sacrifice, whilst others reported that motherhood was a positive experience. Perhaps even within this group of women there are individual differences. A greater understanding of the potential for differences within this

group of women might remind services to continue to provide tailored, individual support to women with eating disorders.

Recommendations

This literature review highlights the need to support women who experience eating disorders before, during and after their pregnancies. It is likely that mental health services will become involved during this period[56]. These women are more likely to become pregnant unexpectedly due to their belief that they are unable to conceive[54] and may benefit from education from clinicians with experience of working with eating disorders. It might be helpful for women to be informed of the benefits of overcoming their eating disorder symptoms prior to conception, and to receive specialist practical and emotional support throughout the transition to motherhood[19, 60].

The findings reveal the importance of early intervention in treating women who experience eating disorders during pregnancy and early motherhood, to help them make positive changes[27, 29]. It might be helpful for professionals to work with the ambivalence these women are more likely to experience regarding their pregnancies[54], to improve the likelihood of a positive pregnancy experience and help women to form good quality attachments with their children. Pregnancy may be an appropriate time for professionals to discuss eating behaviours with women and identify potential difficulties[62, 65]. These women comprise a small yet highly vulnerable group and being unable to access support might result in significant negative consequences for them and their children.

Health professionals might benefit from greater awareness of the types of anxiety women who experience eating disorders report during pregnancy and motherhood, to understand and support them appropriately. One study[61] found that routine weight monitoring during pregnancy was a particular source of anxiety and suggested that instead health professionals might wish to perform weight checks discreetly or eradicate the process completely. Other recommendations include the use of multidisciplinary team working to ensure that women's practical and emotional needs are accommodated. This could include bringing together

women with similar experiences together to share stories and provide mutual support[57].

The findings of this review echo the recommendations of recent public policy which state that women who experience eating disorders should be monitored during pregnancy and offered specialist antenatal care[91] from a multidisciplinary team of health professionals[35]. Recent findings have helped to improve knowledge of pregnancy and motherhood for women who experience eating disorders and the increasing amount of published research over the past five years is testament to increasing professional recognition of this issue.

The role of clinical psychology

Women who experience eating disorders may be reluctant to discuss their difficulties with health professionals. Clinical psychologists are well placed to support women during this period by gathering information about their experiences using a person centred, non-judgemental approach, and using therapeutic questioning skills to help women reflect and consider the benefits of change. These women are more likely to have experienced insecure attachments within their own families, which might impact on their ability to make a successful transition to motherhood[29, 63, 67]. A psychological approach might encourage women to consider how their past experiences influence their current parenting style, and encourage them to move from viewing themselves as the 'problem' to a position where they can acknowledge the patterns of interaction which influence their eating difficulties[15]. This requires the development of a secure, therapeutic relationship within which women can discuss their difficulties without fear of judgement[92]. There may also be a role in planning practical interventions and helping women to connect with other mothers.

Areas for future research

The experience of pregnancy and motherhood for women who experience eating disorders is an emerging area of research and much is still unknown. It would be helpful to know how women who experience eating disorders manage

change and whether their decision to change is motivated more by concern for their unborn child or because their anxieties about weight gain are less severe during pregnancy. Some women have more positive experiences of motherhood than others. It would be useful to know what contributes to this difference by exploring parenting behaviour, attachment styles, coping strategies, beliefs about motherhood and the trans-generational cycle of risk within families.

A range of eating difficulties was represented amongst the women in this literature review. Future research might recruit larger samples of women and focus more on anorexia nervosa and EDNOS as information about these two groups of women is particularly limited. It would be helpful to explore the experiences of women of a non Caucasian origin as the samples in this literature review are not particularly representative. There is little qualitative research exploring the experiences of pregnancy and motherhood for women who experience eating disorders, in particular anorexia nervosa. The qualitative research identified in the current literature review offered valuable insights into an area about which little is currently known and provides grounding for future research.

Conclusions

Research indicates that women who experience eating disorders are vulnerable throughout pregnancy and early motherhood. This review aimed to collate findings published during the past five years, update the literature and make recommendations for future research. This area is under-researched and the small number of articles identified varied in quality; whilst some offered clear aims, methodologies and implications, others offered less detail, making it difficult to generalise the findings. Key findings suggested that women living with eating disorders experience significant weight and shape concerns throughout pregnancy and motherhood, and that their eating disorder symptoms remit and relapse during this period. These women experienced a range of psychological difficulties which impacted on their transition to motherhood and ability to form attachments with their children. Some struggled to balance the needs of their child with their own, hinting at the role of attachment and family factors in the development and

maintenance of eating disorders. It seems likely that women with eating disorders will find pregnancy and motherhood challenging for a range of reasons, and will require individual support which meets their needs. Women might benefit from more practical and emotional support to help them make a transition to motherhood that is happy and healthy for them and their families.

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Breaking the Cycle: The Transition to Motherhood with Anorexia Nervosa

Abstract: **248 words**

Manuscript: **9,174 words (excluding abstract, tables and figures)**

Journal Guidelines

The International Journal of Eating Disorders aims to advance scientific knowledge needed for understanding, treating and preventing eating disorders. The Journal accepts empirical articles reporting research that is novel and definitive.

Reports should be a maximum of 7,000 words in length, excluding abstract, references, tables and figures. The Journal permits an abstract of up to 250 words, up to 40 academic references and a maximum of eight essential tables and figures. Centred upper case headings are reserved for Methods, Results and Discussion sections of the manuscript. Subordinate headings are typed flush left and underlined in upper and lower case letters.

Referencing follows the Vancouver method of reference citation. References are numbered consecutively in the order in which they are first mentioned in the text. References are identified in text, tables and legends by Arabic numbers. All references cited are listed numerically at the end of the paper. When there are seven or more authors, the first six are listed followed by et al. after the name of the sixth author. Individuals are referred to as “people with anorexia nervosa” or “participants with eating disorders”.

For the purposes of thesis submission, the word and reference limit for this journal was not achieved but this paper will be amended accordingly for publication.

Abstract

Objective: This study aimed to explore the experiences of pregnancy and motherhood for women living with anorexia nervosa.

Method: Eight women were interviewed once using a semi structured interview schedule focusing on their experiences of pregnancy, motherhood and anorexia nervosa. Each had a diagnosis of anorexia nervosa and at least one child aged up to five years. Responses were analysed using a grounded theory methodology, resulting in a theory which attempted to explain how these women managed the transition to motherhood with anorexia nervosa.

Results: A core category of “breaking the cycle” emerged. This was supported by four sub processes; “keeping the baby safe”, “making a new start”, “trying to be the best mum I can be” and “fighting the voice”. Women attempted to break the cycle of anorexia nervosa and find ways to manage anorexia nervosa differently.

Discussion: Whilst there is little prior research in this area, these findings suggest that the transition to motherhood with anorexia nervosa is different from the experiences of other mothers. It might be helpful to prepare women for this transition using educational materials and access to support groups for women with similar eating difficulties. Professionals need enhanced awareness of the challenges faced by mothers living with anorexia nervosa. Clinical psychologists might help women to explore their difficulties and find new ways to navigate the ongoing challenges of motherhood which do not involve binging and purging. Future research should continue to encourage women to discuss their experiences without fear of judgement.

BREAKING THE CYCLE: THE TRANSITION TO MOTHERHOOD WITH ANOREXIA NERVOSA

Introduction

Anorexia nervosa is characterised primarily by significantly reduced calorie intake and weight concern. Individuals who experience anorexia nervosa intentionally moderate their food intake and some engage in weight loss behaviours such as excessive exercise. Anorexia nervosa usually develops during adolescence and early adulthood. Whilst there is no identified single cause for anorexia nervosa, contributory factors may include low self-esteem, difficult family relationships and traumatic life experiences[1].

A number of factors may underpin the presence of anorexia nervosa during pregnancy and motherhood. These include beliefs about body image and negative family dynamics. Body image is defined as 'a person's perceptions, thoughts and feelings about his or her body'[2]. In Western culture the notion of 'slim youthfulness' is associated with success and self-control[3, 4]. For women with anorexia nervosa, who may connect weight loss with feelings of self-worth[1], the physical changes of pregnancy may be especially difficult to manage.

A growing body of literature connects the development of anorexia nervosa with negative family dynamics[5]. Women with anorexia nervosa are more likely to have experienced attachment difficulties and unresolved childhood traumas compared to women who experience other forms of eating difficulty[5-7]. Within their families they recall a greater emphasis on individual responsibility and isolation from their peers[7]. Anorexia nervosa may replace the consistency of a secure attachment to another person, or help women to manage the feelings of confusion and rejection which frequently accompany insecure attachments.

Women who experience poor childhood attachments and later develop eating difficulties may risk exposing their own children to similar problems. Eating difficulties are most likely to be transmitted between generations when there is poor communication within the family[8-9]. However there is insufficient evidence to

determine the direction of causality between insecure attachments and eating disorders. Other factors such as stressful life events may be equally influential.

In the UK approximately 12,000 women who experience eating disorders become pregnant every year[10]. Around 10% of women with eating disorders meet the diagnostic criteria for anorexia nervosa[11]. Research suggests that fertility rates amongst women with anorexia nervosa do not differ significantly from the general population[12]. Past research has included mothers with experience of anorexia nervosa[13] indicating that these women do have children, perhaps more often than commonly thought.

Women who experience anorexia nervosa may feel that they have less control over their bodies during pregnancy[10]. Whilst some women report that a strong desire to protect their unborn child helps them reduce the frequency and severity of their eating disorder behaviours[14-15], others continue to binge and purge as they approach maximum pregnancy weight[16].

In the general population, pregnancy and early motherhood are associated with psychological distress and body dissatisfaction[13-14]. Parenthood is a significant event in the family life cycle and there are significant changes in accommodating a new member within a family system[15]. Whilst many mothers feel overwhelmed by the demands of parenthood[16], women with anorexia nervosa may find this transition more challenging, potentially experiencing complications such as post-natal depression[17]. Whilst motherhood can be a positive experience for these women, they may find themselves unprepared for this transition[18]. It is unclear how women with manage the transition to motherhood. Without this information women and their families cannot be fully supported.

Rationale for the current research

Whilst there is growing interest in the experience of pregnancy and motherhood with anorexia nervosa, women's experiences warrant further exploration. Research suggests that pregnancies are likely to be unplanned and eating disorder symptoms may remit and relapse throughout pregnancy[17]. Further

exploration of this pattern might help clinicians to support women throughout pregnancy and postpartum, since this period may be particularly challenging. Women may experience significant feelings of body dissatisfaction and struggle to meet their child's needs[18]. They may benefit from intensive support during pregnancy and postpartum. However the nature of this support remains unclear. More information about how women manage their transition to motherhood, including the strategies they use, might help to design tailored, supportive services.

Women's experiences have not been explored qualitatively and existing findings are based on retrospective data from small clinical samples of women who experience different types of eating difficulties. These findings suggest that motherhood leads women to experience greater ambivalence about their eating disorder behaviours and question their parenting abilities[18]. The longest period for which women have been examined post-natally is three years[19]. This excludes women with older children who are unlikely to have regular contact with perinatal or eating disorder services.

Women who experience anorexia nervosa should be monitored throughout pregnancy and offered specialist treatment if their symptoms become life threatening[10]. Unfortunately women rarely seek help pro-actively[20]. Health professionals may play an important role in monitoring these women and making referrals for more intensive psychological interventions[21].

Study aims

This study aims to explore the transition through pregnancy and early motherhood (up to five years postpartum) for women with anorexia nervosa, using grounded theory methodology. The research question is: "how do women manage the transition through pregnancy and early motherhood with anorexia nervosa?" This approach has been used previously to explore experiences of bulimia nervosa in pregnancy[22].

METHODS

Participants

The sample was recruited between July 2013 and March 2014. Six women were registered with eating disorder and perinatal services within a large county in the UK. Two women were recruited from eating disorder charities. Within grounded theory methodology there are few recommendations for sample size. A similar grounded theory study[22] sampled 16 women with bulimia nervosa. It was hoped that a similar sized sample might be recruited for this study. However the recruitment process was challenging and it was difficult to find eligible participants.

The researcher had planned to recruit from one eating disorder team. As only four women were recruited in this way, the search was widened to include six additional statutory and voluntary services across the county. It is recommended that qualitative research is based on a sample of eight or more participants[23]. During a twelve month recruitment period, eight women were recruited to participate in this study. As this was an academic research project with time constraints for study completion and submission, it was not possible to recruit a larger sample.

A smaller than expected sample size meant that saturation was not fully achieved. However there was evidence that the sub processes within the grounded theory contained sufficient amounts of data. The core process of 'breaking the cycle' was represented within the responses of all women across the sample. The sub processes were less sufficient but did connect to the findings of previous research. For example, the conflict that women experienced when they attempted to protect their baby from the influence of anorexia nervosa has been discussed previously[22].

Design

Semi structured interview techniques were used. Eight women were each interviewed once using an interview schedule exploring the transition to motherhood with anorexia nervosa (see Appendix C).

Procedure

The study was approved by a number of University and NHS ethical committees. Copies of all approval documents can be found in Appendix D. The researcher received supervision from a clinical psychologist working in an eating disorder service, support from clinical leads of perinatal mental health services to identify and recruit participants and academic supervision from a clinical psychologist in a University context.

Participants recruited from NHS services

The eligibility criteria are provided in Table 1. Potential participants were identified by the clinical supervisor or service lead and sent an invitation letter on behalf of the researcher (see Appendix E). Women were contacted as they became known to professionals working within the teams. To register their interest, women were asked to return the reply slip attached to their invitation letter.

Participants recruited from eating disorder charities

Participants recruited from eating disorder charities responded to information about the study which was circulated online (see Appendix F). Women recruited via this route were screened for eligibility by the researcher (see Appendix G).

Table 1: Inclusion and exclusion criteria for recruitment

Inclusion criteria	Exclusion criteria
English speaking/able to participate using an interpreter	Aged under 18 years
Give informed consent independently	No primary diagnosis of anorexia nervosa
Primary diagnosis of anorexia nervosa given by a psychiatrist (secondary diagnoses such as bulimia nervosa also permitted)	Severe psychiatric difficulties (severe depression, acute psychosis, high risk) which require intensive support
Had a child within the last five years	
Aged 18 years or over	
If participant has psychological difficulties they are actively engaged with a treatment plan	

Women recruited via NHS services were interviewed locally at the service they usually attended. Women recruited through eating disorder charities were interviewed at a local community venue.

The researcher provided information before each interview began using an information sheet (see Appendix H) and consent form (see Appendix I). Seven women were interviewed in a quiet room at one of the available venues. One woman who interviewed by telephone was encouraged to complete the interview in a place where she would not be disturbed. Interviews ranged in length from 37 to 55 minutes.

Development of the interview schedule

The topic guide was based on the research question and gaps in the research literature. Example questions include ‘were you worried about becoming a mother with anorexia nervosa?’ and ‘have your eating patterns changed since you had a child?’ Women were encouraged to discuss their experiences in a way

which felt most comfortable for them. The researcher sought more information where appropriate by asking for specific examples. All interviews were audio recorded. The researcher monitored how women were feeling regularly throughout the interviews. Women described their eating difficulties using different language. 'Eating disorder' and 'anorexia nervosa' were used interchangeably, reflecting how women constructed their eating difficulties.

GPs were made aware of the women who participated (see Appendix J). Women received a written debrief with information about local support agencies after their interview (see Appendix K) and a summary of the findings after the study ended (see Appendix L). Identifiable information was anonymised and women chose a pseudonym to represent their responses. A flowchart of the procedure is presented in Appendix M.

Epistemological position

Grounded theory offers a means of exploring lived experiences by explaining how a group of individuals experience a social process. Critical realist approaches acknowledge that whilst scientific investigations require real 'objects', our understanding of these objects is an ongoing, changing process influenced by our experiences and beliefs[24]. A critical realist approach to grounded theory suggests that there are 'truths' to be discovered, but that these are dependent on the personal and professional experiences of the researcher[25-26].

This position best reflects the thoughts of the researcher, whose personal experiences of living with an eating disorder have led to the conclusion that whilst there is an element of truth to the concept of anorexia nervosa, individuals will describe the reality of anorexia nervosa in different ways. The ways in which the researcher made sense of women's stories was influenced by personal and professional experiences. These stimulated her interest in this topic and influenced decisions made with regards to data analysis. For example, the tendency for women to conceptualise anorexia nervosa as an external presence was similar to the researcher's personal experience of anorexia nervosa.

Consequently, stories of ‘battling’ and ‘fighting’ the influence of anorexia nervosa featured prominently in the final grounded theory.

The term ‘anorexia nervosa’ is used throughout. The researcher has experienced the use of ‘anorexia nervosa’ and ‘anorexia’ amongst professionals and individuals with eating disorders, in reference to loss of appetite. ‘Anorexia nervosa’ offers a more complete definition, combining reduced appetite with fear of weight gain and poor body image[27]. In line with a critical realist position, this definition suggests that there is a ‘truth’ to anorexia nervosa, which is filtered through the experiences of individuals who experience eating disorders and the professionals who work with them.

Grounded theory

A grounded theory methodology was considered the most appropriate type of analysis. Grounded theory has sociological foundations and focuses on social processes, including life transitions, rather than specific phenomena or internalised processes, which might be explored using other qualitative methods such as narrative approaches[25]. This study focused on how a group of women managed a social process. The aim was to build a tentative theory explaining how women make a successful transition into motherhood, rather than describe their lived experiences, as might be the focus of an interpretative phenomenological analysis. Whilst all the women have a diagnosis of anorexia nervosa, their experiences were heterogeneous; there were a range of experiences from choking phobia to co-morbid diagnoses of bulimia nervosa. Grounded theory is well suited to exploring social processes experienced by heterogeneous groups of individuals[25].

Within a grounded theory there is also space for consideration of context and culture. As this study explored how women manage the transition to motherhood in the face of societal pressure to maintain a low weight, and dominant narratives around successful motherhood, a methodology which focuses on culture and context seemed appropriate[26].

The process of data analysis is summarised in Table 2. Data analysis began after the first interview. The researcher kept a reflective diary and summarised each interview after it had taken place. Each transcript was coded manually, focusing on single lines and segments of data. A large number of descriptive codes emerged which were recorded in the reflective diary. The researcher used memos to record her thoughts about the interviewing process and any words or phrases which seemed particularly significant. An example of a memo is presented in Appendix N.

As interviewing progressed, the researcher used the constant comparative method to compare earlier interviews with later interviews and identify similarities and differences between participants. An example of this is presented in Appendix O. Memo writing allowed the researcher to speculate on which codes might develop into more significant categories. An example of a code is presented in Appendix P. The interview schedule became more focused as the researcher concentrated on topics which fitted the emergent categories. For example, the concept of 'fighting the voice' of anorexia nervosa quickly emerged. In later interviews when this was mentioned, the researcher explored this further by asking for clarification and specific examples.

The findings were analysed using critical realist grounded theory techniques[26]. A critical realist grounded theory approach to data analysis advocates moving from descriptive coding up to more interpretive processes[26]. When interviewing was complete, the researcher examined all the codes that had been produced and looked for similarities between them. Similar codes were grouped together, forming provisional categories. Through a process of comparing earlier codes with later codes, six categories emerged from the data. These were developed using axial coding[28], exploring the conditions under which each category emerged, the strategies used and the context in which they operated. An example of a category is presented in Appendix Q.

The six categories were collapsed into four sub processes to ensure each sub process contained a sufficient amount of data. An example of a sub process is presented in Appendix R. The researcher identified a core category which

connected all of the sub processes and provided an overarching framework for the grounded theory.

The emerging theory comprised a core category and four sub processes with conditions under which the processes operated. This is one interpretation of how a group of women manage the transition to motherhood with anorexia nervosa. It is possible that this interpretation is influenced by the personal and professional experiences of the researcher[24].

Table 2: Stages of data analysis with example codes and categories

Stage of analysis	Process of analysis	Example
Open coding	Transcripts were coded by hand using brief action codes to describe what was happening in each section of data.	Natasha discussed discovering her pregnancy, saying that she thought it would "probably take at least a year to get pregnant erm it was three weeks and the shock that, I didn't feel prepared". **This was coded as "feeling unprepared"**
Focused coding	As more women were interviewed, line by line codes were revisited and links made between participants' responses. The researcher used the constant comparative method to compare later interviews with earlier codes and categories. This resulted in 34 categories.	The code "feeling unprepared" was linked with other codes from other participants, including "feeling unsure" and "trying new things". **A new category was created called "coping with uncertainty"**
Axial coding	The 34 categories were collapsed into six higher order	The category "coping with uncertainty" was combined with four

	categories. These were developed using axial coding to determine the causal, contextual and intervening conditions for each higher order category.	other categories, including "acceptance" and "making changes". **A new higher order category was created called "Doing things differently"**
Selective coding	To ensure that all data were accounted for without replication, the six higher order categories were collapsed further to create four sub processes	The higher order category "doing things differently" was combined with another, "changing priorities". **A new sub process was created called "Making a new start"**
Development of the core category	The four sub processes were revisited. A core category emerged which linked the four sub processes together	The sub process "making a new start" was linked to the core category. **A core category was created, called "Breaking the cycle"**

Quality control

It is important for qualitative research to demonstrate transparency with regards to data analysis and interpretation[29]. The researcher sought regular supervision with an academic supervisor, where ideas were discussed for resonance as they developed. As the grounded theory developed, a section of transcript was coded by a colleague who was unfamiliar with this clinical area. When the sections of transcripts were compared there were similarities between the two sets of codes. For example, a paragraph which was originally coded as "coping with uncertainty" was coded by the colleague as "managing change".

Further credibility checks

To enhance the credibility of the findings, a brief summary of the emergent results was sent to two women who did not meet the full study criteria. These women had received information about the study when it was circulated online by a local eating disorder chair and had expressed an interest in participating. Both women had a current diagnosis of anorexia nervosa but their children were adolescents, therefore they were ineligible to participate. However their input into the study was welcomed and instead they were asked to provide feedback on the grounded theory as it developed. Both women offered their thoughts and comments by email.

They agreed that the goal of their transition to motherhood was not the elimination of anorexia nervosa, but finding ways of managing it differently. They echoed the participants' feelings that motherhood had afforded them the strength they needed to make the transition, despite continuing to struggle with the demands of anorexia nervosa. Both women highlighted that strong feelings of low self-esteem and worthlessness frequently accompanied their eating difficulties. In addition to the existing findings, they emphasised that whilst motherhood could be demanding, it offered a new purpose for life and a valuable opportunity to make positive changes. The researcher attempted to weave these accounts into the grounded theory by paying attention to stories of personal growth and change as well as conflict and struggles.

Ethical issues

The inclusion and exclusion criteria of this study were designed to ensure that the sample was consistent and fulfilled the requirements of the research question. It was felt that the experiences of women with other eating difficulties were beyond the scope of this study. Despite this, the women who participated reported a range of symptoms, some of which were more consistent with the diagnostic criteria for anorexia nervosa than others.

RESULTS

Demographics

Women's ages, number and age of children are shown in Table 3.

Table 3: Demographic details

Participant name	Age	Number of children	Ages of children	Age of onset of anorexia nervosa
Elise	29	1	14 months	19
Becky	30	2	4 and 8 years	8
Emma	23	1	10 months	16
Natasha	33	2	4 and 6 years	14
Chan	24	2	2 and 5 years	20
Lacey	30	2	4 months and 4 years	16
Sophie	18	1	4 months	7
Rachel	33	1	2 years	31

Data analysis

Line by line coding produced 34 themes which were developed in axial coding to determine causal conditions, resulting in six categories. During selective coding the categories were further refined, resulting in a core category and four sub processes.

The core process guiding the transition to motherhood involved breaking the cycle of anorexia nervosa. Women who made a successful transition found new ways to accommodate anorexia nervosa in their lives. "Breaking the cycle" comprised four sub processes – "keeping the baby safe", "making a new start", "trying to be the best mum I can be" and "fighting the voice". The use of in vivo codes was considered more representative of women's experiences. For example, most women referred to themselves as "mums" rather than "mothers", therefore the term "mum" is used in the grounded theory. These sub processes are illustrated in Figure 1.

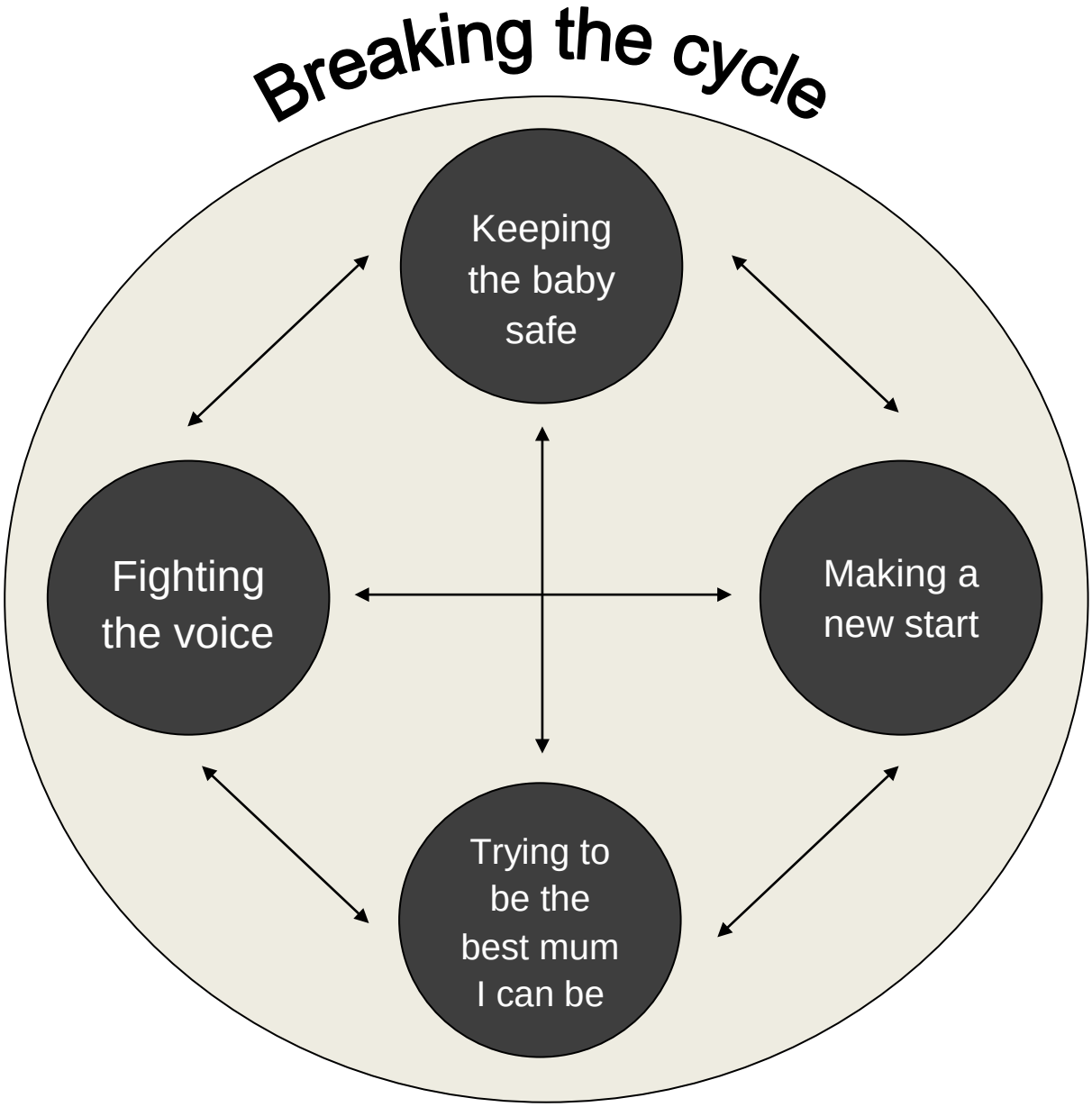
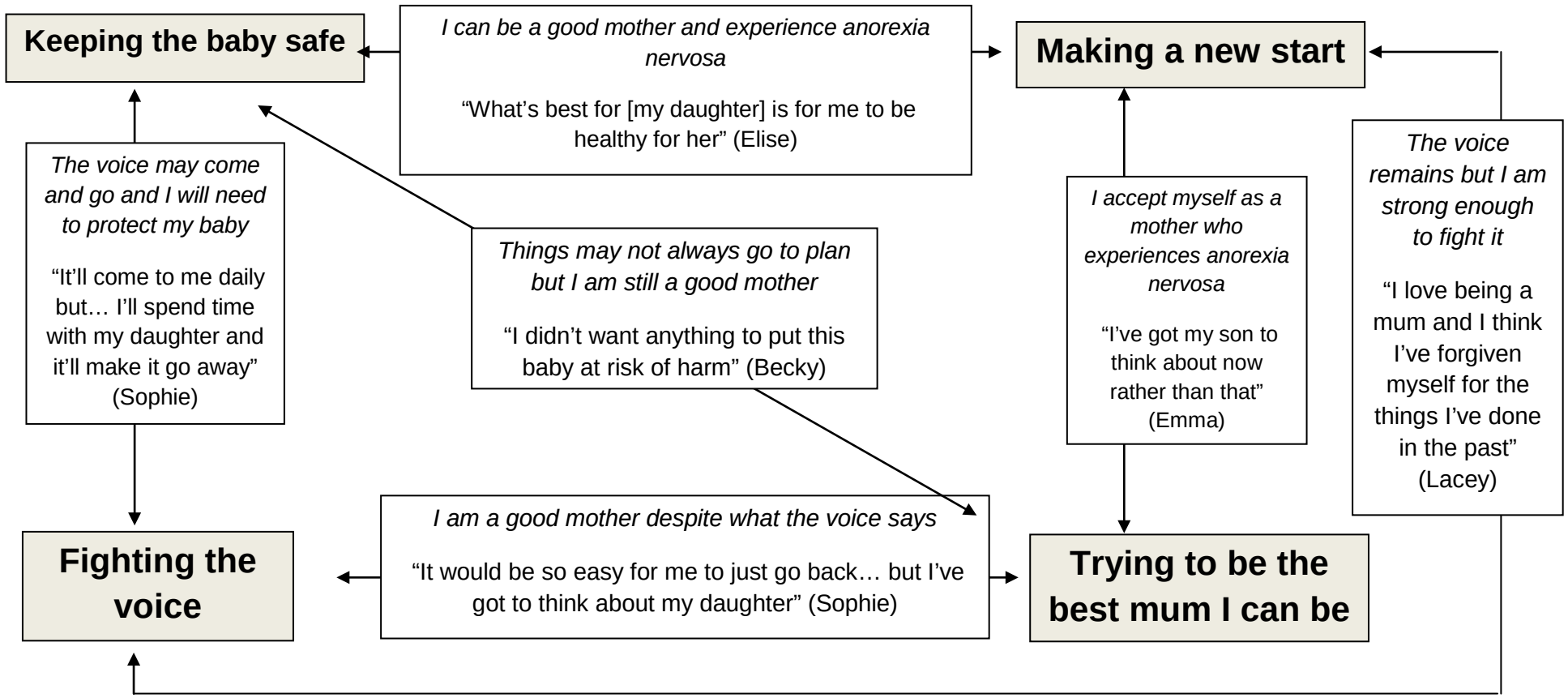


Figure 1: Core category and four sub processes linked together

Generally women conceptualised anorexia nervosa as a separate entity which remained in their lives despite their efforts to leave it behind. During the transition to motherhood, women embraced new perspectives and considered ways of managing anorexia nervosa differently. The four sub processes are illustrated further in Figure 2.

Figure 2: Connections between the four sub processes of "breaking the cycle"



Keeping the baby safe

During pregnancy women recognised that they were now responsible for protecting their children from anorexia nervosa. Sophie described her desire to maintain a healthy body weight during her pregnancy in order to "fuel" her baby as she developed:

> "I know that I'm helping her survive… it kind of feels like when I was pregnant because I was helping her to survive then." (Sophie)

As women prepared for birth the regimes of anorexia nervosa were gradually replaced with new child focused routines. However Rachel remained concerned that despite making these changes, she still might not be able to adequately protect her daughter:

> "I remember reading that mums with eating disorders can inadvertently underfeed their children… because they're unconsciously influenced by their own eating difficulties… I was terrified by that… you start to realise that there's a lot of things you don't notice about yourself and about what you do." (Rachel)

Lacey explained how accommodating anorexia nervosa within motherhood was "the hardest time with the eating disorder that I've had… you've got this feeling of you want to keep your baby safe". Motherhood was unpredictable and women were less able to manage their anxieties using eating disorder behaviours. Whilst they readily accepted their new roles, frequent exposure to distress with few opportunities to use eating disorder behaviours was difficult to manage.

Throughout pregnancy women found ways to create space in their lives, physically and emotionally, for their children. Elise spoke about realistically accommodating anorexia nervosa whilst trying to maintain a healthy diet. Natasha spoke powerfully about the feeling of being "invaded" by her baby during her pregnancy. She felt she had "no choice over what [her] body was doing". Natasha's pregnancy was a physically difficult and emotionally uncertain time and

she became concerned that her negative pregnancy experiences might have affected her relationship with her daughter:

> "I guess I thought I saw her as punishment?… I didn't really like being pregnant with her… We've always had a very strange relationship me and [eldest daughter] it's very up and down we clash a lot." (Natasha)

The process of making room for a baby continued after children were born. Becky described how usual routines went "out of the window" after her sons were born. Elise summarised her difficulties as "having the actual physical time, I can't just put her down and go and make myself sick before you know she'll be there". Rachel did not experience anorexia nervosa until after the birth of her daughter, although she too had a difficult pregnancy experience. She explained how she decided to manage anorexia nervosa differently as her daughter developed:

> "It's an absolute… not to impact on the life of another person it's dependent on me and all I could do was to just you know put my own needs and desires to one side." (Rachel)

Unfortunately anorexia nervosa was so powerful that it overshadowed the space women had created for their children. Women acknowledged that their children might become aware of their eating difficulties despite attempts to limit their exposure by hiding these behaviours. Lacey described the internal battle that ensued when she tried to ignore anorexia nervosa and concentrate on her daughter:

> "At the back of your head you're trying to suppress these thoughts of you're too fat you're eating too much… block[ing] them out makes it worse so when I had [my daughter] I was like, it all hit me." (Lacey)

The battle to make room for the baby intensified as women became overwhelmed by the responsibility of making decisions which impacted on their child's development. Elise recalled a sense of failure when she was unable to continue breastfeeding. Emma suggested that during these times, anorexia

nervosa offered the opportunity to restore a sense of control within her life, explaining that by “limit[ing] the amount I was eating… it just made me feel stable”.

As the transition to motherhood continued, women discussed their hopes that they might be remembered positively by their children. They were concerned that their eating disorder experiences had already impacted negatively on relationships with their children. Chan wondered whether her attachment to her eldest daughter was undermined by the difficulty she experienced in making space for her in her life alongside anorexia nervosa. She felt she had “pushed [her] older [daughter] away”.

The process of making room for children was most apparent during early motherhood when women were forced to accommodate their child’s needs alongside the demands of anorexia nervosa.

Making a new start

Elise spoke of “making a new start” during her pregnancy. Motherhood provided women with valuable opportunities to explore new ways of managing anorexia nervosa. They began to reveal their vulnerabilities and accept help from family, friends and professionals. However motherhood was also unsettling and anorexia nervosa provided familiarity and comfort within an unpredictable environment. Natasha spoke of her shock when she discovered that she was pregnant. Fear of failure and uncertainty about the future prevented women from making positive changes during pregnancy.

During the post-partum period women made significant changes. Elise discussed her search for “other methods that are out there to actually deal with [anxiety] and that takes so much more effort than just giving in [to anorexia nervosa]”. Chan reflected on the improvements she had already made since giving birth, Emma reconnected with her family and friends and Lacey described how she forgave herself for decisions she had made in the past.

Making changes was most difficult when women doubted their parenting abilities and compared themselves negatively to other mothers. Chan described the “constant worry” which accompanied her desire to be a good mother. Whilst change exposed some women to the possibility of failure, others felt that this process had offered them space to reflect on their progress. As women completed the transition to motherhood they acknowledged their ability to make lasting positive changes which would benefit them and their families. Emma described how motherhood had allowed her to “see what’s important”. From early pregnancy through to birth and beyond, motherhood offered new perspectives and possibilities.

From the earliest stages of pregnancy, women identified that their priorities were changing. Unfortunately, whilst anorexia nervosa was generally perceived as a negative influence it also provided structure and routine. Natasha tried to look forward to the birth of her daughter, but a life without anorexia nervosa felt overwhelming. Becky was concerned that she might not cope with the demands of motherhood. Lacey struggled to envisage life without the security of anorexia nervosa and wondered “how do you cope with being pregnant with these thoughts and the eating disorder what if it kicks in”.

As women began to envisage a new life as a mother, they realised new hopes and aspirations. Emma experienced a desire to distance herself from anorexia nervosa after the birth of her son and explained that “I’ve got my son to think about now rather than [anorexia nervosa]”. Becky hoped to introduce more fun into family life whilst both Rachel and Sophie discussed their desire to be “role models” for their daughters. Chan was reminded of her children whenever she felt compelled to use eating disorder behaviours to manage her distress, explaining that “you can’t cause you’ve got kids”. Women began to experience a greater sense of belonging and contentment. Lacey described feeling “loads happier” as a mother. Pregnancy and motherhood posed many obstacles but as women completed their transition they were able to explore a new life with different priorities.

Trying to be the best mum I can be

Lacey spoke of "trying to just be the best mum I can and it seems to be working cause [my daughter] is doing great". Women found it difficult to explain their experiences to others. They felt that family and friends did not appreciate how much negative thinking and low self-worth accompanied anorexia nervosa. Chan spoke with frustration as she described other people's misunderstanding of her difficulties:

> "Because I look normal and act normal they think oh you're alright well no actually that puts pressure on you and gets you down." (Chan)

For Emma, anorexia nervosa was "my only way of… showing how I feel". Women felt they were judged harshly for continuing to engage in eating disorder behaviours during pregnancy, which led them to minimise or hide these experiences. Lacey described "the anorexic mindset" as a way of thinking which was different to mothers without experience of eating disorders. Natasha felt isolated by her own pregnancy experiences and spoke of how she "felt very much like I shouldn't be feeling like this so… don't say it out loud".

During pregnancy women were able to limit their exposure to negative comments but as new mothers they were frequently exposed to judgment from others. Rachel described a feeling of "awkwardness" when she spent time with other mothers and felt it was "difficult to carry on socialising with other mums because it's all tea and cake [and] lunch dates". Emma's experiences of feeling misunderstood led her to react defensively to perceived criticism. Elise summarised the true experience of living with anorexia nervosa:

> "People think it's about like what you put in your mouth and I'd say to me it's what's going on in my head and everything else is a symptom of that." (Elise)

This made women feel isolated and unable to relate to other mothers. Rachel highlighted the importance of feeling accepted by others:

> "You judge yourself quite harshly anyway… so it's quite helpful if others don't do that too." (Rachel)

Women who felt understood were more able to accept themselves and acknowledge the continuing presence of anorexia nervosa in their lives.

Fighting the voice

Anorexia nervosa was conceptualised as an external force which controlled women's thoughts and cast a shadow over their achievements. Lacey described anorexia nervosa as a "dark and consuming and self-perpetuating negative horrible thing". Elise explained how anorexia nervosa attempted to draw her back into old routines and undermine her parenting abilities. She described how "it builds up to a point where [you] have to do something". Rachel recalled her shock at how quickly her health had deteriorated before she was referred to her local eating disorder service. Sometimes anorexia nervosa was so powerful that it prevented women from looking forward to the future.

Throughout the transition to motherhood, women experienced a strong desire to make lasting positive changes. Lacey described a "turning point" where she realised she had to make changes. Rachel was reluctant to accommodate anorexia nervosa within her family as she had "never invited it in". Sophie accepted that anorexia nervosa might continue to "niggle at me now and again… it'll always be there".

All of the women were determined to create a happy environment within which their children could thrive. Emma was concerned that her son might compare her negatively with other mothers:

> "I never want him to see me like that and think it's normal and then see other people like other children's mums and think why can't my mum be like that." (Emma)

Becky and Chan were concerned that they were not disciplining their children correctly. Natasha was fearful that her eating difficulties might influence her daughters' body image and eating patterns. She expressed sadness at the possibility that she had unintentionally "taken the enjoyment of eating away from them". This led women to feel inadequate as mothers.

Elise spoke of the importance of "set[ting] a good example". All of the women had similar hopes and achieved this in various ways. Natasha and Becky provided healthy meals and celebrated when their children ate them. Rachel discovered that other mothers baked with their children and resolved to bake with her own daughter every week. Sophie planned to encourage her daughter to "eat with her and eat in front of her". Chan ensured her daughter always ate enough food, even when she was unable to eat herself. Whilst she clearly intended to encourage her daughter to eat healthily, her approach was perhaps less helpful compared to other women:

> "I have to force her… she keeps putting food in her mouth and taking it out… I have to bribe her with like Santa won't come to you if you don't eat." (Chan)

Women struggled to set a good example whilst simultaneously battling anorexia nervosa. Chan's experiences of feeling blamed for her children's eating difficulties reinforced her own sense of inadequacy. Rachel felt that her daughter noticed anorexia nervosa more now compared to a year ago. She feared that time was "running out" for her to resolve these difficulties without impacting on her daughter, explaining that "you can blag it to a toddler but not to a grown child". Lacey wondered whether her own fear of eating in public places might impact negatively on her daughter:

> "When you've got a little girl and you're going out and she's like mummy can we eat something and you'd have to eat in public… I'd sit there with a drink and obviously as she was getting older she was starting to recognise these patterns." (Lacey)

The desire to set a good example to their children meant that women questioned their parenting abilities and their ability to cope with the demands of motherhood. However the possibility of breaking the cycle of anorexia nervosa and creating a happy family life helped women to navigate the challenges of pregnancy and motherhood.

Battling temptation

> "It would be so easy for me to just go back… given a choice I probably would but like I said I've got to think about my daughter." (Sophie)

At times women felt they had little choice but to use anorexia nervosa to manage the challenges of weight gain, unfamiliar routines and new responsibilities. This was particularly true when women felt lonely and overwhelmed. Emma likened anorexia nervosa to an addiction:

> "It controls the way you think… your thoughts aren't really yours anymore, they belong to the disorder… you lose sight of your family then… all you keep thinking about is [AN]." (Emma)

Natasha found that as the battle became more difficult to fight, she felt "losing weight [was] as important as the girls". This was a lonely battle; women could not be certain of the consequences of discussing their concerns with other people and frequently felt isolated. All continued to build new lives for themselves and their children. Both Emma and Elise had discussed their difficulties with family, friends and professionals and received an unexpectedly positive response, providing them with much needed support and reassurance.

DISCUSSION

Summary of main findings

The aim of this study was to explore the transition to motherhood for women who experience anorexia nervosa. The findings informed a grounded theory which focused on how women managed this transition. The grounded theory centred on a core process of breaking a cycle of certainty and control ('breaking the cycle'). Within this cycle there were four sub processes. Women shielded their children from influence of anorexia nervosa ('keeping the baby safe'). They continued to fight anorexia nervosa even when it exerted an influence on their lives and tempted them to succumb to old routines ('fighting the voice'). They worked hard to prove themselves as good mothers and justify their decision to continue engaging in eating disorder behaviours despite their new role as mothers ('trying to be the best mum I can be'). They viewed motherhood as an opportunity to make a new start and do things differently ('making a new start'). Women's experiences of the transition to motherhood involved all of these sub processes.

Whilst this transition offered a valuable opportunity to make lasting positive changes, women struggled to accommodate anorexia nervosa within motherhood. These findings connect with past research and attachment, systemic and feminist theories of motherhood and anorexia nervosa.

Core process: Breaking the cycle

This core process relates to how women leave behind the routine and rigidity of their previous lives to make way for their transition to motherhood. Systemic theory suggests that an individual's behaviour is best understood in the context of the transitions they make through stages in the family life cycle. Parenthood is one of the most significant stages[30]. Embarking on the transition to motherhood, Natasha was increasingly reluctant to engage in anorexia nervosa. Lacey identified motherhood as a "turning point" where she began to make changes to protect her children from anorexia nervosa.

The transition to motherhood is one of the greatest changes that women experience[9] and can expose women's anxieties about their bodies, children and the future. Pregnancy and post-partum are associated with higher levels of body dissatisfaction[31]. Indeed, Natasha felt her pregnancy experiences might have been different had she not been concerned with her changing body shape. After her daughter was born, Sophie managed her feelings of body dissatisfaction by exercising daily. Women with eating disorders experience more self-doubt and self criticism compared to women in the general population[32]. In the present study women questioned their parenting abilities. Whilst partners, family members, friends and health professionals all provided support, being monitored by other people could also make women feel inadequate.

Keeping the baby safe

Women expressed guilt when they considered the possible repercussions of their eating disorder behaviours for their children. Previous research suggests that mothers with eating disorders remain anxious that their children might develop eating difficulties[33]. Within attachment theory is the notion that feeding offers comfort to a distressed child and helps them to develop the ability to self soothe[34]. Eating difficulties may develop when mothers misread their child's signals for comfort during feeding times[35]. Children may then place greater emphasis on their own weight and shape[36]. Natasha wondered whether her strict behaviour during mealtimes had had a negative and counterproductive effect on her daughters. Chan described how she "bribed" her daughter to ensure she ate enough food. Despite their desire to shield their children from their difficulties, women with negative childhood memories of mealtimes may struggle to provide positive feeding experiences for their own children[9].

This grounded theory connects to other experiences of pregnancy and motherhood, including women who experience postnatal depression. In the current study, women expressed a strong desire to shield their children from anorexia. For women who experience postnatal depression, early motherhood may also be a hazardous period. Throughout pregnancy and early motherhood

there are opportunities to form a physical and emotional bond with the baby[37] like Sophie, who was pleased that she was able to attend regular ultrasound scans as these allowed her to develop an attachment with her unborn daughter. Feeling protective of the baby is an experience that is likely to be common amongst women with and without experience of anorexia nervosa.

Making a new start

The transition to motherhood presented the opportunity for women to make a new start and consider the possibility of positive change. Women living with anorexia nervosa are more likely to have experienced loss, unresolved trauma and insecure attachments[5-6] compared to women who experience other eating difficulties. Research suggests that as a consequence, women living with anorexia nervosa are more likely to be dismissive when they interact with their children[5]. However the present findings suggest that motherhood helped women to change existing patterns of behaviour and try new things. They discussed how they engaged their children in enjoyable activities such as baking and visiting friends, and associated motherhood with greater contentment and belonging. One hypothesis is that these women are working hard to avoid replicating the troubled relationships they experienced within their own families[9, 33].

Making a new start was not without difficulty and some women struggled to manage the ongoing influence of anorexia nervosa in their lives. Anorexia nervosa may replicate the feelings of comfort usually found within a secure attachment to another person. Pregnancy and early motherhood are characterised by physical and emotional uncertainty[9]. When the opportunity to engage in eating disorder behaviours is limited, women may be exposed to unmanageable emotions. Despite their desire to make positive changes, a difficult transition may have implications for the attachments women form with their children. A recent study[38] exploring experiences of first time mothers in the early weeks of motherhood echoed these findings, suggesting that women experience feelings of ‘losing touch’ and ‘restoring balance’ as they establish a new identity as a mother.

Women recognised that the decision to make a new start was part of an ongoing transition to motherhood, within which they also identified new perspectives and began to feel 'good enough'[39]. Many felt that motherhood had made their struggle worthwhile. By tolerating the uncertainty of change, women were able to make a successful transition to motherhood.

There are parallels with women who do not experience anorexia, who also have difficulty accommodating a baby in their lives whilst exhausted and dealing with changes to their weight and shape. Women may feel ambivalent about entering a new life stage[37]. Perhaps if women were given space to grieve for the loss of autonomy, appearance and identity, they might be more able to make a successful transition to motherhood[40].

Trying to be the best mum I can be

Women in the present study frequently felt misunderstood by family and friends, whose narrow definitions of anorexia nervosa did not reflect their experiences. Similarly in past research[41] women with anorexia nervosa reported that they were often labelled as 'attention seeking'. Through the lens of a medical discourse, anorexia nervosa is viewed as preoccupation with weight and use of behaviours intended to rid the body of excess calories. In reality anorexia nervosa is more complex; women experience lower self-esteem and a greater need for control compared to women who diet to lose weight[42-43].

Most misconceptions were based on how mothers *should* think, feel and behave. Within Western society some roles for women, including wives and mothers, are privileged at the expense of others. Dominant discourses for motherhood highlight feelings of happiness and fulfilment. Women deviating from these discourses may struggle to gain acceptance of peers[44-46]. In the present study women were frequently challenged by the demands of motherhood like Elise, who reported feeling rejected by her daughter when she was no longer able to breastfeed. It seems there are few alternative discourses to help women make sense of their experiences.

Women are generally allocated the role of primary caregiver for their children[45]. Women may be expected to sacrifice any non-family interests not directly related to their new roles as mothers[47-48]. Perhaps this explains the pressure women felt to set a good example to their children. Natasha's feeling of "not knowing who the hell [she] was" highlights the disconnection some women feel during the post-partum period[44].

Women are expected to love their children unconditionally and allow them to flourish. Those who do not embrace motherhood may be exposed to judgement from peers[47-49]. In the present study women frequently felt isolated during their pregnancies and compared themselves unfavourably to friends. A more realistic discourse of motherhood might highlight loss of freedom and exhaustion as well as new opportunities[50-51].

In the present study women met with judgement from other people as they worked hard to prove themselves yet fell short of expectations. This was not an experience unique to mothers with anorexia. Women who experience postnatal depression are also subject to comments from strangers and bombarded by images of pregnancy and motherhood in the media[37]. Motherhood may be experienced in various ways. The images espoused by the media are not necessarily a reality. Many new mothers experience depression, stress and anxiety, perhaps partly triggered by the sense of duty and responsibility that accompany pregnancy and motherhood[40].

Fighting the voice

Women used different narratives to describe anorexia nervosa. Most women described a battle in which they fought anorexia nervosa. This connects to previous research in which women described a voice in their heads which dictated their eating disorder behaviours[52]. Elsewhere, Sophie described pregnancy as an opportunity to "fuel" her baby with the necessary nutrients to develop, and Natasha described a feeling of being physically and emotionally heavy during pregnancy. Similar metaphors equating lightness with feelings of success and happiness have been identified in past research[53]. The medical narratives which dominate health

services may not adequately encompass the reality of women's experiences, leading them to reject professional support when it is most needed.

Some women described how the addictive, compulsive qualities of anorexia nervosa made it difficult to fight. Elise described the intense anxiety that accompanied her compulsions, whilst Emma discussed how anorexia nervosa controlled her thoughts. These characteristics of anorexia nervosa have been described previously with comparisons drawn between anorexia nervosa and obsessive compulsive disorder[54]. The current findings suggest that whilst women with anorexia nervosa might present differently, they may experience similar thoughts and compulsions. As new mothers exposed to unfamiliar situations, despite their desire to fight anorexia nervosa, they may at times feel they have little choice but to resort to anorexia nervosa as a means of managing their anxiety.

Perhaps the transition to motherhood with anorexia nervosa is best understood as a process of struggling for control, developing supportive relationships and tolerating uncertainty[50-51]. This connects to the core category of "breaking the cycle" within which women reject familiarity and embrace an uncertain future. Women who make a successful transition are able to accept themselves and acknowledge the ongoing presence of anorexia nervosa in their lives.

<u>Connections between the sub processes</u>

Each of the four sub processes were considered equally important and together they provided a range of ways in which women made a successful transition to motherhood. The four sub processes linked with one another. Many women discussed their desire to protect their children from anorexia nervosa ('keeping the baby safe') and acknowledged that this was the first time they had considered doing things differently ('making a new start'). Some women spoke of making positive changes ('making a new start') by choosing to fight anorexia nervosa rather than allowing it to influence them ('fighting the voice'). Other women demonstrated their worth as mothers ('trying to be the best mum I can be')

by hiding their eating disorder behaviours from their children ('keeping the baby safe').

Methodological and ethical issues

There are limitations to a grounded theory approach. The constant comparative method is designed to encourage researchers to ground findings in the data and reach a point of saturation. This is dependent on the amount of time available for data analysis and the researcher's abilities. The recruitment process was challenging and whilst the sample was an appropriate size for qualitative research, it is unlikely that the sub processes were sufficiently saturated. Critical realist grounded theory provides specific instructions and guidance for novice researchers[25], perhaps at the expense of the creativity of other grounded theory approaches.

Criteria for evaluating the impact of grounded theory studies include credibility, resonance and usefulness[25]. Whilst effort was made to collect enough observations to support the grounded theory, the findings are subject to individual interpretation. As data analysis developed, feedback on the preliminary findings was sought from two women who did not meet the study criteria. For example, they agreed with the concept of a 'voice' of anorexia nervosa and that this encompasses more than appearance concern.

As all of the women were White Caucasian, it is not possible to conclude that the experiences of other women would be the same. Perhaps the transition to motherhood with anorexia nervosa is different for women who have been exposed to different cultural norms and alternative definitions of the family. The semi structured interview schedule was designed to give women the opportunity to share their experiences in ways which made most sense to them. However they may have felt restricted by the questions. A narrative methodological approach may have been more liberating. The interview schedule made reference to 'anorexia nervosa' but some women referred to 'eating problems' or 'eating difficulties' instead. Perhaps 'anorexia nervosa' was less reflective of their experiences. Women were aware that should issues of risk arise during the

interviews, the researcher was obliged to disclose these to relevant health professionals. It is possible that the presence of the researcher prevented women from speaking openly or abstaining from participating.

The study criteria were designed to be unrestrictive. However using an anorexia nervosa diagnosis as a criterion for inclusion adheres to a medical discourse and perhaps disregards different narratives of eating difficulties. Excluding women on the basis of severe psychological difficulties was subjective as the decision about whether women could participate was made by the professionals involved in their care. This potentially limits the validity of this grounded theory. It might have been helpful to triangulate these findings with other standardised measures.

Reflexive analysis

The author's experience of living with an eating disorder strengthened her connection to these women. Whilst this meant the author was less fearful of asking difficult questions, it is possible that personal curiosity makes it more difficult to adhere to a semi structured interview schedule. Prior to meeting women, eight similar stories were expected, characterised by struggles and conflicts. Whilst conflict did feature in data analysis, higher order categories of new priorities, recovery and acceptance suggest a different discourse of motherhood and anorexia nervosa.

Recommendations

It is hoped that the recommendations arising from these findings will help refine current professional practices for mothers living with anorexia nervosa.

Natasha had never met another mother who experienced anorexia nervosa. Women with eating disorders frequently feel misunderstood by others, leading them to seek support from other women with similar difficulties. Whilst this might offer comfort, it may also encourage women to conceal their difficulties and resist professional involvement. Women might experience a renewed desire to engage

in anorexia nervosa if their peers share stories of similar difficulties[43]. Existing recommendations include providing new parents with educational materials and opportunities to discuss their experiences[51]. It might be helpful for women with anorexia nervosa to share experiences of the transition to motherhood, perhaps through service user led support groups, monitored by professionals who can promote healthy weight control practices.

Women experienced difficulty acclimatising to new routines and frequently felt out of control. Research recommends that health professionals work with new mothers to instil self-confidence[51, 55]. Health professionals would benefit from information and training about the common misunderstandings of eating disorders and the language women use to describe their difficulties. This could be delivered in collaboration with mothers with anorexia nervosa, who could advise on how their needs might be best met.

Practical and emotional support to help women manage the uncertainty of motherhood would be beneficial. Educational materials containing practical ideas for managing the challenges of motherhood with anorexia nervosa could include how to ask for support and finding time for self-care. Professionals should be mindful that reassuring women of their abilities might not be sufficient, and it might be more useful to spend time exploring women's anxieties and helping them to develop insight into their difficulties. Rachel spoke of the benefits of having "structure" within recovery. She highlighted the need for professionals to offer women a "safety net" with resources in place to support them during acute phases of anorexia nervosa when they might not recognise the severity of their difficulties. When professionals are equipped with information about the strategies women use to manage the transition to motherhood, they can provide more enhanced support when it is needed.

Natasha was surprised that no one had asked about her experiences of motherhood and anorexia nervosa before this study and felt it would have been helpful to have been asked these types of questions at an earlier stage. Elise recalled her concern that her newborn would be removed from her if she had requested more support. The most helpful professionals in Rachel's support

network were compassionate and willing to learn from her experiences. Health professionals could consider how to engage women sensitively, acknowledging concerns about safeguarding their children and why they might struggle to give up behaviours central to their functioning[9]. Elise, Becky and Sophie described the crucial role of family and friends throughout their transition to motherhood. Systemic therapy, involving the wider system, may help families to navigate through this transition. .

The women who participated in this research breathed life into the experience of anorexia nervosa in ways that diagnostic criteria cannot. NHS services must strike a difficult balance between meeting the needs of a local population and providing tailored, person-centred interventions. There were many examples of positive practice. Natasha and Becky were both supported by their local eating disorders teams. However both Rachel and Elise struggled to obtain support as their body mass index (BMI) did not permit referral to local eating disorder services. Elise was eventually admitted as an inpatient to a general hospital ward, whilst Rachel's GP supported a referral to an outpatient treatment programme. The use of BMI as criteria for admission to services does not fully encapsulate the lived experience of anorexia nervosa. The present findings illuminate the lived experience of anorexia nervosa and the processes women engage in to manage the transition to motherhood. It is hoped that this will help to create supportive, inclusive services for women and their families.

Women spoke about the realities of living with anorexia nervosa and hoped that their participation in this study might help others to understand their commitment to creating a better life for themselves and their families. The transition to motherhood with anorexia nervosa involves fear and uncertainty as well as joy and contentment. Education on myths around anorexia nervosa might prompt professionals to explore issues of self-esteem and negative thinking as well as weight and shape concerns. Within the present findings there is an acknowledgement that the transition to motherhood involves more than simply resolving weight and shape concerns. To make a successful transition, women must overcome various anxieties and concerns, some dating back to childhood and adolescence.

By tolerating difficult and overwhelming feelings, clinicians can create a safe, containing environment for therapeutic work. Clinical psychologists working with mothers who experience anorexia nervosa might find it helpful to spend time building a secure base by engaging women in conversations about how previous support has been helpful and exploring more sensitive topics when the therapeutic relationship strengthens. This could replicate the consistency of a secure attachment[34] and help to overcome the difficult attachment experiences women may have been exposed to in childhood, which may have contributed to and maintained their eating difficulties[8].

Women in this study constructed their experiences in distinctive ways. They described anorexia nervosa as a separate entity from which they protected their children. This connects to narrative approaches which help individuals to resist the influence of problems in their lives[52]. To further separate women from their experiences of anorexia nervosa, current medical practices must be challenged and more power given to women's stories. It might be helpful to challenge the discourses of motherhood which cause women to feel unworthy and isolated[45] by facilitating discussions between health professionals about the heterogeneity of mothering experiences and acknowledging the strengths of women who overcome adverse life experiences to successfully embrace motherhood.

Future research

The experience of motherhood with anorexia nervosa is a topic about which little is known. Further research might include larger samples of women from different backgrounds, with a greater range of psychological difficulties. It might also be helpful to include family members, including partners, to obtain a wider perspective of parenthood and anorexia nervosa.

A key finding of this study was that women appreciated the opportunity to share their stories. A narrative approach might allow women to explore the ways in which they make sense of their experiences. Women discussed how hard they

worked to manage the impact of anorexia nervosa on their lives. Greater understanding of the perceived addictive qualities of anorexia nervosa might help to inform more tailored, person-centred interventions. The findings should be made accessible for eating disorder and perinatal services and disseminated to help services meet the needs of the local population.

Conclusions

Throughout the transition to motherhood, women employed various strategies to break the cycle of anorexia nervosa. They shielded their children from anorexia nervosa, attempted to make a fresh start, tried to be the best mothers they could be and fought temptation to succumb to anorexia nervosa. Specific strategies included exploring different perspectives, making use of social support and accepting the uncertainty of motherhood. It would be helpful to consider these factors when designing interventions to help women manage the transition to motherhood with anorexia nervosa, as their ability to engage in these processes impacts directly on their health and the wellbeing of their families.

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Curiosity, Unicorns and a Cheshire Cat: Adventures through the Research Process

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CURIOSITY, UNICORNS AND A CHESHIRE CAT: ADVENTURES THROUGH THE RESEARCH PROCESS

Introduction

> "'What is the use of a book', thought Alice, 'without pictures or conversation?'"[1] (p. 1-2)

This paper will explore my personal and professional reflections on the research process, covering issues of recruitment, engagement and data analysis, followed by ethical and methodological issues and learning points. I have chosen to tell the story of my research in the same way that I asked my participants to share their stories with me. My interest in creativity led me to liken my experiences to Alice and her adventures in Wonderland[1, 2]. Alice lives in a world of logical rules and consistent routines. These are challenged when she undertakes a journey through the fantasy world of Wonderland. This begins soon after she falls down the rabbit hole:

> "The rabbit hole went straight on like a tunnel for some time, and then dipped suddenly down, so suddenly that Alice had not a moment to think about stopping herself before she found herself falling down a very deep well" [1] (p. 2-3)

Journeying down my own rabbit hole of clinical training I was exposed to new ways of thinking and different perspectives. This was part of a transformative journey for me as a researcher and a clinician.

A brief story of my research

Shortly after Alice lands at the bottom of the rabbit hole, she realises she is lost. Surrounded by locked doors and with no apparent way out, she quickly becomes overwhelmed:

> "There were doors all around the hall, but they were all locked; and when Alice had been all the way down one side and up the other, trying every door, she walked sadly down the middle, wondering how she was ever to get out again" [1] (p. 5)

The process of recruitment was similarly uncertain and it was hard to remain positive when months passed without any potential participants. Women who experience anorexia are unlikely to conceive due to amenorrhea; the absence of menstruation for at least three months[3]. Consequently, recruiting women who were eligible to participate in the study was challenging and I had not anticipated how long the recruitment process would take. Happily, after some searching Alice finds a key to fit one of the locked doors and a way out of the rabbit hole:

> "Behind [the curtain] was a little door about fifteen inches high; [Alice] tried the little golden key in the lock, and to her great delight it fitted!" [1] (p. 5)

When I began to recruit women to participate in the study I felt a comparable sense of relief. My metaphorical 'golden keys' were the ways in which I worked to overcome the resistance I experienced from health professionals and my efforts to be realistic about how much I could achieve in the time available. Equipped with my golden keys I found doors in which they fitted; these were new services and health professionals who were passionate about helping women who experience eating disorders.

The White Rabbit guides Alice through Wonderland[1]. He is cautious, punctual and provides Alice with the logic she needs to make sense of confusing situations. Likewise my academic supervisor guided me through difficult decisions as my research developed. When the university ethics panel suggested that I offer telephone interviews, we concluded that whilst this might compromise data quality, it might allow more women to participate. We discussed my original plan to recruit fifteen women and agreed that given the recruitment difficulties I had experienced, eight women might be more manageable in the time available[4]. When I was contacted by women who did not meet all of my study criteria, we wondered whether I could ask these women to review my findings and comment

on the reliability and validity of my interpretations. This was in keeping with my desire to give more women the opportunity to share their experiences.

Engagement: journeying through Wonderland

As Alice travels through Wonderland she encounters lots of different characters. She is dismayed to find that some are more reluctant to engage in conversation:

> "'Please come back and finish your story!' Alice called after [the Mouse]; and the others all joined in chorus, 'Yes please do!' but the Mouse only shook its head impatiently, and walked a little quicker." [1] (p. 29)

Women who experience anorexia may be more reluctant to engage with research because of previous negative experiences of health services[5]. I wondered how I might help women to share their experiences in a positive and meaningful way. When Alice approaches the Mouse she reassures him that she merely wants to hear his story:

> "So [Alice] called softly after it, 'Mouse dear! Do come back again, and we won't talk about cats or dogs either, if you don't like them!' When the Mouse heard this, it turned round and… said in a low trembling voice, 'Let us get to the shore, and then I'll tell you my history, and you'll understand why it is I hate cats and dogs'" [1] (p. 20-21)

A key finding of this study was that many women choose to keep their eating disorder experiences secret from family and friends. Perhaps this is preferable to feeling judged and blamed by people who misunderstand their difficulties[6]. I recognised women's previous negative experiences and worked hard to remain curious to their stories. As Alice continues to meet new characters she too finds that a sense of curiosity helps her to understand unfamiliar surroundings, exclaiming "'curiouser and curiouser!... now I'm opening out like the largest telescope that ever was!'" (p.11)[1]:

I encouraged women to share their stories with me by using appropriate language and taking time to build rapport and trust[7]. Some women felt that the term 'anorexia' was not reflective of their difficulties. They preferred to use other terms, such as 'eating problems' instead. Equipped with a greater understanding of Wonderland and a healthy sense of curiosity, Alice learns to approach new characters more cautiously:

> "'This here young lady', said the Gryphon, 'she wants for to know your history, she do'. 'I'll tell it her', said the Mock Turtle in a deep, hollow tone: 'sit down, both of you, and don't speak a word till I've finished.'" [1] (p. 104)

Like Alice, I appreciated how these women took the time to share their stories with me. I found it was helpful to take a 'one down' position[7] and allow women the opportunity to discuss their experiences in a way which made most sense for them. For example, as data collection continued I adjusted my interview schedule to give women time to speak and tried not to move through my questions too quickly. Women told me that my initial questions were daunting so following discussions with my academic supervisor I broke my questions down and responded to feedback from the women I met. It was more difficult to ascertain how the woman who was interviewed by telephone responded to my questions. I realised the importance of non-verbal behaviours such as eye contact and smiling in the process of telling and understanding stories.

<u>Analysis: finding a way back home</u>

After some time spent exploring Wonderland, Alice decides she wants to go home. However she finds herself lost and any attempts to help her find a way out are quickly swept away. She is relieved to finally find a path out of the woods:

> "'Oh dear, it's getting dreadfully dark, and nothing looks familiar… it would be so nice if something would make sense for a change… A path! Oh thank goodness! I just knew I'd find one sooner or later…'" [8]

The process of data analysis was similarly overwhelming. Over time I began to make connections between codes and sort them into categories. I started to see how all the data I had collected fitted together. Grounded theories are designed to be supported by quotations taken directly from the data, enhancing the validity of the theory rather than relying on predetermined hypotheses[9]. However my interpretations may be different to other researchers, making the findings difficult to generalise. I attempted to overcome this by asking another trainee to code my transcripts and comparing the results, and asked women with experience of anorexia to check my findings. A larger sample might have enhanced the reliability of the findings and increased the likelihood of data saturation.

Power: Questioning the Queen's authority

When Alice encounters the Red Queen, she finds she is a controlling character whose rules are followed without question by her subjects. Alice's newfound curiosity and attempts to question the dominant narratives of Wonderland are quickly challenged:

> "Red Queen: 'Now, where do you come from?'
> Alice: 'Well, I'm trying to find my way home…'
> Red Queen: 'Your way? All ways here are my ways!'
> Alice: 'Yes, I know, but I was just thinking…'
> Red Queen: 'Curtsy while you're thinking. It saves time.'" [2] (p. 95)

The Red Queen is strong, commanding and discourages original thinking. I wondered about the power of the medical discourse in eating disorders and how it too is frequently unchallenged. Many of the studies contained in my literature review frequently referred to the diagnostic criteria for anorexia. Perhaps these discourses force women into an 'anorexic' role by focusing exclusively on the diagnostic characteristics of an eating disorder, including low body weight and the behaviours women use to rid their bodies of excess calories[10]. The women I met did not align themselves with this definition despite acknowledging that they experienced significant eating difficulties. I wondered how useful the medical

definition of anorexia was for these women, and whether there was an alternative perspective which might help them to communicate their difficulties.

Making space for new stories: Believing in the impossible

Alice's time in Wonderland allows her the space to question the things she thought were certain. However for Alice, who is accustomed to following rules, the opportunity to challenge and question authority is unfamiliar and takes time to develop:

> "Alice laughed. 'There's no use trying', she said, 'one *can't* believe impossible things'. 'I daresay you haven't had much practice', said the Queen. 'When I was your age, I always did it for half an hour a day. Why, sometimes I've believed as many as six impossible things before breakfast…'" [2] (p. 72)

With practice, Alice learns to open her mind to new, equally valid perspectives. I hoped that my research might give power to new stories and challenge the dominant narratives around eating disorders. For example, I noticed that the process of recovery meant different things to different women. Whilst some women hoped to eliminate anorexia from their lives, others accepted that it might continue to influence them despite their new role as mothers. I hoped that by sharing these stories I could help to create a new narrative of what it is like to be a mother living with anorexia, emphasising determination and resilience.

In Western society many women report greater pressure to remain thin in order to be perceived as successful and in control[11]. I wondered whether women who experience eating disorders feel under pressure to embrace typical feminine roles of affection and nurturance when they have children. This is likely to be incompatible with the rigidity of eating disorder routines[12]. I reflected on my position as a female researcher exploring a topic which has been socially constructed and reported as a major health problem amongst women, with the majority of research focused on women's experiences[13] and gave thought to whether women responded differently to me as a female researcher. It is possible

that a female researcher interviewing female participants about experiences of anorexia reinforces the notion that this is difficulty is only experienced by women.

Language: Same words, new meanings

Alice is confused by the language of Wonderland. She soon realises that she is not the only person who has difficulty making sense of what she hears:

> "'Speak English!' said the Eaglet. 'I don't know the meaning of half those long words, and what's more, I don't believe you do either!'" [1] (p. 24)

The characters of Wonderland chastise one another for using incomprehensible language. I connected this to the diagnostic language of eating disorders and wondered how relevant this language is for women who experience eating difficulties. The term 'anorexia nervosa', meaning "nervous loss of appetite", doesn't seem to adequately acknowledge the uniqueness of women's experiences. By virtue of becoming pregnant, my participants defied the diagnostic criteria of anorexia[14]. Indeed, the women I met with rarely referred to feelings of hunger; rather they explained how negative thinking and low self-esteem contributed to the development and maintenance of their eating difficulties.

A diagnosis of anorexia was one of the inclusion criteria for my sample. I found that using a medical diagnosis helped me more in my conversations with health professionals than with the women I met. I wondered if this diagnosis ignores the context in which eating difficulties develop[13]. The term 'anorexia' implies a homogeneous group of women who share a set of characteristics. However there seemed to be as many differences as similarities between the women I met. Whilst using a medical diagnosis helped bring consistency to my sample and enabled me to communicate effectively with health professionals, I feel it also reinforces the medical discourse around anorexia at the expense of other explanations.

Methodological critique

As Alice travels further into Wonderland she becomes less clear of her own identity. Before she fell down the rabbit hole she was certain of who she was and what she knew. Now as she prepares to leave Wonderland, she finds that her role is changing:

> "'Who are *you*?' said the Caterpillar… Alice replied, rather shyly, 'I- I hardly know, sir, just at present – at least I know who I *was* when I got up this morning, but I think I must have changed several times since then'. 'What do you mean by that?' said the Caterpillar sternly. 'I'm afraid I can't put it more clearly', Alice replied very politely… 'being so many different sizes in a day is very confusing.'" [1] (p. 45)

My roles as a researcher and clinician frequently conflicted. As a researcher I wanted to collect interesting data, but as a clinician I saw the women I met as individuals in various stages of recovery. My researcher role helped me to plan my research and design my interview schedule, but my clinical skills were most important in engaging women, supporting them through their distress and recognising when to raise concerns with the professionals involved in their care. I wondered whether my decision to interview the majority of my sample in a traditional therapeutic setting impacted on the women I met, whether this placed me in a powerful position, and whether women might have concerns about confidentiality. I was mindful of this as I continued to meet women in various NHS and community settings.

The teams I worked with suggested that I should recruit women who would give a positive account of their experience of services. We discussed the ethical implications of this and decided that women should be offered the opportunity to participate regardless of their experiences but that care co-ordinators would be consulted if there were any concerns about risk. Women were not permitted to participate in the study if they had current psychiatric difficulties such as severe depression or suicidal ideation. Whilst these experiences were considered equally valuable, it was felt that it might be inappropriate for these women to participate

without access to more intensive support. Psychologists should make every effort to ensure that individuals do not participate in research that might expose them to harm[15]. For a time limited piece of academic research, the risks of including women with more severe psychological difficulties appeared to outweigh any potential benefits. Whilst I took care to debrief women and discussed any concerns with my clinical supervisor, I valued all the stories I heard and wanted to give women the opportunity to share them.

A key characteristic of grounded theory studies is that the literature review is delayed until the grounded theory has developed, to allow the researcher to remain grounded in the data and not be influenced by prior literature or their own preconceptions[16]. Unfortunately the need to present information about the study for peer and ethical approval, coupled with the time limited nature of this research, meant that it was necessary to complete a literature review prior to commencing the study. A reflexive journal was maintained as a means of managing the researcher's assumptions, and any preconceptions were discussed in supervision.

Qualitative vs. quantitative research

Alice meets the White Queen, who quickly exposes her lack of mathematical prowess:

> "'Can you do addition?' the White Queen asked. 'What's one and one and one and one and one and one and one and one and one and one?' 'I don't know', said Alice. 'I lost count.'" [2] (p. 26)

I have a preference for qualitative research and am interested in the language people use to describe their experiences. Grounded theories aim to describe and explain a process experienced by a specific group of people. I felt this approach matched my desire to focus on the lived experience of the transition to motherhood[9]. I aimed to take a position of reflective observer and allow the women I met to be the experts in their own stories[17]. I felt that this fitted with a critical realist approach to grounded theory[18] as I aimed for saturation but could not determine conclusively in the time available that I had achieved this.

I considered the benefits of other methodological approaches. A narrative methodology might consider how women construct their experiences of living with an eating disorder. It would be helpful to compare these stories with mothers without experience of eating disorders. It might be useful to include standardised questionnaires exploring eating disorder types and experiences of motherhood to enhance the reliability and validity of the findings. Whilst this contradicts my earlier thoughts about the helpfulness of the term 'anorexia', I appreciate that to influence services and health professionals, it might be necessary to use standardised measures and terms.

Reflexivity: through the looking glass

Throughout her time in Wonderland Alice is forced to challenge her beliefs about the world. As she is exposed to experiences that she previously thought were impossible, the Unicorn reminds her to always remain open to new opportunities, saying "'well, now that we have seen each other… if you'll believe in me, I'll believe in you'" (p. 86)[2]:

My personal experience of living with an eating disorder helped me to identify with some of the concerns women highlighted. I shared their belief that recovery is a process of change and managing uncertainty. I wanted to use my position as a trainee clinical psychologist to share women's stories and make a positive difference by helping health professionals to understand their experiences. I was reminded of how much I could still learn from these women, like Alice, who is reminded by the Duchess that she too knows less than she thinks:

> "'I didn't know Cheshire cats always grinned; in fact, I didn't know that cats *could* grin.' 'They all can', said the Duchess; 'and most of 'em do.' 'I don't know of any that do,' Alice said very politely... 'You don't know very much', said the Duchess, 'and that's a fact.'" [1] (p. 61-62)

In Wonderland, Alice's encounters remind her not to make assumptions. In order to become more aware of my own assumptions, I used supervision and maintained a reflective journal. This helped me to consider how my personal and professional experiences might impact on data interpretation. Whilst the research process was frequently challenging, these experiences helped me to become a more reflective practitioner and have shaped the clinician I have become.

After some time in Wonderland, Alice begins to question her identity and wonders if she has irreversibly changed:

> "'Yesterday things went on just as usual. I wonder if I've been changed in the night? Let me think; was I the same when I got up this morning?... But if I'm not the same, the next question is, Who in the world am I? Ah, *that's* the great puzzle!'" [1] (p. 14)

Throughout clinical training I have learned to challenge my beliefs and embrace a new position of uncertainty. My specialist systemic placement helped me to be more considerate of the role of family, attachment and the life cycle in the development of eating disorders. When Alice meets the Caterpillar she is uncertain about who she is and what she needs to do to continue through Wonderland. The Caterpillar wonders who Alice would like to become and offers her the opportunity to grow. He uses difficult questions to challenge Alice's assumptions and help her to see that change can be positive and rewarding. Similarly my supervisor on placement helped me to become more curious and exposed me to new ways of working which influenced my interviewing style and the questions I asked of the women I met.

<u>Learning points</u>

> "I give myself very good advice, but I very seldom follow it. That explains the trouble that I'm always in … Be patient, is very good advice, but the waiting makes me curious. And I'd love the change, should something strange begin"[8]

I found the uncertainty of the research process challenging and uncomfortable. My usual proactive, organised approach was well suited to reviewing literature and designing my study. However I could not commence data analysis until I had begun to recruit participants. My anxiety around this was so difficult to manage that I avoided the problem rather than acknowledge that I might have to make significant changes. When I was unable to find eligible participants, my research seemed to grind to a halt. Alice experiences similar difficulties in Wonderland when she is unable to make sense of her surroundings. During this period she meets the Cheshire Cat in the woods. He helps her to understand the rules of Wonderland and accept her unfamiliar surroundings:

> "'Would you tell me, please, which way I ought to go from here?' said Alice. 'That depends a good deal on where you want to get to,' said the Cat. 'I don't much care where-' said Alice. 'Then it doesn't matter which way you go,' said the Cat. '-so long as I get somewhere,' Alice added as an explanation. 'Oh, you're sure to do that,' said the Cat, 'if you only walk long enough.'" [1] (p. 66-67)

The Cheshire Cat is honest yet optimistic. Alice continues to meet him throughout her journey despite him not providing her with the certainty she initially desires. Similarly my personal tutor helped me to consider more realistic ways to manage my anxiety and encouraged me to consult with clinicians from different services to overcome recruitment difficulties. Interestingly this was a parallel process as the women I met with spoke about managing the change and uncertainty of motherhood. I gradually learnt to accept the uncertainty of the research process and now try to seek support and supervision as soon as I encounter difficulties.

Conclusions

I have been privileged to be able to share the stories of these women. Elise discussed the challenges of motherhood honestly. Becky gave important context to her difficulties. Emma and her young son shared a warm, positive bond. Natasha showed courage when she described feeling "invaded" by her pregnancy.

Chan spoke candidly about the attachments she formed with her children. Lacey demonstrated capacity to forgive herself. Sophie described how motherhood had offered new perspectives. Rachel's experiences of practical support helped guide the recommendations of paper 2. The women I met with reassured me of how important it is for other health professionals to understand these experiences. Their stories have changed the way I view the world and the beliefs I hold[1]:

Alice laments: "It's no use going back to yesterday… because I was a different person then'" (p. 115)[1]. This research has been part of a transformative journey within which I have found an approach which is most comfortable for me. I have been exposed to new ways of working and have developed my skills as a clinician and a researcher. The personal and professional challenges I have overcome during my research journey represent some of the most important aspects of my clinical training.

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> "'Oh, I've had such a curious dream!' said Alice, and she told her sister, as well as she could remember them, all these strange Adventures of hers that you have just been reading about; and when she had finished, her sister kissed her, and said, 'It *was* a curious dream, dear, certainly: but now run in to your tea; it's getting late.'"[1] (p. 139)

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Appendix A

Data extraction sheet

Date of extraction:

Title:

Authors:

Publication details:

Reviewer name:

Background to the study:

Aims and objectives:

Sample characteristics: *Population* *Setting* *Method/design* *Sample size* *Age and ethnicity* *Rate of attrition*

Recruitment methods:

Procedure/interventions:

Results/findings:

Follow ups:

Commentary/notes:

Strengths and/or limitations

APPENDIX B

Internal consistency, test retest reliability and validity statistics for psychological outcome measures

Author(s) and year of publication	**Outcome measures**	**Measure details**	**Internal consistency**	**Test retest reliability**	**Validity**
Micali, Simonoff and Stahl (2011)	Denver Development Scale (DDS)	Self report measure of child development status	Not reported	Not reported	Not reported
	Crown Crisp Experiential Inventory (CCEI)		Not reported	Not reported	Not reported

	Edinburgh Postnatal Depression Scale (EPDS)		Not reported	Not reported	Not reported
	Eating Disorders Examination Questionnaire (EDE-Q)		Not reported	Not reported	Not reported
Berg, Torgersen and Von Holle	Hopkins Symptom Checklist - 25 (HSC)	5 item version measuring anxiety and depression	Not reported	Considerable temporal stability	Correlates highly with the original scale (.92)

(2011)	Satisfaction with Life Scale	5 item measure of life satisfaction (cognitive component)	Reported “reliable”	Reported “valid”	Not reported
	Rosenberg Self Esteem Scale	4 item version used in eating disorder research	Not reported	Not reported	Not reported

	Relationship Satisfaction Scale	10 item scale of satisfaction with partner relationship	Not reported	Not reported	Correlates highly with the original 10 item scale (.95) Correlates highly with Quality of Marriage Index
Reba-Harrelson, Von Holle and Hamer (2010)	Child Feeding Questionnaire (CFQ – restriction and pressure to eat subscales)	Measure parental control in child feeding	Not reported	Not reported	Not reported
	Child Behaviour Checklist (CBC)	Child eating problems and psychological status	Not reported	Not reported	Not reported

Lai and Tang (2008)	Parental Image Differential (Mother Treatment Scale)	Self report 15 item measure of maternal concern, restrictiveness and warmth	Cronbach's alpha = .78 to .88	Reported "satisfactory"	Predictive of child's life satisfaction and academic competence
	Eating Disorders Inventory 2 (EDI-2 – Chinese version – bulimia subscale)	Self report measure of eating disturbance	Reported "good"	Not reported	Not reported
	General Health Questionnaire (GHQ)	A self report measure of maternal distress	Cronbach's alpha = .87 to .93	Not reported	Not reported

	Maternal Prenatal Attachment Scale (MPAS)	Measures affectional bond with foetus during pregnancy	Cronbach's alpha = .82 to .84	Not reported	Predictive of adjustment after miscarriage
Koubaa, Hallstrom and Hirschberg (2008)	Maternal Adjustment and Maternal Attitude (MAMA) questionnaire	60 item self-report questionnaire measuring body image, somatic symptoms, marital relationships, attitude to sex and attitude to pregnancy and baby	.86	.84	Good comparisons between the MAMA, semi structured interview and the Neonatal Perception Inventory = good criterion validity

Crow et al. (2008)	Eating Disorders Examination (EDE)	Semi structured interview measure: this study utilised EDE weight concern, shape concern and restraint	Not reported Interrater reliabilities: purging .99, eating concerns .98, restrained eating .99, weight concerns .90	Not reported	Not reported
Berg, Bulik and Von Holle (2008)	Hopkins Symptom Checklist - 25 (HSC)	Short form 5 item self report version of anxiety and depression	Not reported	Reported considerable temporal stability	Not reported

	Satisfaction with Life Scale	5 item cognitive component of subjective well-being	Reported “reliable”	Reported “reliable”	Reported “valid measure of life satisfaction”
	Rosenberg Self Esteem Scale	Short version 4 items, widely used in ED research	Not reported	Not reported	Correlates well with the original item scale (.95)
	Relationship Satisfaction Scale	10 item scale	Not reported	Not reported	Correlates highly with Quality Marriage Index

Soares et al. (2009)	Eating Disorders Examination Questionnaire (EDE-Q – Portuguese version)	Self report version of the EDE	Not reported	Not reported	Validated in a Portuguese sample in a previous study
	Primary Care Evaluation of Mental Disorders (PRIME-MD)	Assesses diagnoses of lifetime mood disorders based on DSM-IV criteria	Not reported	Not reported	Not reported
Micali, Simonoff and Treasure	Crown Crisp Experiential Inventory (CCEI)		Not reported	Not reported	Widely used measure of anxiety

(2011)	Edinburgh Postnatal Depression Scale (EPDS)		Not reported	Not reported	Widely used self report measure of post natal depression Not reported
	Eating Disorders Examination Questionnaire (EDE-Q – shape and weight concern subscales)		Not reported	Not reported	

EPDS, Edinburgh Postnatal Depression Scale[68]; CCEI, Crown Crisp Experiential Inventory[69]; EDE, Eating Disorders Examination[70]; DDS, Denver Developmental Scale[71]; SWL, Satisfaction with Life scale[72]; HSC, Hopkins Symptom Checklist[73]; EDI-2, Eating Disorder Inventory 2[74]; GHQ, General Health Questionnaire[75]; MAMA, Maternal Adjustment and Maternal Attitude Questionnaire[76]; RSES, Rosenberg Self Esteem

Scale[77]; PRIME-MD, Primary Care Evaluation of Mental Disorders[78]; CBC, Child Behaviour Checklist[79]; CFQ, Child Feeding Questionnaire[80]; MPAS, Maternal Prenatal Attachment Scale[81]; EDE-Q, Eating Disorders Examination Questionnaire[82]; PID, Parental Image Differential[83]; RSS, Relationship Satisfaction Scale[84]

APPENDIX C

Interview schedule

South Staffordshire and Shropshire Healthcare NHS
NHS Foundation Trust
A Keele University Teaching Trust

Interview schedule

Time: 0-10 minutes

- Introducing researcher and the purpose of the interview - ensuring the participant is comfortable, understands and signs consent form.
- Asking general questions about the participant (family, hobbies, etc)

Time: 10-50 minutes

I would like you to tell me a little about your eating disorder – how long have you had an eating disorder and what kind of symptoms do you experience?

I would like you to tell me how many children you have and how old they are?

What do you think/how do you feel about becoming a mother?

I would like you to tell me about your day to day life now as a mother?

Has that changed much over the past [five] years?

How does your life now compare to how life was before you were a mother?

Do you think becoming a mother was different because you have an eating disorder – if so how?

I would like you to tell me how you have managed your eating disorder since you had a child/children?

Were you worried about being a mother with anorexia?

Did you have any other concerns about motherhood and if so what were they?

How did you adjust to becoming a mother particularly with anorexia?

Have your eating patterns changed since you had a child?

What is the best thing about motherhood for you? What is the worst thing?

Has your life changed since you became a mother – if yes then how?

Time: 50-60 minutes

- Debriefing the participant on the nature of the study, asking for feedback on the interview, is the participant happy with the interview, answer any other questions they may have.

Probes	**Eliciting further information**
How did you feel about that? Can you tell me more about that? Do you have an example of when that happened? When did that happen? Where were you during that time? Where did it happen? What was your involvement in that situation?	Could you elaborate further on that? Could you give me some more detail about that? That's helpful. I'd appreciate if you could give me more detail. I'm beginning to get the picture: but some more examples might help. You said “xxxxx” – could you tell me what you meant by “xxxxx”? What you're saying now is very useful, and I want to make sure I understand it correctly, could you explain it further? What happened next?

APPENDIX D

Copies of approval documents

NHS
Health Research Authority

National Research Ethics Service

NRES Committee West Midlands - The Black Country
HRA NRES Centre Manchester
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7821

17 April 2013

Miss Gemma O'Leary
Trainee Clinical Psychologist
South Staffordshire and Shropshire Healthcare NHS Foundation Trust
School of Psychology (Faculty of Health Sciences)
Leek Road
Stoke on Trent, Staffordshire
ST4 2DF

Dear Miss O'Leary

Study title:	**How do women experience and manage motherhood when they have a pre-existing diagnosis of anorexia nervosa?**
REC reference:	**13/WM/0119**
Protocol number:	**N/A**
IRAS project ID:	**107553**

The Research Ethics Committee reviewed the above application at the meeting held on 08 April 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Shehnaz Ishaq via email at nrescommittee.westmidlands-blackcountry@nhs.net.

Ethical opinion

1. The Committee asked to explain the choice of the research topic. You explained that the

choice was based on your interest in the eating disorders and was linked to your previous experience of working in behavioural psychology.

2. The Committee asked to describe a recruitment process to be used in the study. You clarified that you will recruit mainly via eating disorder services in South Staffordshire and Shropshire (inpatients and outpatients). The recruitment packs will be distributed to inpatients by the clinical supervisor who will be approaching own work case patients. Other clinicians will get involved in the recruitment process by discussing the research with the outpatients who, if interested, will receive an information pack by post. Same process will apply with regard to participants recruited via the North and South Staffordshire perinatal health services where interested patients will receive a pack in a post.

   Additionally, posters will be displayed in the baby units to facilitate the recruitment. All staff taking part in the recruitment process will receive the study training covering the protocol requirements including the inclusion and exclusion criteria. This training will be provided by yourself and will be delivered in a form of the power point presentations.

3. The Committee queried whether the sample size of fifteen participants will fulfil the requirements for a doctorate project. You explained that the sample size had been consulted with the university. You clarified that the minimum number of participants required by the grounded theory would be between three and four but assured the Committee that the final sample size would be adjusted in order to achieve data saturation point which may take more than fifteen participants to be recruited. The Committee advised to send out as many information packs as possible to see what the response rate would be and then to adjust the decisions on sample size.

4. The Committee asked to explain the data storage arrangements. You confirmed that the study data will be encrypted and stored on a password protected laptop. You will ensure that the interviews' transcripts will not contain any identifiable data.

5. The Committee noted that the interview schedule contains closed questions and that it would be advisable to change 'Could you tell me' questions into ' I would like you to tell me'. You thanked for the advice.

6. The Committee noted that approaching the eating disorder population of patients might cause distress and asked if you had thought of that. You confirmed that you will anticipate anxiety around information disclosure issues.

   The Committee advised using a reflective diary as a good way of addressing any arising issues which would add value to the data analysis and which content should be consulted with the supervisor. You agreed with the advice.

   You was thanked for attending and left the meeting room.

   The Committee considered your responses.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, **subject to the conditions specified below.**

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Please consider revising the Interview Schedule and change 'Could you tell me' questions into 'I would like you to tell me'.
2. You may wish to shorten the PILs to remove any repetition.

You must notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Covering Letter from Gemma O'Leary		06 March 2013
REC application		04 March 2013
Protocol	2	01 February 2013
Summary/Synopsis: Flowchart		01 January 2013
Investigator CV: Gemma O'Leary		01 January 2013
Investigator CV: Dr Alison Tweed		
Letter of invitation to participant	1	01 January 2013
Participant Information Sheet	2	01 January 2013
Participant Consent Form	1	01 January 2013
Information sheet and debrief	2	01 January 2013
GP/Consultant Information Sheets	1	01 January 2013
Interview Schedules/Topic Guides	1	01 January 2013
Covering letter summary findings for participants	1	01 January 2013
Advertisement: Poster for recruitment		01 January 2013
Advertisement: Beat recruitment screening questionnaire		01 January 2013
Advertisement: Beat recruitment information		01 January 2013
Letter from Sponsor from Dr Elizabeth Boath		21 January 2013
Evidence of insurance or indemnity		15 August 2012

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance

on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

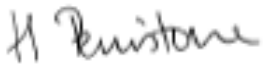
Further information is available at National Research Ethics Service website > After Review

13/WM/0119	Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely



On behalf of
Dr Jeff Neilson
Chair

Email: nrescommittee.westmidlands-blackcountry@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to:

Ms Audrey Bright,
South Staffordshire and Shropshire Healthcare NHS Foundation Trust
Research and Development Block 7
St George's Hospital
Corporation Street
Stafford
ST16 3AG

Vish Unnithan
School of Psychology
Brindley Building
Leek Road
Stoke on Trent
ST4 2DF

NRES Committee West Midlands - The Black Country

Attendance at Committee meeting on 08 April 2013

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Joseph Arumainayagam	Consultant and Honorary Senior Clinical Lecturer in HIV and GUM	No	
Dr Nicola Erb	Consultant Rheumatologist	No	
Mrs Chris Bell	Lay Member	Yes	
Dr Jeff Neilson	Consultant Haematologist	Yes	
Dr Hilary Paniagua	Chair of the research ethics committee, School of Health and Wellbeing	Yes	
Mr Nanak Singh Sarhadi	Consultant Plastic Surgeon	Yes	
Dr Julian Sonksen	Consultant in Anaesthesia and Critical Care	No	
Reverend Mark Stobert	Hospital Chaplin	Yes	
Dr David Vallance	Clinical Biochemist	Yes	
Mrs Jennifer Walton	Retired Research Nurse	No	
Mrs Veronica A Wells	Lay Member	No	
Dr Tony Zalin	Expert Member	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Ms Anna Sekula	Senior Co-ordinator

NHS
Health Research Authority

National Research Ethics Service

NRES Committee West Midlands - The Black Country
HRA NRES Centre Manchester
3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7821
Facsimile: 0161 625 7299

01 May 2013

Miss Gemma O'Leary
Trainee Clinical Psychologist
South Staffordshire and Shropshire Healthcare NHS Foundation Trust
School of Psychology (Faculty of Health Sciences)
Leek Road
Stoke on Trent, Staffordshire
ST4 2DF

Dear Miss O'Leary

Study title:	**How do women experience and manage motherhood when they have a pre-existing diagnosis of anorexia nervosa?**
REC reference:	**13/WM/0119**
Protocol number:	**N/A**
IRAS project ID:	**107553**

Thank you for your email of 30 April 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 17 April 2013

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Covering Letter		29 April 2013
Interview Schedules/Topic Guides	2	29 April 2013
Letter of invitation to participant	2	29 April 2013
Participant Information Sheet	3	29 April 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Advertisement	Poster for recruitment	01 January 2013
Advertisement	Beat recruitment screening questionnaire	01 January 2013

Advertisement	Beat recruitment Information	01 January 2013
Covering Letter	from Gemma O'Leary	06 March 2013
Covering Letter		29 April 2013
Evidence of Insurance or Indemnity		15 August 2012
GP/Consultant Information Sheets	1	01 January 2013
Interview Schedules/Topic Guides	2	29 April 2013
Investigator CV	Gemma O'Leary	01 January 2013
Investigator CV	Dr Alison Tweed	
Letter from Sponsor	from Dr Elizabeth Boath	21 January 2013
Letter of Invitation to participant	2	29 April 2013
Other: Covering letter summary findings for participants	1	01 January 2013
Other: Information sheet and debrief	2	01 January 2013
Participant Consent Form	1	01 January 2013
Participant Information Sheet	3	29 April 2013
Protocol	2	01 February 2013
REC application		04 March 2013
Summary/Synopsis	Flowchart	01 January 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/WM/0119	**Please quote this number on all correspondence**

Yours sincerely

Miss Shehnaz Ishaq
Committee Co-ordinator

E-mail: nrescommittee.westmidlands-blackcountry@nhs.net

Copy to: Ms Audrey Bright,
South Staffordshire and Shropshire Healthcare NHS Foundation Trust
Research and Development Block 7
St George's Hospital
Corporation Street
Stafford
ST16 3AG

Vish Unnithan
School of Psychology
Brindley Building
Leek Road
Stoke on Trent
ST4 2DF

Our Ref: AB/R239

12 June 2013

Research and
Development
Block 7
St George's Hospital
Corporation Street
STAFFORD
ST16 3AG

Tel: (01785) 221168
Email:
audrey.bright@sssft.nhs.
uk

Mrs Gemma Worthington
[redacted]

Dear Gemma

Study title: The experience of being a mother with anorexia

We have considered your application for access to patients and staff from within this Trust in connection with the above study.

On behalf of the Trust the Lead Officer for Research Governance (Eleanor Bradley), and the Responsible Care Professionals within the Directorate have now satisfied themselves that the requirements for Research Governance, both Nationally and Locally, have been met and are happy to give approval for this study to take place in the Trust, with the following provisos:

- That all researchers coming into the Trust have been issued with either a letter of access or honorary contract by ourselves
- That you conform to the requirements laid out in the letters from the REC dated 1 May 2013 which prohibits any changes to the agreed protocol
- That you keep the Trust informed about the progress of the project at 6 monthly intervals
- If at any time details relating to the research project or researcher change, the R&D department must be informed.

Your research has been entered into the Trust database and will appear on the Trust website.

As part of the Research Governance framework it is important that the Trust are notified as to the outcome of your research and as such we will request feedback once the research has finished along with details of dissemination of your findings. You will be asked to provide a copy of the final report and receive an invitation to present final feedback via our research seminar series. To aid dissemination of findings, copies of final reports are placed on our Trust Website. To this end, please contact me towards the completion of the project to discuss the dissemination of findings across the Trust and a possible implementation plan.

If I can help in any other way please do not hesitate to contact me.

Yours sincerely

Kim Thompson
R&D Manager
Cc Dr Felix Davies, Director of Psychological Services

North Staffordshire Combined Healthcare NHS
NHS Trust
RESEARCH AND DEVELOPMENT DEPARTMENT
Trust Headquarters
Bellringer Road
Trentham
Stoke-on-Trent ST4 8HH
Telephone: 01782 441687/651
Fax: 01782 441637
Email: r&d@northstaffs.nhs.uk

14 June 2013

Gemma O'Leary (now Worthington)
South Staffordshire & Shropshire Healthcare NHSFT
St George's Hospital
Corporation Street
Stafford
ST16 3AG

Dear Gemma

NHS-NHS Letter of Access for Research

This letter confirms your right of access to conduct the research project "**How do women experience and manage motherhood when they have a pre-existing diagnosis of anorexia nervosa?**" through North Staffordshire Combined Healthcare for the purpose, and on the terms and conditions set out below. This right of access commences on **14/06/2013** and ends on **01/04/2014** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct the above named research project as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out, and as such have confirmed in writing to this NHS organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in this organisation.

You are considered to be a legal visitor to North Staffordshire Combined Healthcare premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through North Staffordshire Combined Healthcare, you will remain accountable to your employer, **South Staffordshire & Shropshire Healthcare NHSFT**, but you are required to follow the reasonable instructions of Laurie Wrench, Research & Development Manager in this NHS organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with North Staffordshire Combined Healthcare policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with North Staffordshire Combined Healthcare in discharging its duties under the Health and Safety at Work Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on North Staffordshire Combined Healthcare premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear an ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

North Staffordshire Combined Healthcare NHS
NHS Trust

North Staffordshire Combined Healthcare will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or if your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

L. Wrench

Laurie Wrench
Clinical Audit/R&D Manager

cc: **HR Directorate at North Staffordshire Combined Healthcare NHS Trust**
Sue Garvey, HR Manager, Bucknall Hospital, Eaves Lane, Bucknall, Stoke-on-Trent ST2 8LD

HR Department of the Substantive Employer:
Audrey Bright, RGF, SSSFT, St George's Hospital, Stafford, ST16 3AG

Birmingham and Solihull NHS
Mental Health NHS Foundation Trust

Research & Innovation
Suite O
Radclyffe House
66/68 Hagley Road
Edgbaston
Birmingham
B16 8PF

Tel: 0121 301 4327
Fax: 0121 301 4340

Miss Gemma Worthington
[redacted]

Dear Gemma

The experience of being a mother with anorexia nervosa

Letter of access for research

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement check are in place in accordance with the role you plan to carry out in this organisation. This letter confirms your right of access to conduct research through **Birmingham & Solihull Mental Health Foundation Trust** for the purpose and on the terms and conditions set out below. This right of access commences on **31 October 2013** and ends on **30 April 2014** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to **Birmingham & Solihull Mental Health Foundation Trust** premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through **Birmingham & Solihull Mental Health Foundation Trust**, you will remain accountable to **your employer**, but you are required to follow the reasonable instructions of your nominated manager **Dr Paul McDonald, Research & Innovation Manager** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with **Birmingham & Solihull Mental Health Foundation Trust** policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with **Birmingham & Solihull Mental Health Foundation Trust** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on **Birmingham & Solihull Mental Health Foundation Trust** premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Birmingham & Solihull Mental Health Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Where applicable, your substantive employer will initiate your Independent Safeguarding Authority (ISA) registration in-line with the phasing strategy adopted within the NHS and the applicable legislation. Once you are ISA-registered, your employer will continue to monitor your ISA registration status via the on-line ISA service. Should you cease to be ISA-registered, this letter of access is immediately terminated. Your substantive employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or ISA registration, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Dr Paul McDonald
Research & Innovation Manager

Clinical Psychology Doctorate Programme
School of Psychology
Science Centre
Staffordshire University
Leek Road
Stoke on Trent
ST4 2DF

31 July 2013

Dr Elizabeth Boath
School of Social Work and Public Health
Brindley Building
Staffordshire University
Leek Road
Stoke on Trent
ST4 2DF

Dear Liz,

I write to formally make you aware of an amendment to my research project, which was originally given favourable ethical approval by Staffordshire University Independent Peer Review in January 2013 and by Black Country Research Ethics Committee in April 2013. I have added a new recruitment site to my project, a Derbyshire based eating disorders charity called First Steps. My contact at this site, Catherine Cleary, is CEO of the charity and has agreed to circulate information about my study to service users. The procedure I will follow at this site will be the same as other non NHS sites as already detailed in my research proposal. I have contacted the Black Country Research Ethics Committee who advised that I do not need to inform them of any additional NHS or non NHS recruitment sites, but that I do need to make the sponsor aware of the changes.

Thank you for signing my amended Research and Development form on behalf of the University.

If you have any queries or concerns please do not hesitate to contact me.

Best wishes

Gemma O'Leary
Trainee Clinical Psychologist
Staffordshire University

CC Audrey Bright, Research Governance Facilitator, South Staffordshire and Shropshire NHS Healthcare Foundation Trust

Clinical Psychology Doctorate Programme
School of Psychology
Science Centre
Staffordshire University
Leek Road
Stoke on Trent
ST4 2DF

31 October 2013

Dr Elizabeth Boath
School of Social Work and Public Health
Brindley Building
Staffordshire University
Leek Road
Stoke on Trent
ST4 2DF

Dear Liz,

I write to formally make you aware of some amendments to my research project, which was originally given favourable ethical approval by Staffordshire University Independent Peer Review in January 2013 and by Black Country Research Ethics Committee in April 2013.

I have added several new recruitment sites to my project:

- Beat: Beat, the national eating disorder charity has already been assisting me with recruitment by advertising my study on the 'research' section of their website. However my contact at Beat, Jonathan Kelly (Research Officer) has since given permission for me to share the link to this website via social media.
- Somerset and Wessex Eating Disorder Association (SWEDA): SWEDA do not directly link service users and researchers but their Client Services Manager, Anita Worcester has agreed to advertise my study on the 'research' section of their website.
- SEED Eating Disorder Support Services: SEED is based in Hull. My contact Marg Oates, Secretary and Co-Founder of SEED has agreed to circulate information about my study to service users who can contact me directly if they are interested in taking part.

The procedure I will follow at these sites will be the same as other non NHS sites as already detailed in my research proposal. I have contacted the Black Country Research Ethics Committee who advised that I do not need to inform them of any additional NHS or non NHS recruitment sites, but that I do need to make the sponsor aware of the changes.

Thank you for signing my amended Research and Development form on behalf of the University.

If you have any queries or concerns please do not hesitate to contact me.

Best wishes

Gemma O'Leary
Trainee Clinical Psychologist
Staffordshire University

CC Audrey Bright, Research Governance Facilitator, South Staffordshire and Shropshire NHS Healthcare Foundation Trust

APPENDIX E

Invitation letter to participants

South Staffordshire and Shropshire Healthcare NHS
NHS Foundation Trust
A Keele University Teaching Trust

NHS address
Line 1
Line 2
Postcode

Our ref: GO'L
NHS Number: 123 456 7890
Date

In Confidence

Name
Address line 1
Address line 2
Town
Postcode

Dear

You are invited to participate in research taking place at [place here]. We are making contact with women with anorexia nervosa who have had a child within the past five years to find out more about their experiences. Participation in the study will involve an informal interview, approximately one hour in length, conducted by a trainee clinical psychologist. Participation is entirely voluntary and will not impact on other aspects of your care. If you may be interested in participating, please fill in the reply slip below, detach and return to [place here] using the stamped addressed envelope provided. You will be contacted by the researcher, Gemma O'Leary, by telephone to arrange a convenient time, date and venue for your interview.

Kind regards

[Name here]
[Position and location]

Please detach and return the reply slip below using the stamped addressed envelope provided

---

Name *(print)* ..... **Telephone number** .....

(Please tick to indicate your preference)

I **may be** interested in taking part in the research ☐

I **am not** interested in taking part in the research ☐

Signature .....

APPENDIX F

Online recruitment information

South Staffordshire and Shropshire Healthcare NHS
NHS Foundation Trust
A Keele University Teaching Trust

The experience of being a mother with anorexia

My name is Gemma O'Leary and I am a trainee clinical psychologist at Staffordshire University. I am currently conducting a study looking at the experiences of motherhood for women with anorexia nervosa. In order to carry out this study I would like to interview women with a pre-existing diagnosis of anorexia nervosa who have young children.

By taking part in this research you will be providing useful and valuable information and the experience of having anorexia and being a mother. This evidence will help researchers and health professionals to better understand your experiences and improve the way they work with women who have experienced anorexia nervosa and now have young children of their own.

To be eligible to take part you must:

- Be aged over 18 years
- Have been given a diagnosis of anorexia nervosa by a psychiatrist in the past
- Have had a child within the past five years
- Be currently engaged in treatment if you experience any other psychological difficulties such as low mood or anxiety

This study involves a semi-structured interview which will last approximately 1 hour. The interview will be one to one and focus on your experiences of having anorexia nervosa and being a mother. If you live locally (in South Staffordshire, North Staffordshire or Shropshire) you have the option of being interviewed at a local community venue, such as a library or health centre, or you can complete your interview over the telephone if you prefer. If you do not live locally your interview will be completed over the telephone.

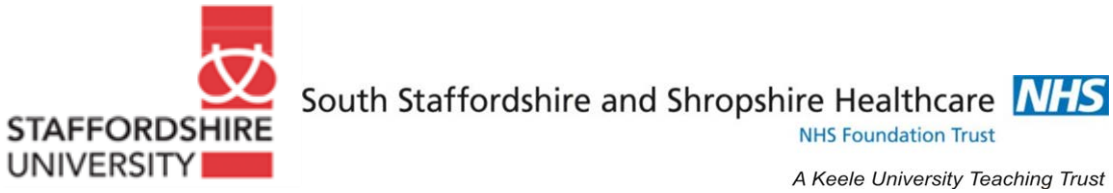
If you are interested in taking part and would like some further information please contact the researcher at ow002426@student.staffs.ac.uk.

This study has been approved by Staffordshire University Ethics Committee and by the Black Country NHS Research Ethics Committee.

Thank you for reading this information. Without you, this type of research would not be possible.

APPENDIX G

Online recruitment screening questionnaire



Screening questionnaire for participants recruited online

	Yes	No
• Is English your first language or would you require the assistance of an interpreter in order to complete the interview?		
• Have you been diagnosed with anorexia nervosa by a psychiatrist?		
• Have you had a child within the past five years?		
• Are you aged over 18?		
• Are you currently experiencing any psychological difficulties (i.e. low mood, anxiety)? Are you receiving support or treatment in relation to these difficulties?		
• Are you currently experiencing severe psychiatric difficulties such as suicidal ideation or hallucinations?		

APPENDIX H

Information sheet

South Staffordshire and Shropshire Healthcare NHS
NHS Foundation Trust
A Keele University Teaching Trust

The experience of being a mother with anorexia nervosa

Participant information sheet

Part 1: Purpose of the study

Why have I been chosen to participate in this study?

My name is Gemma O'Leary and I am a trainee clinical psychologist. I am studying at Staffordshire University and completing a piece of research as part of my doctorate. I am interesting in finding out more about the experience of motherhood for women with anorexia nervosa. I am focusing specifically on women who have had a child within the past five years.

What will participation involve?

You will complete a face to face interview. The interview will be informal, allowing us to discuss your experiences at length if you are happy to do so (although there is no obligation to do this). There is a list of core topics to be covered which are related to your experiences of motherhood.

You will complete <u>one</u> interview at a venue convenient to you.

It is up to you whether you would like to take part in the study. Participation is entirely voluntary and your decision will not impact on any aspect of your usual health care. You are free to withdraw at any time during the study.

Interviews will be tape recorded. Only myself, my project supervisor Dr Kierron Worley (Clinical Psychologist, Staffordshire and Shropshire Eating Disorders service) and academic supervisor Dr Alison Tweed (Clinical Psychologist, Staffordshire University), will listen to the tape recording of the interview. You can review a copy of your interview in written form before the data is analysed.

How long will participation take?

The whole interview usually lasts no longer than one hour.

Confidentiality

Yes. All information about you will be handled in confidence.

However your responses are anonymous but not confidential. This means whilst no identifiable information (e.g. names) will be used anywhere in the study, any response you do give during your interview will be read by my clinical and academic supervisors, and if the study is published in an academic journal, other people will also be able to read your responses. This may include direct quotes. You will be assigned a number which will be used in place of your real identity for the remainder of the study. Any identifying information about you (such as family names) will be changed.

An audio recorder will be used to record the interview. Afterwards a written transcript will be produced. This is a written record of what was said during the interview, produced using the audio recording. After the study has been completed, the audio recording of the interview will be deleted and no other copy will remain. The written transcript will not include information which could be used to identify you.

Risks and benefits

It is possible that discussing your experiences may cause you to feel upset. If any questions make you feel uncomfortable or upset you do not have to answer them. Please let me know and we will move on to the next question.

Your GP or consultant will be made aware of your participation in this study. However they will not be informed of specific responses you give during the interview. If you are concerned about this please let me know. If you become distressed I may contact a member of the health care team for assistance. I will discuss this with you if this situation arises.

If you disclose information which indicates to me that you or someone else might be at risk of harm, I will need to contact a member of the health care team for assistance. I will need to inform your GP about any disclosures related to risk.

Although there are no guarantees that the study will help you, the information you provide will help health professionals to understand the experience of motherhood for women with anorexia.

If the information in Part 1 has interested you and you are considering participating, please read the additional information in Part 2 before making any decision.

Part 2: Information about the conduct of the study

What happens if I wish to withdraw from the study?

It is up to you whether you would like to take part in the study. Participation is entirely voluntary and your decision will not impact on any aspect of your usual health care. If you wish to withdraw from the study at any point during your interview you can do so immediately by telling me you no longer wish to take part. If you wish to withdraw from the study after you have completed your interview you can do so by contacting me by email at ow002426@student.staffs.ac.uk or by contacting my clinical supervisor Dr Kierron Worley on 01785 221 331 (South Staffordshire Eating Disorders Service). You are free to withdraw at any time

during the study. However unless you state otherwise, any responses you have already given will be used in the study, anonymously.

What if I have concerns about the study or would like to make a complaint?

If you have any concerns about any aspect of the study, you should ask to speak to Dr Alison Tweed, Academic Supervisor on 01782 294007. If you remain unhappy and wish to complain formally, you can do this by contacting the Patient Advice and Liaison Service on 01785 783028.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against South Staffordshire and Shropshire Healthcare NHS Foundation Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

How will my participation remain confidential?

Identifiable information is not necessary and therefore will not be used. Data will be stored in a locked cabinet in the offices of South Staffordshire and Shropshire Eating Disorers Service when it is not in use. Only I, Dr Kierron Worley (Clinical Psychologist, South Staffordshire and Shropshire Eating Disorders service) and Dr Alison Tweed (Clinical Psychologist, Staffordshire University) will have access to the data. Audio records will be deleted after the study is completed in July 2014. Paper transcripts must be kept for a minimum of ten years on the premises of Staffordshire University, in a locked cabinet, but will contain no identifiable information.

What will happen to the results of the study?

It is hoped that the results of the study will help health professionals to support women with anorexia who have children.

A report will be prepared based on the findings of this study which will be submitted to Staffordshire University as part of my doctoral thesis. A summary of the overall findings will be prepared and sent by post to each participant after the study is complete.

The results of the study may be published and will be shared amongst other health professionals. Direct quotes will be included, although identifiable information will not be used – participant numbers will be used in place of names. If you are concerned about this please let me know.

Who is organising the research?

I am completing this research as part of a doctorate course at Staffordshire University. The study is sponsored by Staffordshire University.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Black Country Research Ethics Committee.

Further information and contact details:

If you would like general information about research please feel free to speak with me at any time during the study. I am available at ow002426@student.staffs.ac.uk. If you would like specific information about this study, please feel free to speak with me at any time.

For advice as to whether or not you should participate, please feel free to speak to others, including your health professionals, alternatively you can speak to Dr Kierron Worley, Clinical Supervisor by calling 01785 221 331. If you would like an independent source of advice you can also contact the Patient Advice and Liaison Service on 01785 783028.

If you are unhappy with the study please approach Dr Alison Tweed by calling 01782 294007.

APPENDIX I

Consent form

South Staffordshire and Shropshire Healthcare NHS
NHS Foundation Trust
A Keele University Teaching Trust

Patient identification number:
Title of project: Becoming a mother with anorexia nervosa
Name of researcher: Gemma O'Leary

CONSENT FORM

Please initial box

1. I confirm that I have read and understand the information sheet dated (version 3/April 2013) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
1.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of the data collected during the study may be looked at by Gemma O'Leary, Dr Kierron Worley (Clinical Supervisor) and Dr Alison Tweed (Academic Supervisor). I give my permission for these individuals to have access to my data. ☐

4. Interviews will be recorded and I can request a copy of my interview in written form to review before the data is analysed (see below) ☐

5. I understand that data collected during the study may be looked at by individuals from regulatory authorities or from the NHS trust where it is relevant to my taking part in this research. My GP/consultant will be made aware of my participation and will be informed if I become distressed during the interview. I give permission for these individuals to access my data. ☐

6. I understand that any data I give, including direct quotations, may be used in any publications which arise from this study, and that the data will be used anonymously ☐

7. I agree to take part in the above study ☐

Name of participant	Date	Signature

Name of person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

APPENDIX J

GP information letter

South Staffordshire and Shropshire Healthcare NHS
NHS Foundation Trust
A Keele University Teaching Trust

NHS address
Line 1
Line 2
Postcode

Our ref: GO'L
NHS Number: 123 456 7890

Date

In Confidence

GP/Consultant name
Address line 1
Address line 2
Town
Postcode

Dear

Re: Participant name Participant DOB Participant address

The above patient has been recruited to participate in a piece of research entitled **"The experience of being a mother with anorexia nervosa"** for which they will complete a one to one semi structured interview with a researcher registered with Staffordshire University. This study is taking place following NHS ethical approval by [name here] Research Ethics Committee and the Research and Development department of [name here]. South Staffordshire and Shropshire eating disorders team and perinatal mental health teams in North and South Staffordshire have ongoing input into the study. The interview will be tape recorded and analysed by the researcher.

A copy of the Participant Information Sheet is enclosed for your reference.

If you have any queries or concerns please do not hesitate to contact me using my email address: gemma.o'leary@sssft.nhs.uk.

Kind regards
Gemma O'Leary
Researcher – Staffordshire University

APPENDIX K

Participant debrief

South Staffordshire and Shropshire Healthcare NHS
NHS Foundation Trust
A Keele University Teaching Trust

Debrief and useful contacts

Thank you for taking part in this study. Your responses are much appreciated and will help to increase health professionals' understanding of the experiences of women with anorexia nervosa.

The purpose of this study is to gather information about the experiences of motherhood for women who have anorexia nervosa. Currently little is known about the experiences of this group of women; we don't know what their perspective is on parenting young children as well as managing an eating disorder, and consequently we don't know whether there is anything health professionals could do to support them. It is expected that around fifteen women will take part in the study, each completing an interview during which they will be asked questions about their experiences. After analysing the responses given, the researcher will attempt to make links between them and try to highlight common experiences which are unique to mothers with anorexia nervosa and young children.

What happens if I wish to withdraw from the study?

You are free to withdraw from this study at any point until the study is completed, even if you have already completed your interview. Should you wish to withdraw from the study you can do this either by contacting me directly using my email address, ow002426@student.staffs.ac.uk or by contacting my clinical supervisor Dr Kierron Worley on 01785 221 331 (South Staffordshire Eating Disorders Service).

How can I access the findings of this study?

A report will be prepared based on the findings of this study which will be submitted to Staffordshire University as part of my doctoral thesis. A summary of the overall findings will be prepared and sent by post to each participant after the study is complete. The summary of findings will be sent no later than April 2014.

Further information and support

You may have found the interview process upsetting. This is understandable given the issues you have discussed with me. If you feel further support is necessary details are provided below. You can also access advice, support and information from your GP surgery.

Beat

National charity supporting people with eating disorders
Access to information, helpline, online community and local support groups
0845 634 1414
help@b-eat.co.uk

Rethink

National charity supporting people with a variety of difficulties including eating disorders
Access to information, helpline and signposting to other services
0300 5000 927
advice@rethink.org

South Staffordshire and Shropshire Eating Disorders Service

St Chads House,
Corporation Street,
STAFFORD,
ST16 3AG

Telephone number: 01785 221331/221502

The Berrington Suite,
Shelton Hospital,
SHREWSBURY,
SY3 3DN

Telephone number: 01743 492256

The Samaritans

If you or anyone you know is in distress and struggling to cope, The Samaritans are available 24 hours a day, 7 days a week, to speak on the telephone confidentially.

www.samaritans.org
08457 90 90 90

APPENDIX L

Summary of findings to participants

South Staffordshire and Shropshire Healthcare NHS
NHS Foundation Trust
A Keele University Teaching Trust

NHS address
Line 1
Line 2
Postcode

Our ref: GO'L
NHS Number: 123 456 7890

Date

In Confidence

Name
Address line 1
Address line 2
Town
Postcode

Dear

Thank you for your participation in a recent piece of research: **"The experience of being a mother with anorexia nervosa"**. The research has since been completed and a summary of the findings is attached for your reference. As you directly participated in the research, this is your personal copy and you do not have to return it.

May I take the opportunity to thank you again for taking the time to participate; your responses are invaluable and will help health professionals and researchers to better understand the experience of motherhood for women with anorexia nervosa.

If you have any further questions you are welcome to contact me at gemma.o'leary@sssft.nhs.uk.

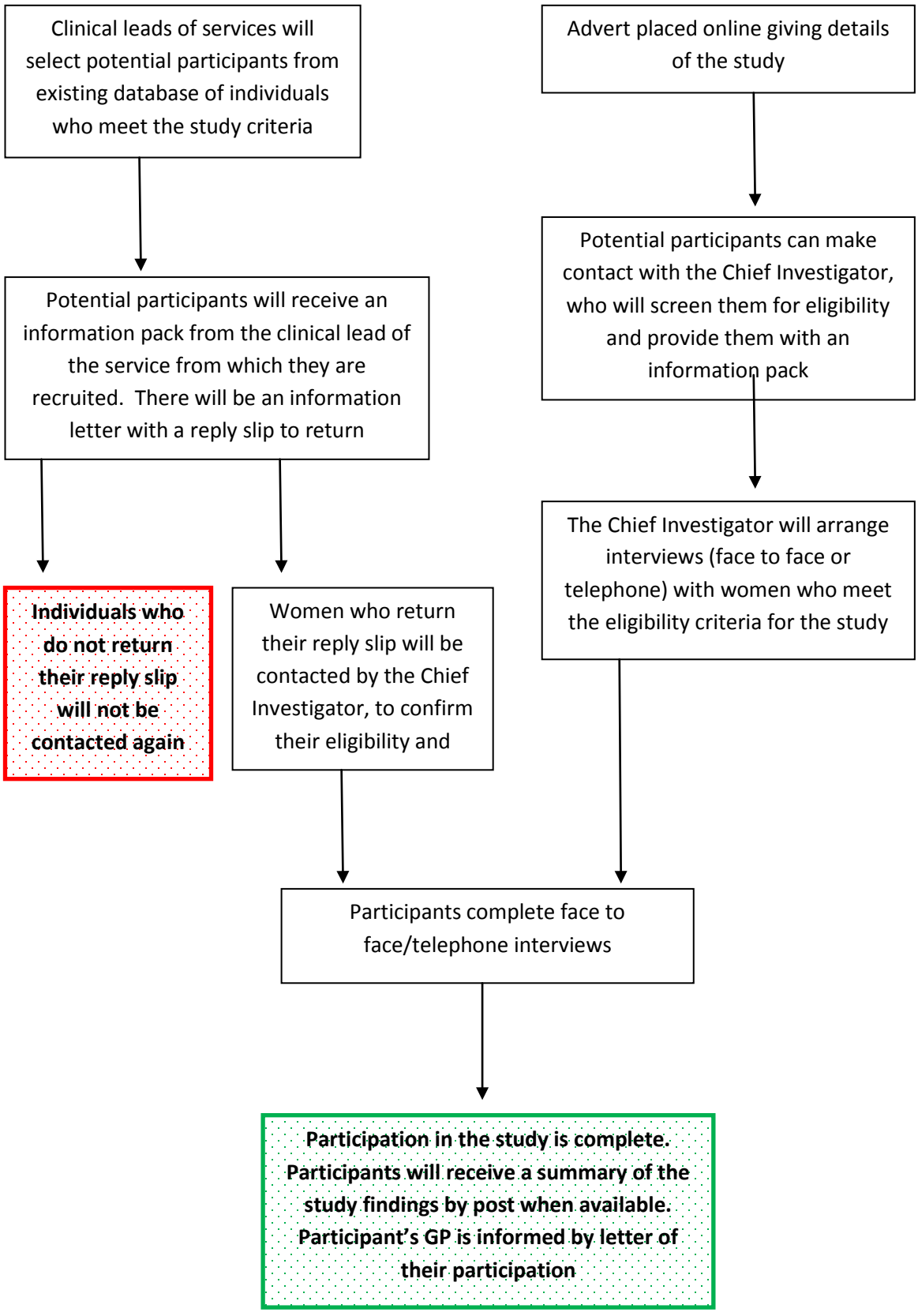
Kind regards

Gemma O'Leary
Researcher – Staffordshire University

[Staff member name]
[Staff member role]

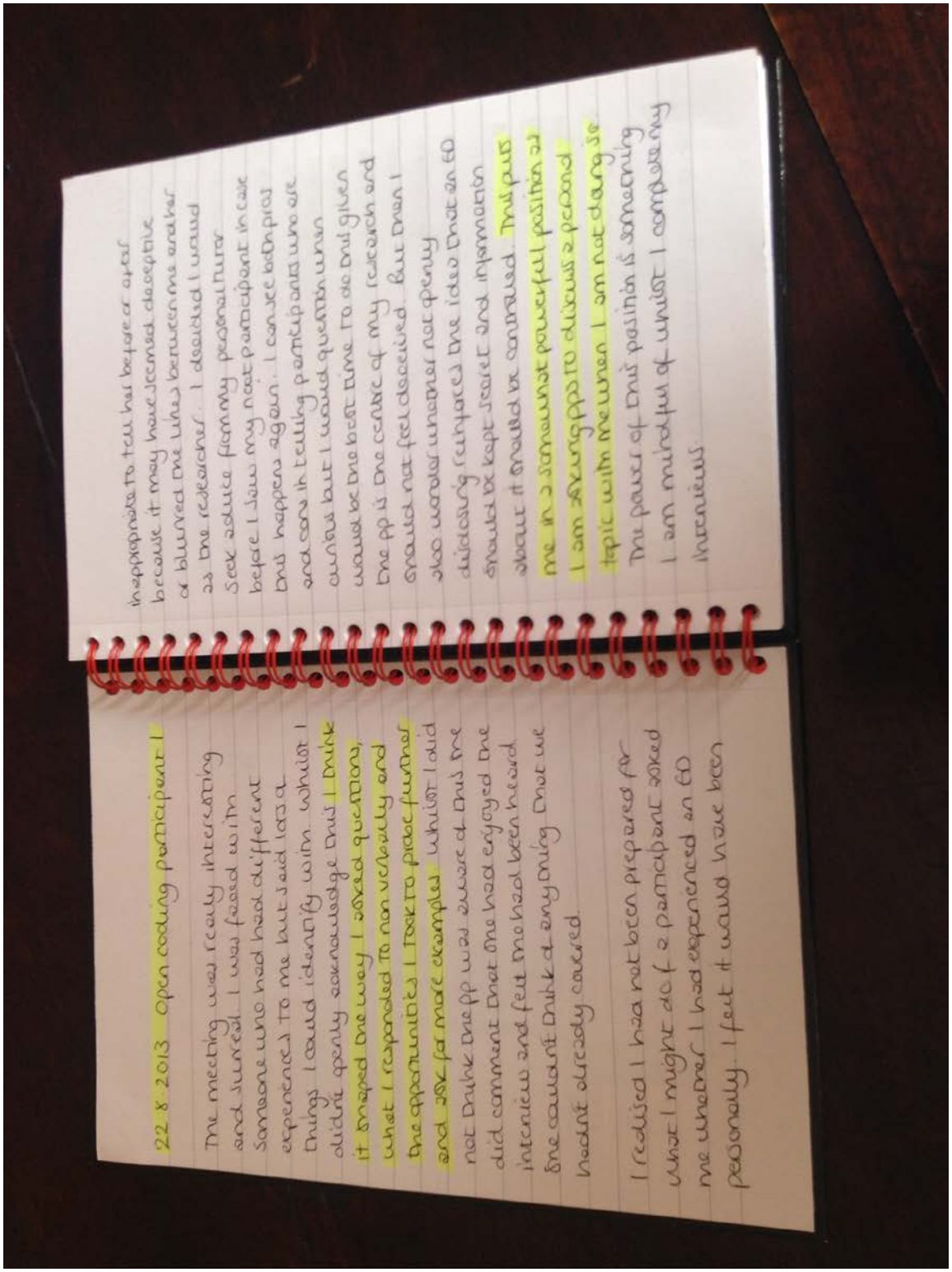
APPENDIX M

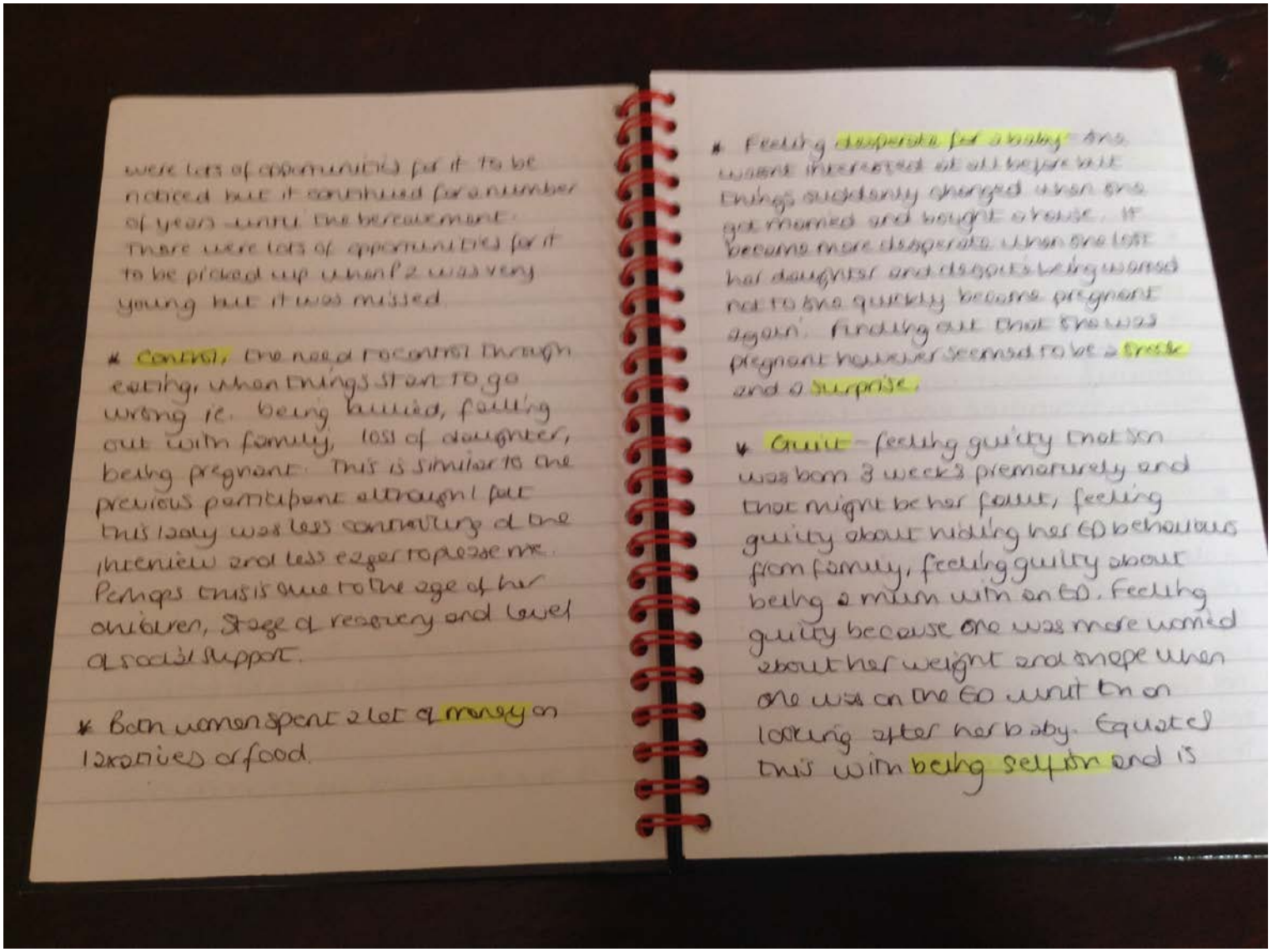
Flowchart of protocol



APPENDIX N

Examples of memos taken from reflective diary





were lots of opportunities for it to be noticed but it continued for a number of years until the bereavement. There were lots of opportunities for it to be picked up when I was very young but it was missed.

* Control, the need to control through eating, when things start to go wrong ie. being bullied, falling out with family, loss of daughter, being pregnant. This is similar to the previous participant although I felt this baby was less controlling of the interview and less eager to please me. Perhaps this is due to the age of her children, stage of recovery and level of social support.

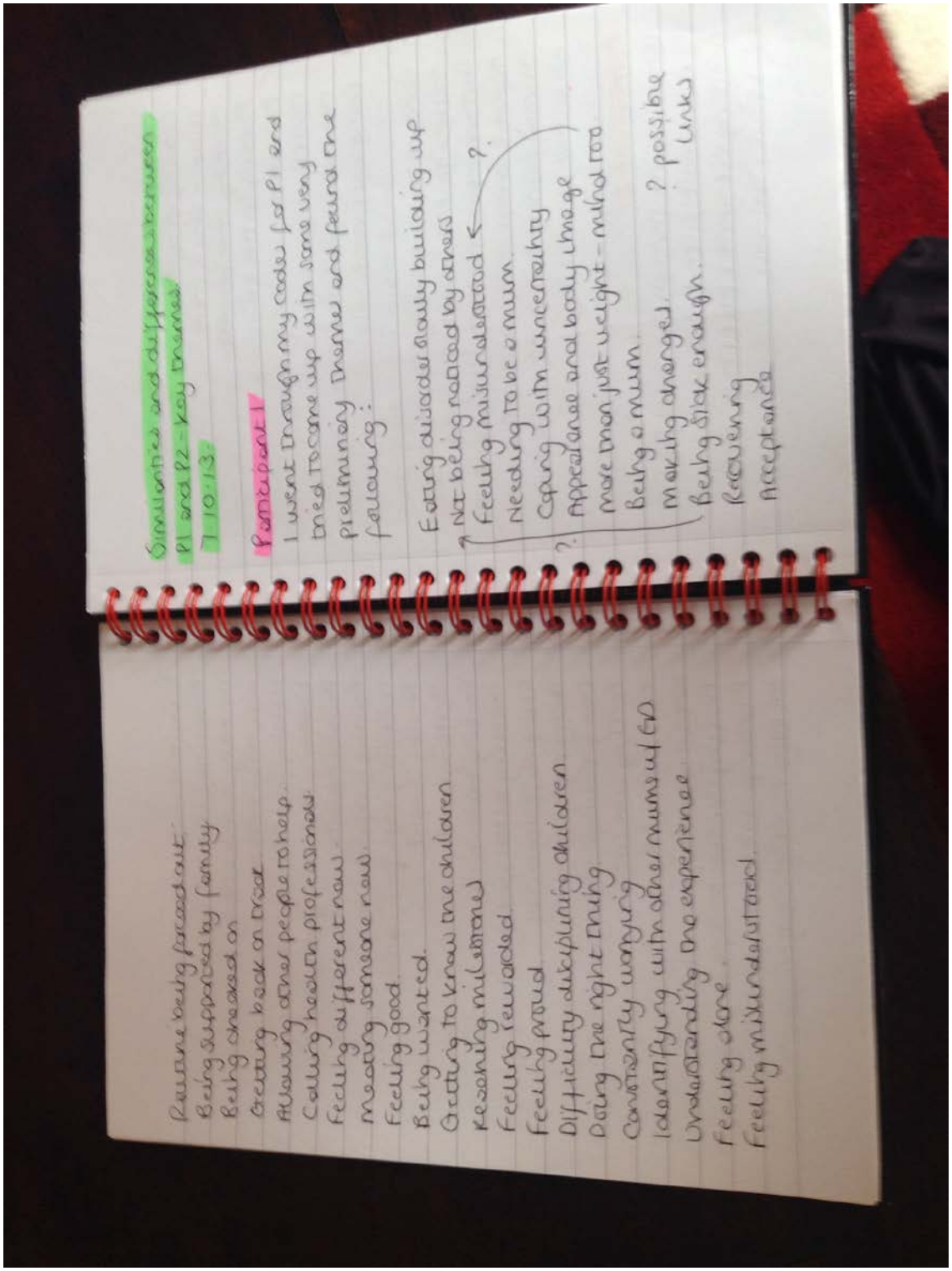
* Both women spent a lot of money on laxatives or food.

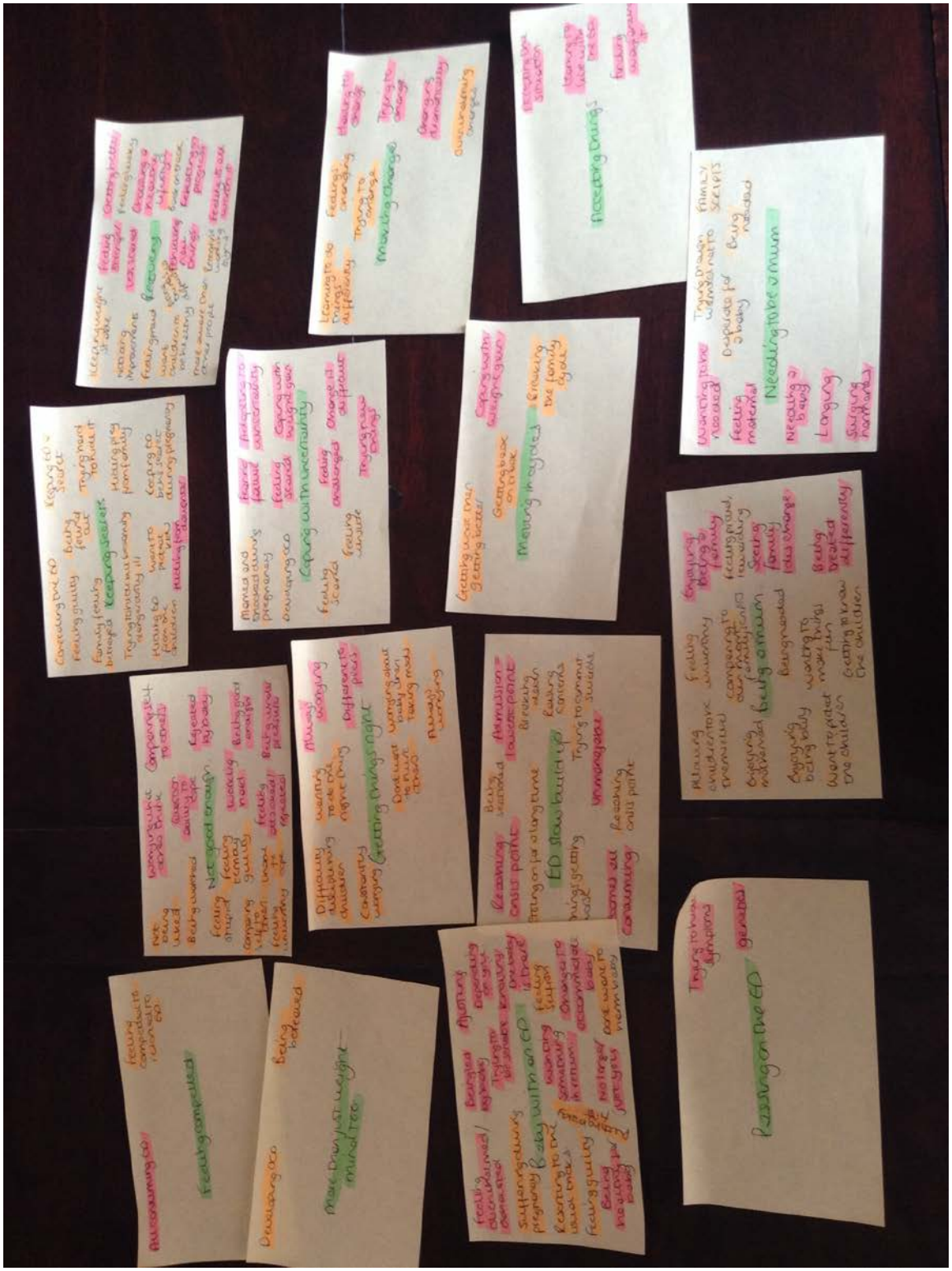
* Feeling desperate for a baby. She wasn't interested at all before but things suddenly changed when she got married and bought a house. It became more desperate when she lost her daughter and despite being warned not to she quickly became pregnant again. Finding out that she was pregnant however seemed to be a shock and a surprise.

* Guilt - feeling guilty that Jon was born 3 weeks prematurely and that might be her fault, feeling guilty about hiding her ED behaviours from family, feeling guilty about being a mum with an ED. Feeling guilty because she was more worried about her weight and shape when she was on the ED unit than on looking after her baby. Equated this with being selfish and is

APPENDIX O

Examples of the constant comparative method




Recovering ED
Being beloved
Feeling guilty
Feeling
Feeling
Feeling

APPENDIX P

Example of contributory code

Code 3: Keeping secrets

Definition

For some women their ED had been or was still a major secret, which they had concealed for a long time. Even now some women were trying to hide their symptoms from their families. Sometimes the pregnancy was kept secret until a late stage because discovering the pregnancy was a shock. They had to keep their ED away from their child and sometimes from their partners. They were concerned about the consequences of what might happen if other people found out about their eating disorders now they have children. Sometimes there were family secrets because the women had had bad experiences when telling their family previously. When other family members suffered from similar problems then covered them up it seemed like the normal thing for these women to do the same. At times it seems like the worst kept secret and as children get older the secret gets more difficult to keep, because children notice and talk about it, meaning these women resort to even more extreme measures to keep the behaviour going in secret without it harming their children. Women experienced a great deal of guilt and shame about this.

Links to other categories

- Control
- Feeling misunderstood
- Not feeling good enough
- Passing on the ED to children
- Balancing the eating disorder and the baby

Line by line codes by participant

PP	Line code	Key quotes
1	Hiding the ED from daughter	I can't just put her down and go and make myself sick because you know she'll be there (l. 326-7) I try to keep as much of my symptoms away from her as physically possible, and that isn't always possible… but I manage it as best as I can (l. 463-5) I can't jump in my car go and buy a load of food and sit for hours chewing and spitting because she's there (l. 621-3) When she gets older she will start to notice (l. 650-1)
2	Concealing the ED	My mom didn't realise what I was doing (l. 27-8) It wasn't an option for me to do what I did so… I didn't do it anymore (l. 49-50) I was still in the whole…thing of buying and wearing clothes that were too big to hide everything (l. 63-5)
	Feeling guilty	I'm convinced to this day that has something to do with me (l. 124-5)
	Family	They went why haven't you told us you know they were

	feeling betrayed	deeply upset (l. 152-3)
	Trying to hide the ED but becoming very ill	Even if I didn't eat anything I felt compelled to take [the laxatives] (l. 92-3) I still managed to sneak off now and again but it didn't really work (l. 160-1)
	Hiding the ED from children	I'm lucky that [my sons] haven't picked up on any of my eating habits cause obviously that was a major concern to me (l. 289-90)
	Wanting to protect children	I see the warning signs a lot quicker than anyone else (l. 302-3) I want the kids to be kids (l. 304-5) I was absolutely terrified I was like I'd grab things off him (l. 332-3)
	Being found out	His mom came and I'd got this BMI chart blu-tacked to the cupboard door and everything… they found it and they came upstairs (l. 147-152)
	Keeping the ED a secret	My ex-husband and I had kept the eating disorder to ourselves (l. 146-7)
	Trying hard to hide the ED	I'd do the whole eating it and bringing a cup to my face and spitting what I was eating into the cup (l. 121-2)
	Hiding the pregnancy from family	We didn't tell anyone because there was so much hurt and that in the family (l. 110-1)
	Keeping ED secret during pregnancy	While I was pregnant I was still doing what I'd been doing you know making myself sick (l. 117-8)
3	Covering it up	I was always like unsure with myself. But I'd cover it up because I'd always be the loudest one (l. 128-9)
	Being outgoing	I'd always be… the most outgoing but that was kind of a cover and once I stopped going out and doing those things that was my only way of expressing myself was through my eating (l. 129-32)
	Isolating self	I stopped going out and doing those things (l. 131) You do isolate yourself anyway especially at the beginning and it's hard to get out of that (l. 192-3)
	Wanting to be alone	When you're unwell you don't really want to do anything or see anyone (l. 190-1)
4	Parent never admitting it	When I grew up my mom had erm she still has got a bit of an eating disorder not that she would ever admit it (l. 32-3)
	Making excuses	There's only so many times you can make excuses (l. 41-2)
	Not being able to hide it	It got to the point when I couldn't even hide being sick (l. 42-3)
	Physically hiding	I can't physically hide things when they're there all the time (l. 44-5)
	Keeping it secret	When they were tiny and they didn't really know what was going on I could just [pause] keep it secret but now they're

		at that age that they know that's not right (l. 45-7)
	Feeling like a hypocrite	I'm trying to intill in them eating and I feel like a hypocrite and they say but you haven't eaten your dinner, I'm not going to eat mine! (l. 48-9)
	Feeling horrid	It's horrid (l. 55)
	Being sick in secret	I plan things like erm if we have dinner a bit later and they can go to bed and then I can be sick and they won't know (l. 55-7)
	Children telling people	It sounds silly but then because they're telling people as well, because kids don't know any different, mummy's not very well she's been sick (l. 66-8)
	Keeping quiet	I didn't say anything I felt very much like I shouldn't be feeling like this so don't say it out loud (l. 194-5)
	Not telling people	I guess I've [sighs] it's just not telling people what was going on, erm making out that I've eaten something when I haven't (l. 414-5)
	Keeping secrets	It's just easier, it's like it sounds horrendous saying it but to keep it secret (l. 58)
	Easier to lie	When you're the cook at home it's easier to say well I had something when I was cooking (l. 416-7)
	Getting away with things	Just get away with things that way (l. 417)
	Wearing big clothes	People do notice you've lost weight, that's when I resort to jumpers [pause] I'll always say I'm cold and then I can put a big fleece on (l. 418-20)
6	Hiding the problem x 2	The anorexia was like, I'd hide it to a lot of people (l. 91) The binge eating side I'd do when no one was in the house, I wouldn't want anyone to know (l. 195-6)
	Keeping it hidden	It was very dark and hidden (l. 197-8)
	Feeling dirty	It somehow felt a bit dirty and horrible (l. 198)
	Making excuses	If your friends say oh come on out for a meal I'd make excuses so I wouldn't have to go (l. 208-9)
	Finding excuses	I wouldn't even come out and tell anyone I'd find an excuse like oh I don't really like that anymore (l. 212-3)
7	Hiding eating disorder	When I first started realising that I did have anorexia I used to hide it as much as I could from people (l. 80-82)
	Not wanting daughter to see	I'll keep it separate obviously from [my daughter] but like cause I don't want her to see any symptoms (l. 94-96)

<u>My observations during the interview</u>

I'm interested in the idea of family scripts and sometimes family secrets felt like a kind of script. I was also interested in the reality of managing an eating disorder with a baby – that complete recovery is very difficult and there are times when these women still resort to their ED behaviours. This reinforced for me how stressful the process of becoming a mother can be particularly when these women have prior vulnerabilities.

I wondered about the shame and guilt these women might experience in trying to keep secrets from their friends and family and how much they were willing to discuss with me as a stranger.

Key theories and references

Siebold, C. (2008). Shame, the affective side of secrets: commentary on Barth's hidden eating disorders. *Clinical Social Work Journal*, 36 (4), 367-71.

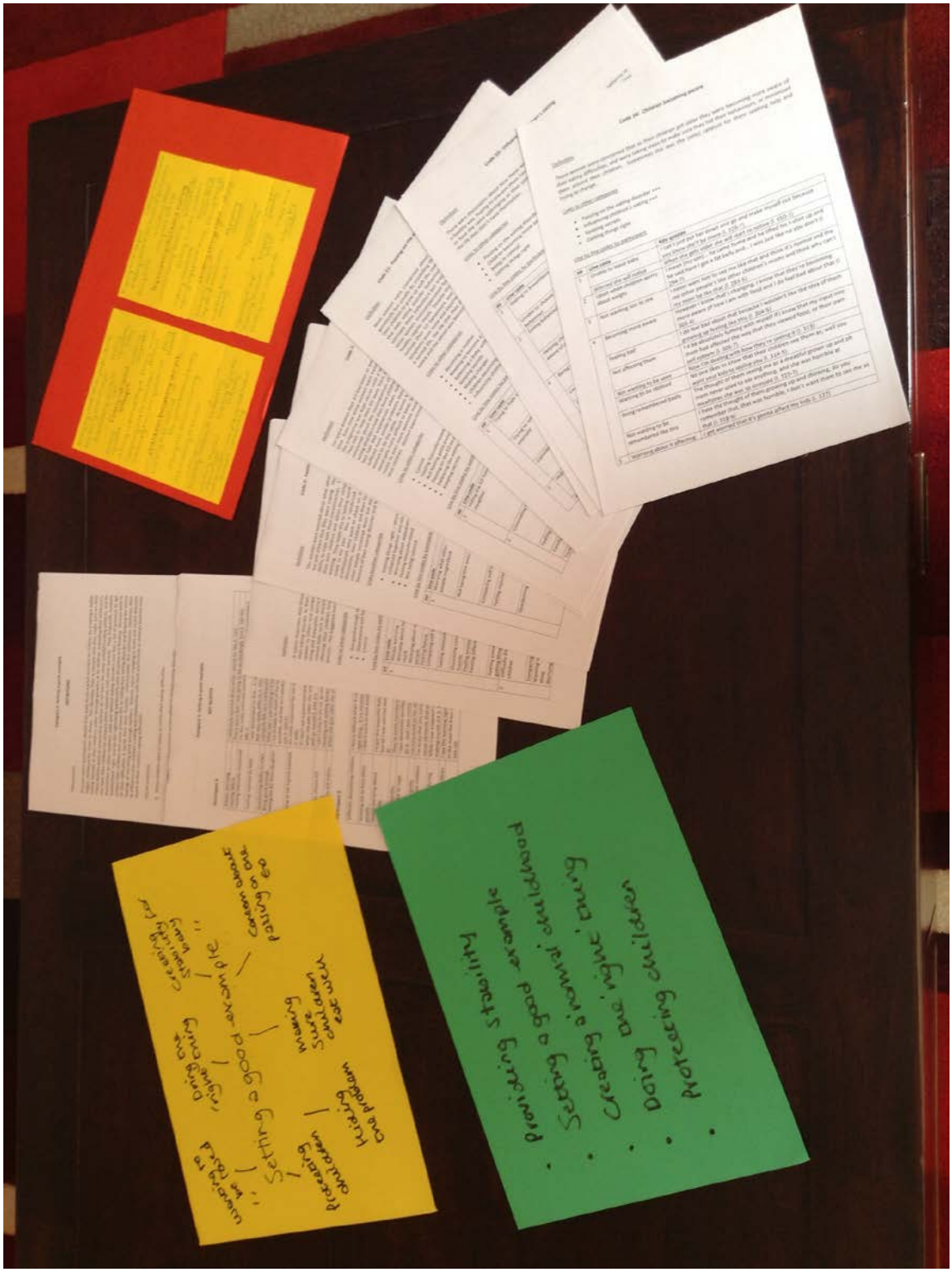
Dalzell, H. (2000). Whispers: the role of family secrets in eating disorders. *Eating Disorders: The Journal of Treatment and Prevention*, 8 (1), 43-61.

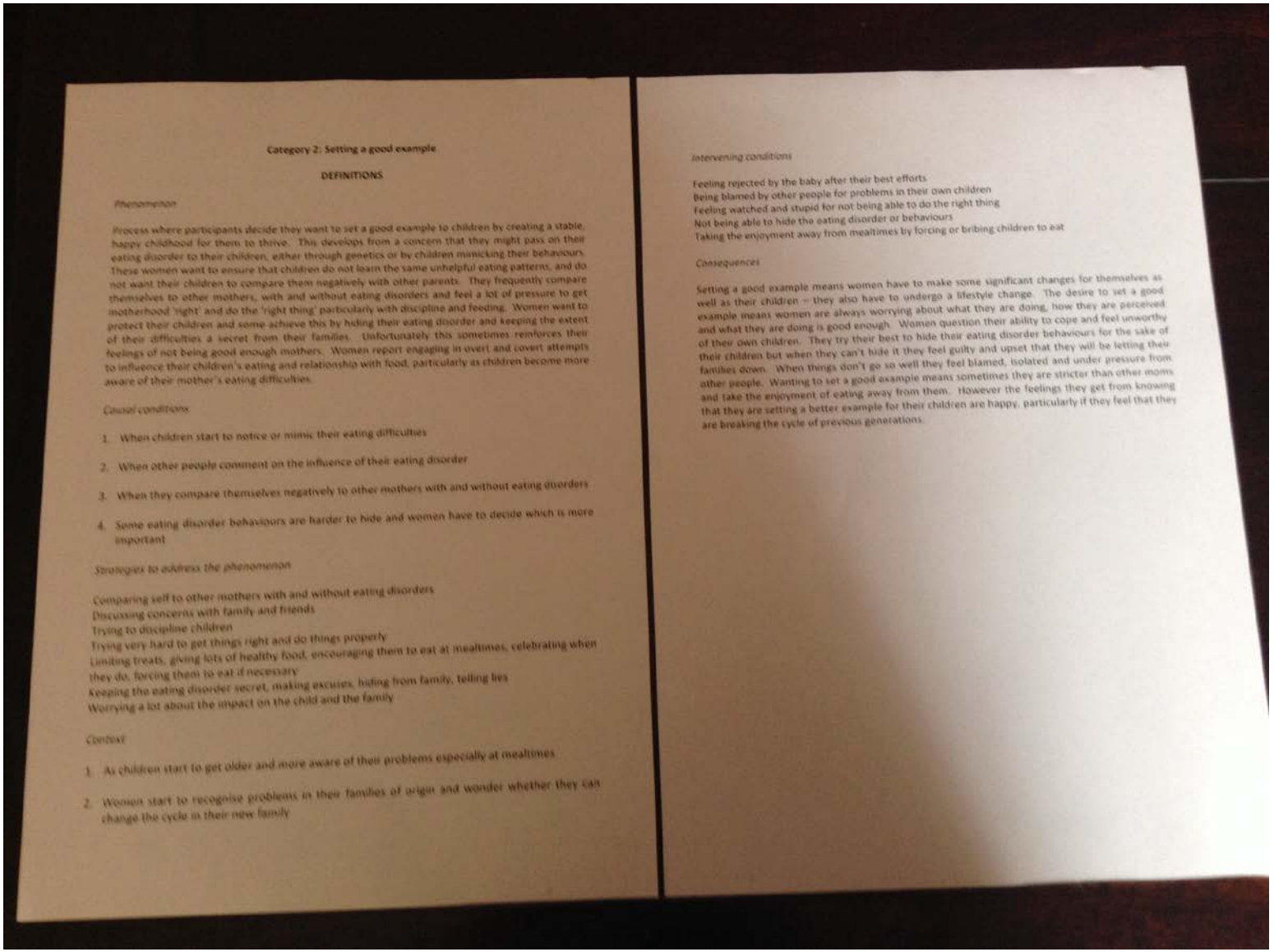
Barth, F. (2008). Hidden eating disorders: attachment and affect regulation in the therapeutic relationship. *Clinical Social Work Journal*, 36 (4), 355-65.

Sanftner, J. (1995). The relation of shame and guilt to eating disorder symptomatology. *Journal of Social and Clinical Psychology*, 14 (4), 315-324.

APPENDIX Q

Example of a category developed in axial coding





Category 2: Setting a good example

DEFINITIONS

Phenomenon

Process where participants decide they want to set a good example to children by creating a stable, happy childhood for them to thrive. This develops from a concern that they might pass on their eating disorder to their children, either through genetics or by children mimicking their behaviours. These women want to ensure that children do not learn the same unhelpful eating patterns, and do not want their children to compare them negatively with other parents. They frequently compare themselves to other mothers, with and without eating disorders and feel a lot of pressure to get motherhood 'right' and do the 'right thing' particularly with discipline and feeding. Women want to protect their children and some achieve this by hiding their eating disorder and keeping the extent of their difficulties a secret from their families. Unfortunately this sometimes reinforces their feelings of not being good enough mothers. Women report engaging in overt and covert attempts to influence their children's eating and relationship with food, particularly as children become more aware of their mother's eating difficulties.

Causal conditions

1. When children start to notice or mimic their eating difficulties
2. When other people comment on the influence of their eating disorder
3. When they compare themselves negatively to other mothers with and without eating disorders
4. Some eating disorder behaviours are harder to hide and women have to decide which is more important

Strategies to address the phenomenon

Comparing self to other mothers with and without eating disorders
Discussing concerns with family and friends
Trying to discipline children
Trying very hard to get things right and do things properly
Limiting treats, giving lots of healthy food, encouraging them to eat at mealtimes, celebrating when they do, forcing them to eat if necessary
Keeping the eating disorder secret, making excuses, hiding from family, telling lies
Worrying a lot about the impact on the child and the family

Context

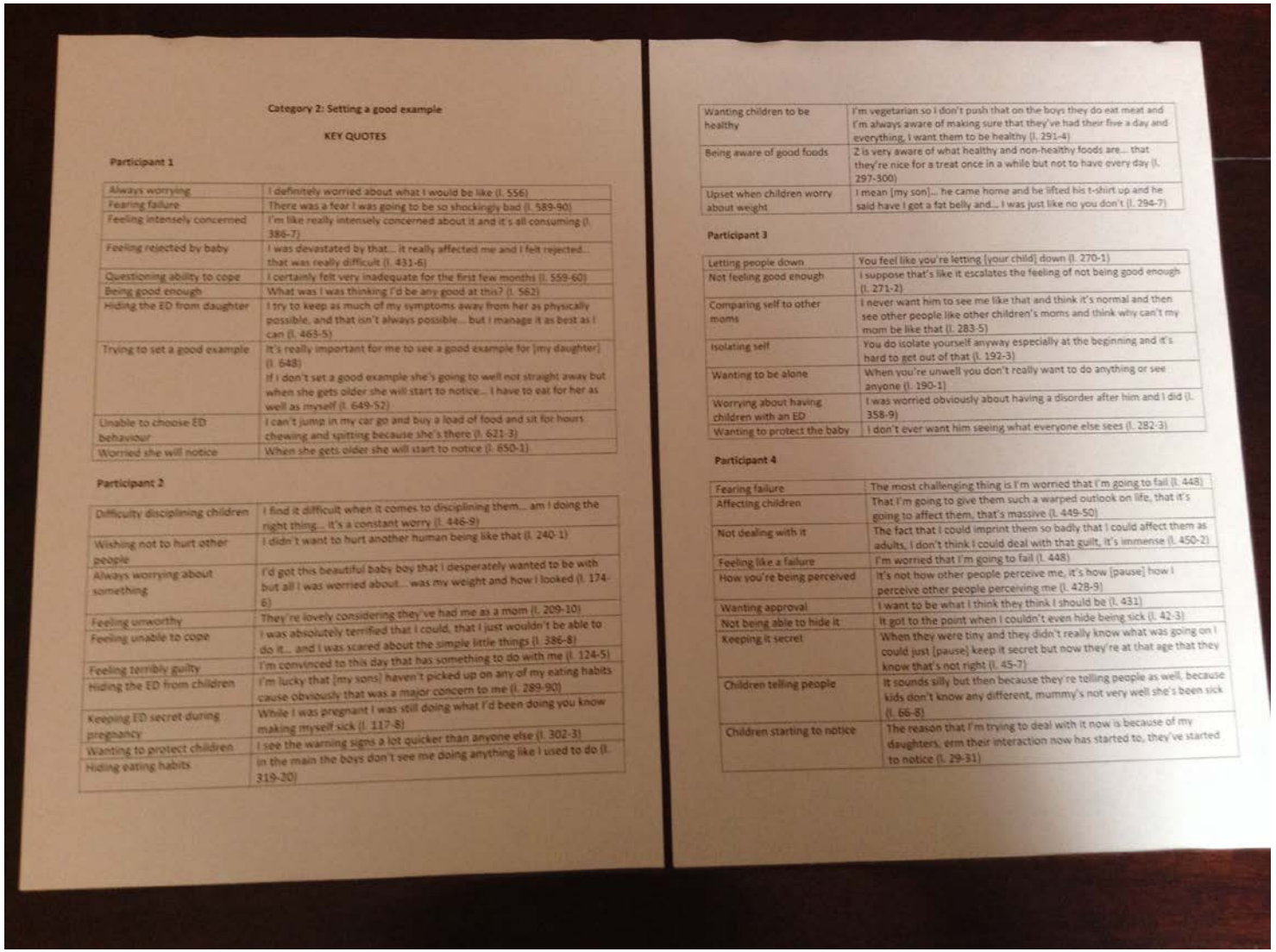
1. As children start to get older and more aware of their problems especially at mealtimes
2. Women start to recognise problems in their families of origin and wonder whether they can change the cycle in their new family

Intervening conditions

Feeling rejected by the baby after their best efforts
Being blamed by other people for problems in their own children
Feeling watched and stupid for not being able to do the right thing
Not being able to hide the eating disorder or behaviours
Taking the enjoyment away from mealtimes by forcing or bribing children to eat

Consequences

Setting a good example means women have to make some significant changes for themselves as well as their children – they also have to undergo a lifestyle change. The desire to set a good example means women are always worrying about what they are doing, how they are perceived and what they are doing is good enough. Women question their ability to cope and feel unworthy of their own children. They try their best to hide their eating disorder behaviours for the sake of their children but when they can't hide it they feel guilty and upset that they will be letting their families down. When things don't go so well they feel blamed, isolated and under pressure from other people. Wanting to set a good example means sometimes they are stricter than other moms and take the enjoyment of eating away from them. However the feelings they get from knowing that they are setting a better example for their children are happy, particularly if they feel that they are breaking the cycle of previous generations.



Category 2: Setting a good example

KEY QUOTES

Participant 1

Always worrying	I definitely worried about what I would be like (l. 556)
Fearing failure	There was a fear I was going to be so shockingly bad (l. 589-90)
Feeling intensely concerned	I'm like really intensely concerned about it and it's all consuming (l. 386-7)
Feeling rejected by baby	I was devastated by that... it really affected me and I felt rejected... that was really difficult (l. 431-6)
Questioning ability to cope	I certainly felt very inadequate for the first few months (l. 559-60)
Being good enough	What was I was thinking I'd be any good at this? (l. 562)
Hiding the ED from daughter	I try to keep as much of my symptoms away from her as physically possible, and that isn't always possible... but I manage it as best as I can (l. 463-5)
Trying to set a good example	It's really important for me to see a good example for [my daughter] (l. 648) If I don't set a good example she's going to well not straight away but when she gets older she will start to notice... I have to eat for her as well as myself (l. 649-52)
Unable to choose ED behaviour	I can't jump in my car go and buy a load of food and sit for hours chewing and spitting because she's there (l. 621-3)
Worried she will notice	When she gets older she will start to notice (l. 650-1)

Participant 2

Difficulty disciplining children	I find it difficult when it comes to disciplining them... am I doing the right thing... it's a constant worry (l. 446-9)
Wishing not to hurt other people	I didn't want to hurt another human being like that (l. 240-1)
Always worrying about something	I'd got this beautiful baby boy that I desperately wanted to be with but all I was worried about... was my weight and how I looked (l. 174-6)
Feeling unworthy	They're lovely considering they've had me as a mom (l. 209-10)
Feeling unable to cope	I was absolutely terrified that I could, that I just wouldn't be able to do it... and I was scared about the simple little things (l. 386-8)
Feeling terribly guilty	I'm convinced to this day that has something to do with me (l. 124-5)
Hiding the ED from children	I'm lucky that [my sons] haven't picked up on any of my eating habits cause obviously that was a major concern to me (l. 289-90)
Keeping ED secret during pregnancy	While I was pregnant I was still doing what I'd been doing you know making myself sick (l. 117-8)
Wanting to protect children	I see the warning signs a lot quicker than anyone else (l. 302-3)
Hiding eating habits	In the main the boys don't see me doing anything like I used to do (l. 319-20)
Wanting children to be healthy	I'm vegetarian so I don't push that on the boys they do eat meat and I'm always aware of making sure that they've had their five a day and everything, I want them to be healthy (l. 291-4)
Being aware of good foods	Z is very aware of what healthy and non-healthy foods are... that they're nice for a treat once in a while but not to have every day (l. 297-300)
Upset when children worry about weight	I mean [my son]... he came home and he lifted his t-shirt up and he said have I got a fat belly and... I was just like no you don't (l. 294-7)

Participant 3

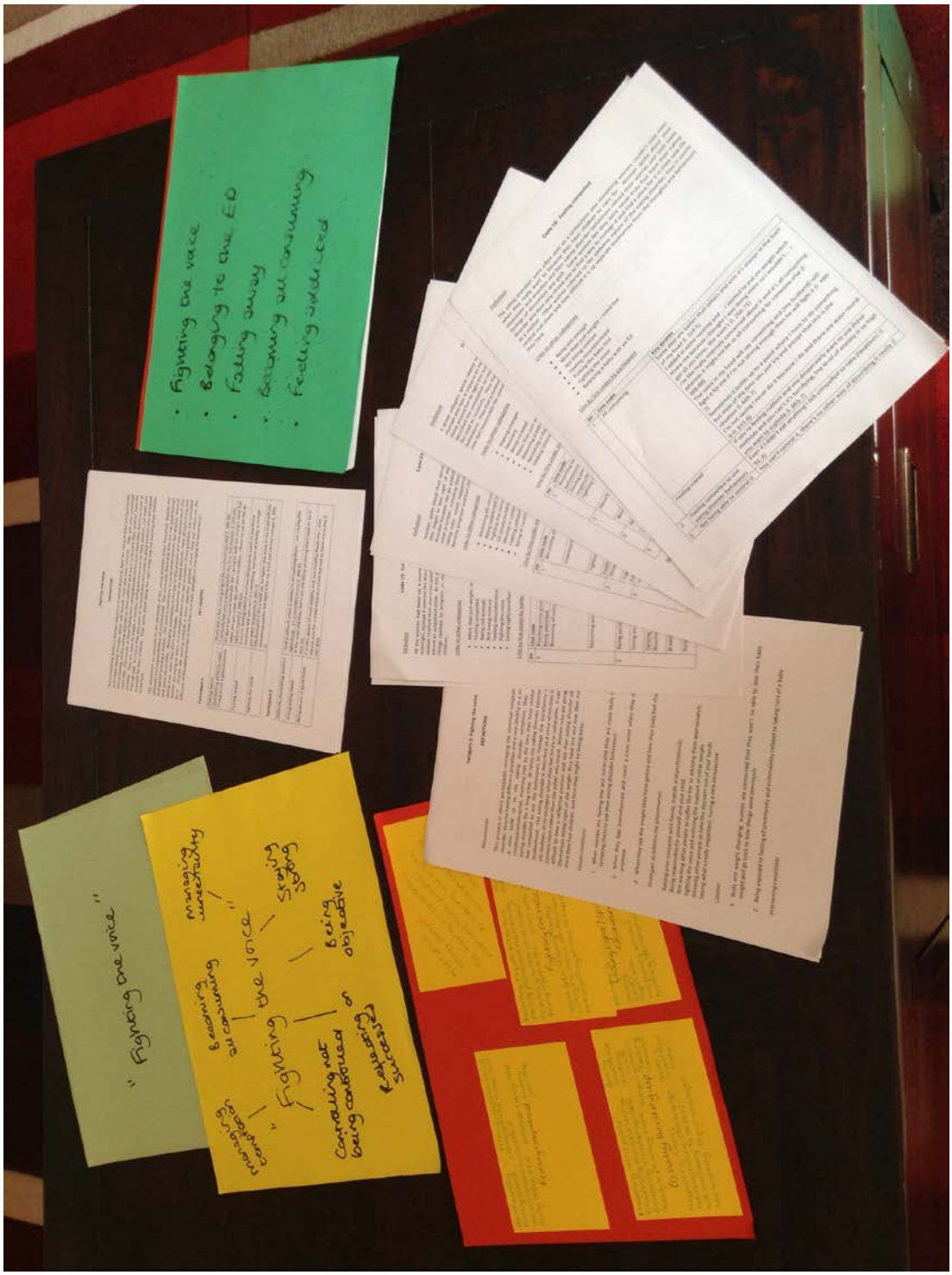
Letting people down	You feel like you're letting [your child] down (l. 270-1)
Not feeling good enough	I suppose that's like it escalates the feeling of not being good enough (l. 271-2)
Comparing self to other moms	I never want him to see me like that and think it's normal and then see other people like other children's moms and think why can't my mom be like that (l. 283-5)
Isolating self	You do isolate yourself anyway especially at the beginning and it's hard to get out of that (l. 192-3)
Wanting to be alone	When you're unwell you don't really want to do anything or see anyone (l. 190-1)
Worrying about having children with an ED	I was worried obviously about having a disorder after him and I did (l. 358-9)
Wanting to protect the baby	I don't ever want him seeing what everyone else sees (l. 282-3)

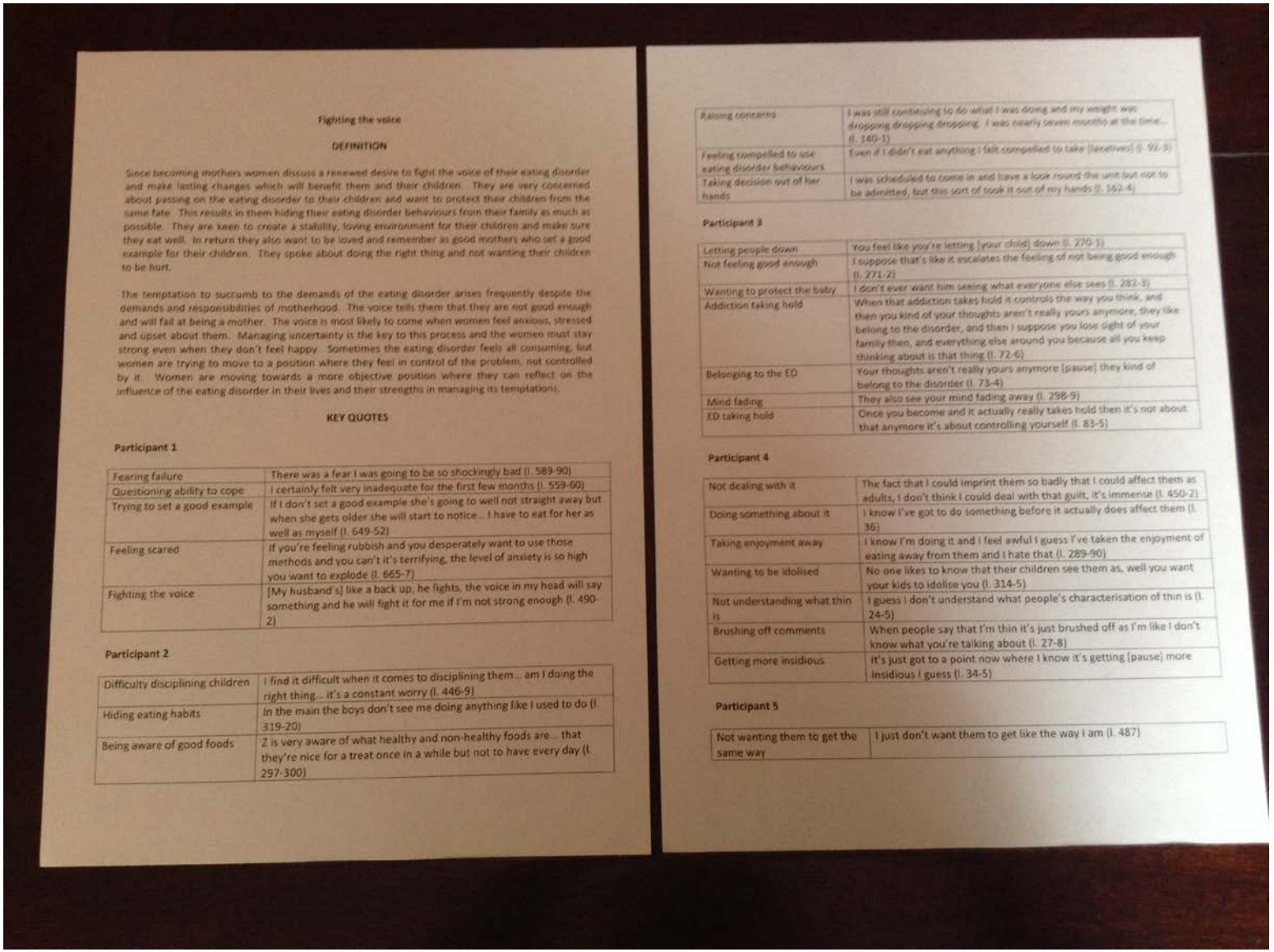
Participant 4

Fearing failure	The most challenging thing is I'm worried that I'm going to fail (l. 448)
Affecting children	That I'm going to give them such a warped outlook on life, that it's going to affect them, that's massive (l. 449-50)
Not dealing with it	The fact that I could imprint them so badly that I could affect them as adults, I don't think I could deal with that guilt, it's immense (l. 450-2)
Feeling like a failure	I'm worried that I'm going to fail (l. 448)
How you're being perceived	It's not how other people perceive me, it's how [pause] how I perceive other people perceiving me (l. 428-9)
Wanting approval	I want to be what I think they think I should be (l. 431)
Not being able to hide it	It got to the point when I couldn't even hide being sick (l. 42-3)
Keeping it secret	When they were tiny and they didn't really know what was going on I could just [pause] keep it secret but now they're at that age that they know that's not right (l. 45-7)
Children telling people	It sounds silly but then because they're telling people as well, because kids don't know any different, mummy's not very well she's been sick (l. 66-8)
Children starting to notice	The reason that I'm trying to deal with it now is because of my daughters, erm their interaction now has started to, they've started to notice (l. 29-31)

APPENDIX R

Example of a sub process





Fighting the voice

DEFINITION

Since becoming mothers women discuss a renewed desire to fight the voice of their eating disorder and make lasting changes which will benefit them and their children. They are very concerned about passing on the eating disorder to their children and want to protect their children from the same fate. This results in them hiding their eating disorder behaviours from their family as much as possible. They are keen to create a stability, loving environment for their children and make sure they eat well. In return they also want to be loved and remember as good mothers who set a good example for their children. They spoke about doing the right thing and not wanting their children to be hurt.

The temptation to succumb to the demands of the eating disorder arises frequently despite the demands and responsibilities of motherhood. The voice tells them that they are not good enough and will fail at being a mother. The voice is most likely to come when women feel anxious, stressed and upset about them. Managing uncertainty is the key to this process and the women must stay strong even when they don't feel happy. Sometimes the eating disorder feels all consuming, but women are trying to move to a position where they feel in control of the problem, not controlled by it. Women are moving towards a more objective position where they can reflect on the influence of the eating disorder in their lives and their strengths in managing its temptations.

KEY QUOTES

Participant 1

Fearing failure	There was a fear I was going to be so shockingly bad (l. 589-90)
Questioning ability to cope	I certainly felt very inadequate for the first few months (l. 559-60)
Trying to set a good example	If I don't set a good example she's going to well not straight away but when she gets older she will start to notice... I have to eat for her as well as myself (l. 649-52)
Feeling scared	If you're feeling rubbish and you desperately want to use those methods and you can't it's terrifying, the level of anxiety is so high you want to explode (l. 665-7)
Fighting the voice	[My husband's] like a back up, he fights, the voice in my head will say something and he will fight it for me if I'm not strong enough (l. 490-2)

Participant 2

Difficulty disciplining children	I find it difficult when it comes to disciplining them... am I doing the right thing... it's a constant worry (l. 446-9)
Hiding eating habits	In the main the boys don't see me doing anything like I used to do (l. 319-20)
Being aware of good foods	Z is very aware of what healthy and non-healthy foods are... that they're nice for a treat once in a while but not to have every day (l. 297-300)
Raising concerns	I was still continuing to do what I was doing and my weight was dropping dropping dropping. I was nearly seven months at the time... (l. 140-1)
Feeling compelled to use eating disorder behaviours	Even if I didn't eat anything I felt compelled to take [laxatives] (l. 92-3)
Taking decision out of her hands	I was scheduled to come in and have a look round the unit but not to be admitted, but this sort of took it out of my hands (l. 162-4)

Participant 3

Letting people down	You feel like you're letting [your child] down (l. 270-1)
Not feeling good enough	I suppose that's like it escalates the feeling of not being good enough (l. 271-2)
Wanting to protect the baby	I don't ever want him seeing what everyone else sees (l. 282-3)
Addiction taking hold	When that addiction takes hold it controls the way you think, and then you kind of your thoughts aren't really yours anymore, they like belong to the disorder, and then I suppose you lose sight of your family then, and everything else around you because all you keep thinking about is that thing (l. 72-6)
Belonging to the ED	Your thoughts aren't really yours anymore [pause] they kind of belong to the disorder (l. 73-4)
Mind fading	They also see your mind fading away (l. 298-9)
ED taking hold	Once you become and it actually really takes hold then it's not about that anymore it's about controlling yourself (l. 83-5)

Participant 4

Not dealing with it	The fact that I could imprint them so badly that I could affect them as adults, I don't think I could deal with that guilt, it's immense (l. 450-2)
Doing something about it	I know I've got to do something before it actually does affect them (l. 36)
Taking enjoyment away	I know I'm doing it and I feel awful I guess I've taken the enjoyment of eating away from them and I hate that (l. 289-90)
Wanting to be idolised	No one likes to know that their children see them as, well you want your kids to idolise you (l. 314-5)
Not understanding what thin is	I guess I don't understand what people's characterisation of thin is (l. 24-5)
Brushing off comments	When people say that I'm thin it's just brushed off as I'm like I don't know what you're talking about (l. 27-8)
Getting more insidious	it's just got to a point now where I know it's getting [pause] more insidious I guess (l. 34-5)

Participant 5

Not wanting them to get the same way	I just don't want them to get like the way I am (l. 487)