Understanding women's experiences of fear of childbirth

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UNDERSTANDING WOMEN'S EXPERIENCES OF FEAR OF CHILDBIRTH

Section A

What are the psychosocial associates of fear of childbirth (FOC), and do they differ for nulliparous and parous women? A review of the literature

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Section B

"Like living with a monster": A Grounded Theory of women's journey to motherhood with primary tokophobia

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Summary of the Major Research Project

Section A is a systematic review of studies exploring psychosocial associates of fear of childbirth (FOC), and whether these associates differ according to parity. The existing literature was systematically searched, with thirty-one papers being selected for review. Psychosocial associates of FOC are presented by identified themes: mental health; self-efficacy, self-esteem and decisional conflict; personality traits; precipitating life events and stressors; stress and fatigue, perceived social support; and cultural influences. Psychosocial associates of FOC according to parity are also summarised. Papers are critiqued, and practice and research implications are discussed.

Section B is an empirical paper presenting a Grounded Theory study exploring women's lived experiences of primary tokophobia. Eight women who were experiencing, or who had experienced in the last five years, primary tokophobia (intense fear of childbirth unrelated to previous birth trauma) were interviewed. A cyclical model was developed, representing conceptual relationships between nine superordinate categories: making sense; facing the fear; becoming lost in the terror; losing control; running out of time; finding a way to cope; surviving and reflecting; going through it alone; and changing fear. The categories were organised into three phases; understanding; experiencing; and appraising. Findings are related to existing literature, and practice and research implications are discussed.

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Section A: Literature Review

What are the psychosocial associates of fear of childbirth (FOC), and do they differ for nulliparous and parous women? A review of the literature

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Abstract

Objective: Fear of childbirth (FOC) can have negative implications for women during and following pregnancy. This review aimed to gain a clearer understanding of FOC by synthesising peer-reviewed literature that had explored psychosocial associates of FOC.

Design: Five electronic databases were systematically searched for studies related to FOC in nulliparous and parous women. Thirty-one papers met the inclusion criteria. Data were extracted and described in a narrative analysis.

Findings: Psychosocial associates of FOC were grouped by identified themes: mental health; self-efficacy, self-esteem and decisional conflict; personality traits; precipitating life events and stressors; stress and fatigue, perceived social support; and cultural influences. Psychosocial associates of FOC according to parity were also summarised.

Key conclusions: Anxiety, depression, low self-esteem, low self-efficacy, poor social support, certain personality traits, precipitating life events (including previous traumatic and subjectively negative pregnancy and childbirth experiences, prior trauma unrelated to childbirth, and experiences of childhood abuse and experiences of abuse in healthcare), stress and fatigue and exposure to 'horror stories' were associated with FOC. Some differences according to parity were identified, however, findings were mixed for most psychosocial factors. This could be understood through the concept of a 'vicious' circle of FOC.

Implications for practice: An individualised, biopsychosocial perspective is suggested when working with women experiencing FOC. Early identification of FOC through routine screening is recommended, along with implementation of interventions that provide accurate childbirth information, build self-esteem, self-efficacy and optimism, reduce stress, manage anxiety, and improve mood. Future research is recommended.

Keywords: Fear of childbirth, FOC, tokophobia, psychosocial, review

Introduction

Fear of childbirth

The term of 'fear of childbirth', or 'FOC', first appeared in obstetric literature following a study exploring women's 'fear of delivery' (Areskog, Kjessler & Uddenberg, 1982). However, the concept of FOC can be dated back to the 1800s, when French psychiatrist Louis Victor Marcé (1858) described it as follows:

> *"If they are primiparous, the expectation of unknown pain preoccupies them beyond all measure and throws them into a state of inexpressible anxiety. If they are already mothers, they are terrified of the memory of the past and the prospect of the future."*

FOC is best understood in terms of fearful thoughts and feelings about pregnancy and childbirth. These fears sit on a continuum; the fear can range from normal and reasonable to severe fear that affects daily functioning, has implications for becoming pregnant, the pregnancy period, birth and the post-natal period (Wijma, 2003). When the fear reaches severe levels, it is often called 'tokophobia', which has been described as an "unreasoning dread of childbirth" (Hofberg & Brockington, 2000) and a "severe fear of childbirth" (Raisanen et al., 2014).

Prevalence and parity

Estimates of the prevalence of FOC vary. One explanation for this is that various definitions and measurements of FOC are used clinically and in the literature (Nilsson et al. 2018), therefore, figures reported should be considered with caution. Research referring to a ' "troublesome fear of childbirth" has suggested a prevalence rate of 6-10% (Kjærgaard, Wijma, Dykes & Alehagen, 2008). A more recent review of the literature reported that the worldwide prevalence of tokophobia was increasing, and was estimated at 14% (O'Connell, Leahy-Warren, Khashan, Kenny & O'Neill, 2017).

FOC can affect women who have never given birth (nulliparous) and women who have had one or more babies (parous). When FOC was measured with the Wijma Delivery Expectancy/Experience Delivery Questionnaire (W-DEQ), nulliparous women achieved higher mean scores (e.g. Rouhe, Salmela-Aro, Gissler, Halmesmäki & Saisto, 2011; Ternström, Hildingsson, Haines & Rubertsson, 2015; O'Connell, Leahy-Warren, Kenny, O'Neill & Khashan, 2019), but more parous women reported severe FOC than nulliparous women (Nieminen, Stephansson & Ryding, 2010). Prevalence of FOC also appears to be higher in nulliparous women than in parous women (e.g. O'Connell, Leahy-Warren, Khashan, Kenny & O'Neill, 2017; O'Connell et al., 2019).

Possible psychosocial factors and implications of FOC

A variety of factors have been related to FOC, including mental health problems, previous traumatic or abusive experiences, poor social support and economic problems (Klabbers, Hedwig, Marit & Vingerhoets, 2016; Rondung, Thomten & Sundin, 2016). For women who have experienced a previous negative birth, FOC is related to post traumatic stress disorder (PTSD), and can follow them through future pregnancies (NHS London, 2018). The concept of 'pre'traumatic stress has also been suggested in the literature; Soderquist, Wimja & Wimja (2004) reported that women with severe FOC, in anticipation of an upcoming birth, can experience symptoms that resemble those experienced following a traumatic event.

High levels of fear and anxiety during pregnancy have been associated with depression (Hall et al., 2009), and an increased need for mental health care after birth (Rouhe et al., 2011). Women's relationships with their partner and baby can also be negatively impacted (Nicholls & Ayers, 2007; Parfit, Pike & Ayers, 2013). Some research has suggested that high levels of fear during pregnancy are associated with more difficult, longer births (e.g. Adams, Eberhard-Gran & Eskild, 2012; Fenwick, Gamble, Nathan, Bayes & Hauck, 2009) and an increased likelihood that emergency caesarean will be required (Hall, Stoll, Hutton & Brown, 2012).

Women experiencing FOC are more likely to request an elective caesarean (Hofberg & Brockington, 2000), where risk to mother and baby can be higher than in vaginal birth (Miesnik & Reale, 2007).

Theoretical perspectives

Few studies have used an explicit psychological perspective when exploring FOC. This has resulted in the psychological mechanisms of FOC remaining largely unclear (Rondung et al., 2016). However, FOC is commonly framed within the domain of anxiety (e.g. Huizink, Mulder, de Medina, Visser, & Buitelaar, 2004) and when severe, can be considered a specific phobia. Psychological models of anxiety usually include cognitive, behavioural and physiological aspects of anxiety. It has been proposed that an individual's cognitive processing is the key to personal experiences of anxiety, and that the cognitive appraisal of a stressful event can lead to a subjective experience of emotions and the physiological arousal associated with said emotions (Lazarus, 1982).

The conditioning theory of fear-acquisition has also been discussed in the literature in relation to understanding FOC. According to Rachman (1977), there are at least three major pathways by which fears can be acquired: by conditioning, where a certain object or situation (e.g. being in hospital or thoughts of childbirth) is paired with aversive experiences (e.g. pain) and a learned association develops; by vicarious exposure (e.g. when witnessing another person give birth); and by indirect transmission via information (e.g. being exposed to 'horror stories' about childbirth). Research has demonstrated that vicarious experiences can result in both fear acquisition (Bandura, 1977b) and fear reduction (Bandura, 1977a).

Rationale for the review

Two recent reviews have examined and summarised the literature on possible causes and predisposing factors relating to FOC (Klabbers et al., 2016; Dencker et al., 2019), however these reviews also focused on other factors such as prevalence, birth outcomes and possible

interventions. Inclusion and exclusion criteria in these reviews varied. To our knowledge, there have been no systematic reviews focused specifically on synthesising the literature describing psychosocial associates of FOC. Furthermore, there are no known systematic reviews that have summarised psychosocial associates of FOC organised by parity. It has been suggested that nulliparous and parous women have essentially separate reasons for experiencing FOC (Klabbers et al., 2016; Dencker et al., 2019). It is therefore hypothesised that psychosocial factors associated with FOC might be different for nulliparous and parous women.

A clearer understanding of the psychosocial associates of FOC, and how they might differ according to parity, could help with assessment and formulation of women experiencing these fears, and lead to appropriate support and a reduction in the negative implications associated with FOC.

Aim of the review

The aim of this review is to synthesise and evaluate the available literature that addresses the following questions:

a) What are the psychosocial associates of fear of childbirth (FOC)?

b) Are psychosocial associates of FOC different for nulliparous and parous women?

Methodology

Literature Search

An electronic search of the literature was completed on 2nd, 4th and 6th December 2019 to identify suitable studies for review (Figure 1). Five databases (Table 1) were searched for papers containing the following search terms in their title:

("Fear of childbirth") OR (tokophobi*) OR (tocophobi*) OR ("childbirth fear*") OR (fear*AND childbirth)* OR (fear *AND birth*) OR (fear* AND pregnan*)

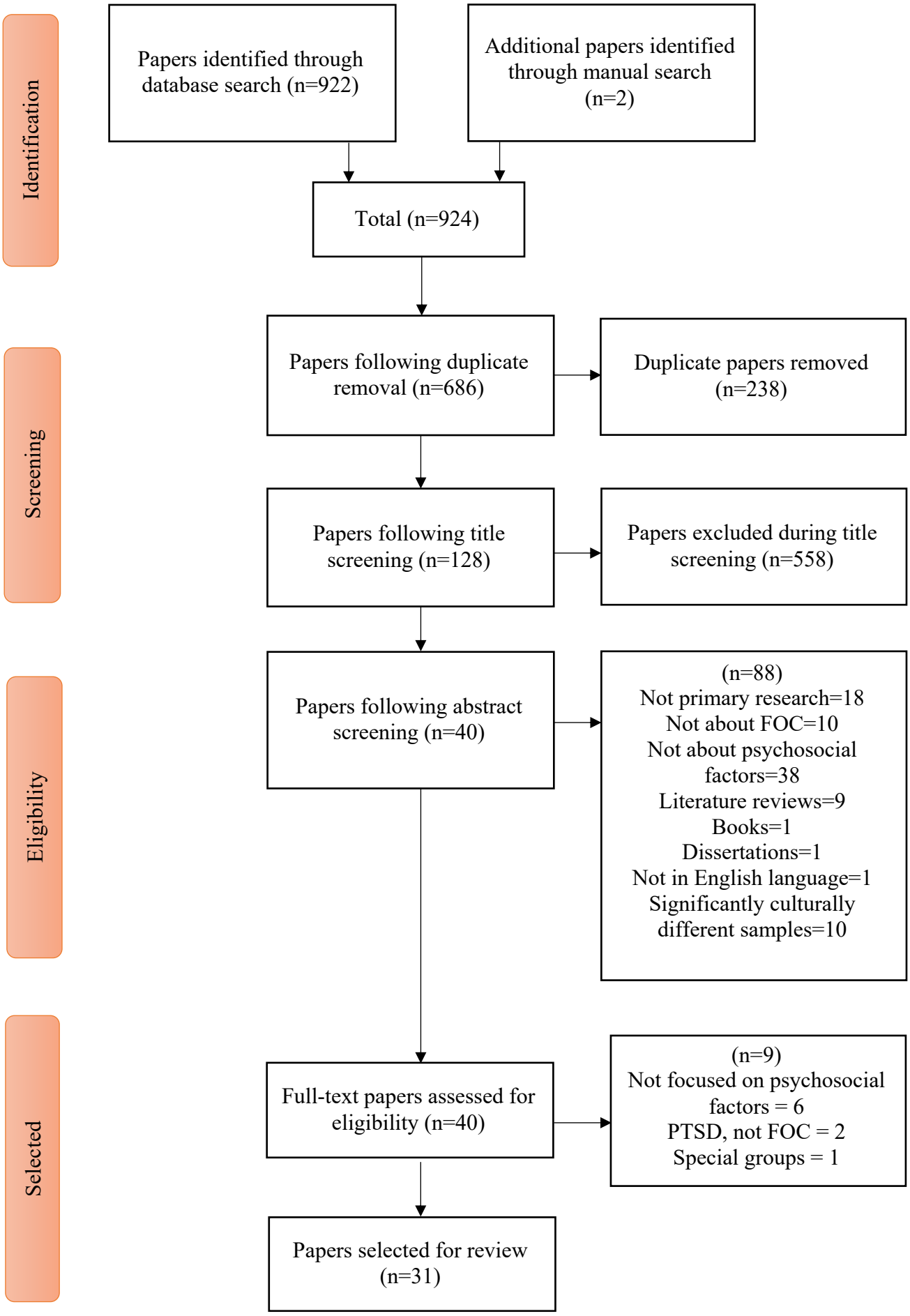
Only papers published in English were included and the search was not filtered by a time period to maximise its scope.

Table 1. Electronic databases searched

Electronic database	**Papers retrieved**
PsycINFO	116
Maternity & Infant Care Database (MIDIRS)	241
Ovid MEDLINE(R)	254
Applied Social Sciences Index and Abstracts (ASSIA)	70
Web of Science	241
Total	922

Further to the electronic search, a manual search of the literature was conducted on 12th and 14th December 2019. This included a search of Google Scholar, references from relevant papers already identified and relevant existing literature reviews.

Figure 1. PRISMA diagram of study selection process



Inclusion and exclusion criteria

Of the papers retrieved in the literature searches, duplicates were removed, titles, then abstracts, then full papers were screened for eligibility for inclusion in the review, using the inclusion and exclusion criteria detailed in table 2. A quality assessment tool was used to assess the quality of the papers. Thirty-one papers met the criteria and were included in the review.

Table 2. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
• Peer-reviewed papers • Papers written in English • Papers with psychosocial factors associated with FOC as the main focus. Psychosocial factors were defined as influences that affect a person psychologically or socially • Papers with a sample of nulliparous and/or parous women • Papers with a general sample of women (i.e. not papers focused on specific groups, such as those with specific health conditions)	• Papers assessed as poor quality • Studies which were carried out in developing countries, or countries/regions where maternal and birthing care and sociocultural experiences of pregnancy likely differed to that of the UK (e.g. due to undeveloped health care systems and/or cultural beliefs about childbirth) • Special groups • Papers related to PTSD following childbirth (as opposed to FOC)

Data extraction and quality assessment

In order to facilitate the process of reviewing and synthesising the findings of the papers, data on psychosocial associates of FOC were extracted from the selected papers. From this, themes emerged, which were used to organise the findings in a narrative synthesis. As different methodologies were used in the reviewed studies, different assessment tools were required to evaluate quality. The National Institute of Health (NIH, 2014) quality assessment

tool for observational cohort and cross-sectional studies (Appendix A) and the Critical Appraisal Skills Programme (Public Health Research Unit, 2006) checklist for qualitative research were employed (Appendix B). In line with other reviews (e.g. Dencker et al., 2019), an overall quality rating was also assigned to each study using the Effective Public Health Practice Project (EPHPP) tool as a guide (Effective Public Health Practice Project, 2010) (Appendix C). A rating system was employed where studies were rated as 'strong' (where no weak ratings were given), 'moderate' (where there was one weak rating) or 'weak' (where there were two or more weak ratings). None of the studies rated as 'weak', so all papers were included in the review.

Structure of the review

A summary of the papers' characteristics and assigned quality ratings are presented (Table 3). The findings of the review are outlined, organised by the research questions posed and the themes identified. The methodologies of the papers are then critiqued. Implications of the findings are discussed in the context of the wider literature, clinical practice, and further research.

Literature Review

Table 3. Summary of paper characteristics and assigned quality ratings

Author(s)	Country	Aims	Design	Participants	Data collection	Analysis	Key findings	EPHPP quality rating
Fenwick, Gamble, Nathan, Bayes & Hauck (2009)	Australia	To investigate pre- and postpartum levels of childbirth fear and explore the relationship to birth outcomes	Prospective correlational design	121 parous and 122 nulliparous women	Questionnaires and open-ended questions	Multivariable logistic regression	Univariately, high antenatal fear was associated with emergency caesarean delivery however, after adjustment for nulliparity and foetal compromise, the association disappeared	Moderate
Fisher, Hauck & Fenwick (2006)	Australia	To address the limited sociological understanding of the phenomena of childbirth fear	Qualitative, exploratory descriptive design	22 women identified as being fearful of birth; 8 nulliparous and 13 parous women	Interviews	Constant comparison	The analysis identified prospective fear as both social and personal. The social dimensions were labelled as 'fear of the unknown', 'horror stories' and 'general fear for the well-being of the baby'. Personal dimensions included the 'fear of pain', 'losing control and disempowerment' and 'uniqueness of each birth'. Retrospective fear was	N/A

							exclusively personal and was clustered around the themes of 'previous horror birth' and 'speed of birth'	
Gourounti, Kouklaki & Lykeridou (2015)	Greece	To explore how fear of childbirth was related to childbirth self-efficacy, state anxiety, depression, neur oticism, self-esteem and optimism	Cross-sectional design	145 nulliparous pregnant women, in late pregnancy, attending routine antenatal visits in private maternity clinic	Self-report questionnaires	Multiple linear regression	Self-efficacy, self-esteem and optimism were negatively and significantly associated with fear of childbirth	Strong
Hall, Hauck, Carty, Hutton, Fenwick & Stoll (2009)	Canada	To explore women's levels of childbirth fear, sleep deprivation, anxiety, and fatigue and their relationships during the third trimester of pregnancy	Cross-sectional descriptive study	650 English-speaking nulliparous (60%) and parous women (40%), between 35 and 39 weeks gestation, with uncomplicated pregnancies	Questionnaires	Hierarchical regression	Childbirth fear, fatigue, sleep deprivation, and anxiety were positively correlated. Women with high childbirth fear were more likely to have more daily stressors, anxiety, and fatigue, as well as less help. Higher levels of anxiety predicted higher levels of childbirth fear	Strong
Heimstad, Dahloe, Laache, Skogvoll &	Norway	To assess the prevalence of fear of childbirth, and	Cohort design	1452 nulliparous and parous women at 18 weeks gestation	Questionnaires	*t*-tests chi-square tests and Fisher's exact tests	Women who reported being exposed to physical or sexual abuse in childhood had a higher	Moderate

Schei (2006)		to find possible associations to selected sociodemographic factors and important life events					W-DEQ score than did the non-abused. Sexual abuse in childhood influenced the W-DEQ-score similarly	
Jokic-Begic, Zigic & Rados (2014)	Croatia	To examine the role of demographic variables, expected pain level, trait anxiety and anxiety sensitivity in FOC among nulliparous and multiparous women in the last trimester of pregnancy	Cross-sectional design	200 pregnant women; 106 nulliparous, 94 parous	Questionnaires	Hierarchical multiple regression	Amongst all women, anxiety sensitivity (physical concerns dimension) was identified as an important vulnerability factor for FOC. Different associates were established in nulliparous and multiparous women. While higher anxiety sensitivity (dimension physical concern) was a significant associate in both groups, trait anxiety was significant for nulliparous women only	Strong
Laursen, Hedegaard & Johansen (2008)	Denmark	To describe the association between fear of childbirth and social, demographic and psychological factors	Nationwide population-based study	30,480 healthy nulliparous women with singleton pregnancies	Computer-assisted telephone interviews and national health registers	Logistic regression model	Fear of childbirth among nulliparous women was most often seen in individuals with few social and psychological resources	Moderate

Lowe (2000)	USA	The relationship between self-efficacy for labour and childbirth fears in healthy nulliparous women was investigated during the third trimester of pregnancy	Cross-sectional design; Secondary analysis	280 nulliparous women	Questionnaires	Correlation analysis	Outcome expectancies for childbirth were unrelated to childbirth fears while self-efficacy expectancies were significantly correlated with childbirth fears. Women in the high-fear group were characterised by significantly lower self-esteem and generalised self-efficacy	Moderate
Lukasse, Vangen, Oian, et al. (2010)	Norway	To examine the association between a self-reported history of childhood abuse and fear of childbirth	Cross-sectional design	2,365 pregnant women; 1034 primiparous, 1331 parous	Questionnaires	Multiple logistic regression	A history of childhood abuse significantly increased the risk of experiencing severe fear of childbirth among primiparas. FOC among multiparous women was most strongly associated with negative birth experience	Strong
Lukasse, Schei & Ryding (2014)	Belgium, Iceland, Denmark, Estonia, Norway and Sweden	To compare the prevalence, content and associated factors of fear of childbirth in six European countries.	Cross-sectional design	6870 pregnant women	Questionnaires	Logistic binary regression	There was a significant relationship between depressive symptoms, experiencing a 'negative life event', subjectively rated previous negative birth experiences, previous emergency caesarean section, post-traumatic stress, experiences of abuse in	Strong

							healthcare, having no social support and FOC	
Melender (2002)	Finland	To describe the objects, causes, and manifestations of FOC, and to identify factors associated with the fears	Cross-sectional design	329 pregnant women	Questionnaires	Rotated factor analysis	Causes of fears were negative mood, negative stories told by others, alarming information, diseases and child-related problems, and, in multiparas, negative experiences of previous pregnancy, childbirth, and baby's health and care. Parity and antenatal training were the most important variables related to objects of fears	Moderate
Molgora, Fenaroli, Prino et al. (2018)	Italy	To investigate whether fear of childbirth can be predicted by socio-demographic variables, distressing experiences before pregnancy, medical-obstetric factors and psychological variables	Cross-sectional design	426 primiparous pregnant women between the 34nd and 36th week of pregnancy	Questionnaires	Multiple logistic regression	Anxiety, as well as couple adjustment, was associated with fear of childbirth when treated as a continuous variable, while clinical depression was associated with severe fear of childbirth	Strong

Nilsson, Lundgren, Karlstrom & Hildingsson (2012)	Australia	To explore fear of childbirth during pregnancy and one year after birth, and its association to birth experience and mode of delivery	Longitudinal population-based design	763 pregnant parous women	Questionnaires	Multivariate logistic regression	Fear of childbirth during pregnancy in parous women was associated with a previous negative birth experience and a previous emergency caesarean section. Women's perception of the overall birth experience as negative seems to be more important for explaining subsequent FOC than mode of delivery	Moderate
O'Connell, Leahy-Warren, Kenny, O'Neill & Khashan (2019)	Ireland	To determine the prevalence of high and severe fear of childbirth, and to identify risk factors of childbirth fear	Cross-sectional design	882 pregnant women attending antenatal care; 298 nulliparous, 581 parous, 3 unknown	Questionnaires	Univariate and multivariate multinomial logistic regression	High fear of childbirth was significantly associated with low perceived informational support and possible depression	Strong
Pazzagli, Laghezza, Capurso, Sommella, Lelli & Mazzesch (2015)	Italy	To explore the differences in the role of specific personal and interpersonal risk factors in predicting fear of childbirth and to examine	Prospective correlational design with two time periods (pre- and postnatal)	158 women (85 nulliparous and 73 parous)	Questionnaires	Pearson's correlations and multiple regressions	In the prenatal period, higher state anxiety, lower dyadic adjustment, and higher insecurity in attachment relationships were associated with fear of childbirth in nulliparous women only	Moderate

		whether fear of childbirth predicts postnatal maternal adaptation in nulliparous and parous women						
Raisanen, Lehto, Nielsen, Gissler, Kramer & Heinonen (2014)	Finland	To identify risk factors for fear of childbirth according to parity and socioeconomic status, and to evaluate associations between fear of childbirth and adverse perinatal outcomes	Cohort design	All 788,317 singleton births during 1997–2010 in Finland; 302,479 nulliparous, 442,992 parous	Finnish Medical Birth Register	Multivariable logistic regression	The strongest risk factors for fear of childbirth in nulliparous women were depression, advanced maternal age and high or unspecified socioeconomic status. In parous women, the strongest risk factors for fear of childbirth were depression, previous caesarean section (CS) and high or unspecified socioeconomic status	Strong
Rondung, Ekdahl, Hildingsson, Rubertsson & Sundin (2018)	Sweden	To investigate possible subgroups in a sample of pregnant women reporting fear of birth in mid-pregnancy	Cross-sectional design	206 pregnant women reporting fear of birth in mid-pregnancy; 120 nulliparous, 86 parous	Questionnaires and written feedback	Various non-parametric tests	Nulliparous women were more likely to report clinically relevant levels of blood- and injection phobia, while parous women more often reported previous negative experiences in health care or previous trauma. The results indicate that women	Strong

							reporting fear of birth are a heterogeneous group	
Rouhe, Salmela-Aro, Gissler, Halmesmaki & Saisto (2011)	Finland	To investigate whether women with fear of childbirth have more mental health problems than women of childbearing age in general	Register-based retrospective study	2405 pregnant women; 1030 nulliparous, 1375 parous	Data collected from the Medical Birth Register, the Hospital Discharge Register And the Drug Reimbursement Register	Logistic regression	Mental health problems were twice as common among women with a fear of childbirth as in non-fearful controls. Mood and anxiety disorders were the most common psychiatric diagnoses in both groups	Strong
Ryding, Wirfelt, Wangborg, Sjogren & Edman (2007)	Sweden	To investigate the associations between stable personality traits, fear of childbirth during late pregnancy, and experience of the delivery	Cohort design	85 women who had sought help from a fear-of-childbirth team, and a group (n = 177) from routine antenatal care; 53 nulliparous, 103 parous	Questionnaires	Logistic regression	The women who had sought help tended to be more anxiety-prone, more short-tempered, and lower in socialisation, although within the normal range. In spite of counselling, they reported more intense fear of delivery and fear of pain compared with the comparison group	Moderate
Saisto, Ylikorkala & Halmesmaki (1999)	Finland	To identify factors associated with fear of childbirth during and after first labour	Cohort design	100 women during second pregnancy	Data collected retrospectively from patient files	Logistic regression	The prevalence of emergency caesarean and vacuum extraction during first delivery was much higher in participants with FOC than controls, and labours lasted longer. They received epidural	Moderate

							analgesia more often, but its timing and the amount used were not different between groups. Of the group with fear, 44% could not define any specific cause for fear and regarded the entire delivery as frightening	
Saisto, Salmela-Aro, Nurmi, et al. (2001)	Finland	To examine the personal characteristics and socio-economic background of women and their partners fearing vaginal childbirth	Cross-sectional design	278 women and their partners; 47% nulliparous, 53% parous	Questionnaire survey	Sequential (hierarchical) logistic regression	The more anxiety, neuroticism, vulnerability, depression, low self-esteem, dissatisfaction with the partnership, and lack of social support the women reported, the more they showed pregnancy-related anxiety and fear of vaginal delivery	Strong
Salomonsson, Bertero & Alehagen (2013)	Sweden	To apply and test the concept of childbirth self-efficacy to expectations of the upcoming birth in the context of severe fear of childbirth (SFOC)	Qualitative study	17 nulliparous women with severe fear of childbirth	Semi-structured interviews	Content analysis	Behaviours for coping with labour and childbirth were related to six domains of childbirth self-efficacy: concentration, support, control, motor/relaxation, self-encouragement, and breathing. Most of these behaviours referred to capabilities to carry out (self-efficacy expectancy) rather than to beliefs in effectiveness (outcome expectancy)	N/A

Schwartz, Toohill, Creedy, Baird, Gamble & Fenwick (2015)	Australia	To investigate socio-demographic, obstetric and psychological factors affecting self-efficacy in childbearing women	Cross-sectional design	1410 women recruited during pregnancy; 43% nulliparous, 57% parous	Questionnaires	Pearson's R	Regardless of parity, women who reported low childbirth knowledge, who preferred a caesarean section, and had high W-DEQ and EPDS scores reported lower self-efficacy. Fear correlated strongly with low childbirth self-efficacy	Strong
Söderquist, Wijma & Wijma (2004)	Sweden	To explore if traumatic stress can occur before an event that is perceived as threatening or feared	Cohort design	951 pregnant women; 376 nulliparous, 575 parous	Questionnaires	ANOVA	Traumatic stress and fear of childbirth correlated significantly. High trait anxiety, depressive symptomatology, psychological/psychiatric counselling related to childbirth, and self-reported psychological problems, measured in early pregnancy, were risk factors for traumatic stress and fear of childbirth in late pregnancy	Strong
Spice, Jones, Hadjistavropoulos, Kowalyk & Stewart (2009)	Canada	The relationship between Anxiety Sensitivity (AS) and FOC was examined given that AS is a risk	Cross-sectional design	110 women in their final 4 months of pregnancy; 44 nulliparous, 66 parous	Questionnaires	Multiple regression analysis	Higher levels of AS-physical concerns, higher trait anxiety, and expecting a first child all independently predicted greater FOC.	Strong

		factor for other fears. Specifically, the contribution of three AS dimensions (physical, psychological or social concerns) relative to other factors (e.g., parity, trait anxiety) in accounting for FOC was explored						
Storksen, Eberhard-Gran, Garthus-Niegel & Eskild (2012)	Norway	To study the associations of anxiety and depression with fear of childbirth	Cross-sectional design	1642 pregnant women, 49.9% nulliparous and 50.1% parous	Questionnaires	Chi-squared test	More than half (56.2%) of the women with fear of childbirth did not have anxiety or depression; however, presence of anxiety or depression increased the prevalence of fear of childbirth. Women with both anxiety and depression had the highest prevalence of fear of childbirth	Moderate
Storksen, Garthus-Niegel, Vangen & Eberhard-	Norway	To assess the relation between fear of childbirth and	Cohort design	1357 parous women	Questionnaires	Logistic regression	The association between a previous subjectively negative birth experience and fear of childbirth was high and was greater than	Strong

Gran (2013)		previous birth experiences					the association between previous obstetric complications and fear of childbirth	
Toohill, Fenwick, Gamble, Creedy, Buist & Ryding (2014)	Australia	To identify psycho-social factors associated with childbirth fear and possible antenatal predictors of childbirth fear according to women's parity	Cross-sectional design	1410 women in second trimester	Questionnaires	Multivariate analysis	Having a history of mental health problems, desiring a caesarean section, reporting moderate to high pain during pregnancy, having a non-supportive partner and perceiving less childbirth knowledge than peers, were associated with childbirth fear. Depression, decisional conflict, low social support and less perceived knowledge predicted levels of childbirth fear. The model explained 32.4% of variance in child- birth fear for nulliparous and 29.4% for multiparous women	Strong
Vitek & Ward (2018)	USA	To explore how portrayals of pregnancy and childbirth on reality TV affect women's childbirth fear	Cohort design	213 undergraduate nulliparous women	Questionnaires completed following exposure	Post hoc Tukey tests	Childbirth attitude varied across conditions, with participants in the medicalised condition reporting the highest FOC. Participants' feelings about potential pregnancy also varied	Strong

							depending on which clip was viewed	
Zar, Wimja & Wimja (2001)	Sweden	A possible expression of trait (T-fear) and state (S-fear) aspects of FOC was investigated	Cohort design	162 pregnant women; 77 nulliparous and 85 parous	Questionnaires	ANOVA	Nulliparous women had a higher level of FOC but a lower level of trait anxiety than did parous women. Differences in FOC between nulliparous and parous women disappeared after delivery, suggesting childbirth comprises a considerable part of T-fear, with the risk of a vicious cycle	Strong
Zar, Wijma & Wijma (2002)	Sweden	To explore the relation between anxiety disorders and fear of childbirth	Cohort design	506 women, 206 nulliparous and 300 parous	Questionnaires and interviews	Chi-square test, *t*-test, Mann–Whitney *U* test and analysis of variance (ANOVA)	Nulliparous women had a higher level of fear of childbirth but a lower level of trait anxiety than did parous women	Strong

What are the psychosocial associates of fear of childbirth (FOC)?

Mental health. Seventeen of the papers reviewed considered the association between mental health and FOC. Having a history of mental health problems prior to pregnancy (Toohill et al., 2014), particularly anxiety disorders (Zar, Wimja & Wimja, 2002), was associated with FOC. It was reported that women experiencing FOC were more likely to receive psychiatric care and psychotropic medication than those who did not experience FOC, usually to treat mood and anxiety disorders (Rouhe et al. 2011).

Anxiety and depression. The relationship between FOC and anxiety has been widely explored in the literature. The State-Trait Anxiety Inventory (STAI-Y) was used to assess for both trait and state anxiety (Molgora et al., 2018; Pazzagli et al., 2015), the STAI-Trait was used to assess for trait anxiety only (Jokić-Begić, Žigić & Radoš, 2014; Spice, Jones, Hadjistavropoulos, Kowalyk & Stewart, 2019; Soderquist et al. 2004; Zar, Wijma & Wijma, 2001), and the STAI-State was used to assess for state anxiety only (Gourounti, Kouklaki & Lykeridou, 2015; Hall et al., 2009). Of the papers that assessed for both state and trait anxiety, one reported both state anxiety and trait anxiety were significantly associated with FOC (Molgora et al. 2018), and the other found only a significant association between state anxiety and FOC (Pazzagli et al. 2015). In the four studies that employed the STAI-Trait, trait anxiety was found to be significantly correlated with FOC (Jokic-Begic et al. 2014; Spice et al. 2019; Soderquist et al. 2004; Zar et al. 2001). Of the studies that assessed for only state anxiety, one found state anxiety to be an associate of FOC (Hall et al., 2009) but the other reported no significant relationship between state anxiety and FOC (Gourounti et al., 2015). In the latter study, it was acknowledged that independent variables may have correlated with each other in the analysis (e.g. state anxiety with symptoms of depression), making it difficult to assess the unique contribution of each.

Ryding, Wirfelt, Wängborg, Sjögren & Edman (2007) used the Karolinska Scales of Personality (KSP) which is a validated measure used to study personality changes. They reported that women experiencing FOC generally described themselves as more anxiety-prone, and the higher the anxiety-proneness, the higher the fear. Similarly, in Laursen, Hedegaard, Johansen & Danish National Birth's (2008) study, symptoms of anxiety were associated with an almost five-fold increase in FOC. However, only nulliparous women were sampled, so findings cannot be generalised to all women experiencing FOC. Furthermore, symptoms of anxiety and presence of FOC were measured using two non-validated questions devised specifically for the study.

The potential relationship between Anxiety Sensitivity (AS) and FOC was explored in two studies using the Anxiety Sensitivity Index (ASI) measure. Both found that AS-physical concern was significantly associated with FOC, and this was distinct from trait anxiety (Jokic-Begic et al., 2014; Spice et al., 2009). The other dimensions of AS were not significantly associated with FOC, a finding that points to the role of anxiety in the physical aspect of childbirth rather than in relation to social concerns (e.g. embarrassment) or the experience of psychological symptoms (e.g. fear of losing control).

Two studies considered a possible link between phobias and FOC. Results were mixed, with one study finding a higher prevalence of blood and injection phobias in women with FOC than those in a general sample of women without FOC (Rondung, Ekdahl, Hildingsson, Rubertsson & Sundin, 2018), and another reporting no significant relationship between blood-injection-injury phobia and FOC (Zar et al., 2002). However, it should be noted that the latter was in reference to women with extreme FOC, so the findings cannot be generalised to all women experiencing FOC.

A significant relationship between depressive symptoms and FOC was reported, as measured by the Edinburgh Postnatal Depression Scale (EPDS) (Storksen, Eberhard-Gran,

Garthus-Niegel & Eskild, 2012; Molgora et al., 2018; O'Connell et al., 2019; Toohill et al., 2014), Edinburgh Depression Scale (EDS) short version (Lukasse, Schei, Ryding & Bidens Study Group, 2014), ICD-10 classifications (Raisanen et al., 2014) and Beck Depression Inventory (BDI) (Saisto, Salmelo-Aro & Halmesmäki, 2001). In their study, Laursen et al. (2008) reported a more than two-fold increase in FOC when symptoms of depression were present, however, as with anxiety, symptoms of depression were measured using a single, unvalidated question. Findings in this area were not entirely consistent, with one study using the EPDS (Gourounti et al. 2015), reporting no significant link between depression and FOC, and another which used the BDI (Soderquist et al. 2004) reporting a significant relationship with FOC as a sum-score, but no relationship with severe FOC. It was suggested in the latter study that the variable findings for different levels of FOC could be due to methodological issues (i.e. loss of variance when using a dichotomous variable).

In one study, the majority of women experiencing FOC experienced neither anxiety nor depression. However, the presence of anxiety or depression increased the prevalence of FOC, and even more so when both conditions were present. The authors, therefore, hypothesised that anxiety and/or depression may have been the most influential psychosocial associates of FOC (Storksen et al. 2012).

Self-efficacy, self-esteem and decisional conflict. The role of childbirth self-efficacy (confidence in labour and birth) has been considered in relation to FOC and was highlighted in six of the papers reviewed. All of the papers used the Childbirth Self-efficacy Inventory (CBSEI) which comprises of a total score and subscale scores for outcome efficacy (a woman's belief that a specific behaviour will lead to a given outcome) and efficacy expectancy (the belief that she can indeed 'perform' that behaviour). In two studies, both outcome efficacy scores and efficacy expectancy scores were negatively and significantly associated with FOC (Gourounti et al., 2015; Schwartz et al. 2015). However, Lowe (2000) reported that only

efficacy expectancy was significantly correlated with FOC. Although women's beliefs about how useful certain behaviours were for coping with birth was not related to their own fear, the greater their confidence in their abilities to use coping behaviours with their own birth experiences, the lower their FOC. Similarly, Salomonsson, Bertero & Alehagen's (2013) qualitative study found that most behaviours for coping with labour and childbirth were related to capabilities to carry out (efficacy expectancy) rather than to beliefs about effectiveness (outcome efficacy). Both of these studies sampled only nulliparous women; outcome efficacy might be associated to a lesser extent with FOC for these women due to them having no prior negative experience to refer to.

Three studies reported on a link between self-esteem and FOC, using the Rosenberg Self-esteem Scale (SES) as a measure. All studies reported that women who had lower self-esteem experienced higher levels of FOC (Gouranti, 2015; Lowe, 2000; Saisto et al. 2001). One study explored the role of decisional conflict in FOC (Toohill et al., 2014) using the Decisional Conflict Scale (DCS); a validated psychometric used to investigate concepts that can compromise or facilitate effective decision making (O'Connor, 2010). They reported a moderate, significant relationship between FOC and decisional conflict, indicating that women with FOC have some difficulty implementing decisions.

Personality traits. The association between personality traits and FOC have been explored in the literature. Using the Karolinska Scales of Personality (KSP), Ryding et al. (2007) investigated the associations between stable personality traits, FOC, and experience of delivery. Women with FOC were reported as being more short-tempered (more irritable and monotony-avoidant) than those in a control group of women not experiencing FOC. Gourounti et al. (2015) used the Life Orientation Test-Revised (LOT-R) to measure optimism and found that woman who had lower levels of optimism had higher levels of FOC.

Saisto et al. (2001) used the Neuroticism-Extroversion-Openness Personality Inventory (NEO PI) scales to measure vulnerability and neuroticism. They found that women who reported increased vulnerability and neuroticism were more likely to report FOC. In contrast, Gourounti et al. (2015), using the Eysenck personality questionnaire, reported that neuroticism was not significantly related to FOC. However, the validity of this measure could be called into question given that many of Eysenck's articles have recently been retracted from publication due to concerns about validity and reliability of findings (Psychological Reports, 2020).

Precipitating life events and stressors. It has been documented in the literature that experiencing a 'negative life event' is strongly associated with FOC (Lukasse et al., 2014). Various 'negative life events' have been linked with FOC, as detailed below.

Previous experiences of pregnancy and birth. For parous women, a previous traumatic birth has been shown to be associated with FOC in the following pregnancy (Söderquist et al., 2004); this association was significantly related to severe FOC and FOC as a sum-score. Other studies considered the influence of a subjective previous negative birth experience, and similarly found it to be strongly associated with FOC (Melender, 2002; Lukasse et al., 2010; Nilsson, Lundgren, Karlstrom & Hildingsson, 2012). A six-country cohort study reported that a subjectively rated previous negative birth experience resulted in a five times increased likelihood of experiencing severe FOC (Lukasse et al., 2014). Obstetric complications have been linked with FOC, with three studies showing a strong association between previous emergency caesarean section and FOC (Saisto, Ylikorkala & Halmesmaki, 1999; Lukasse et al., 2014; Nilsson et al. 2012). However, one study found no significant relationship between emergency caesarean section and antenatal FOC after adjustment for confounding variables (Fenwick et al., 2009), and another failed to demonstrate a significant relationship between pregnancy complications and FOC (Molgora et al., 2018). This inconsistency in findings could

be due to different complications being analysed in each study. It has been suggested that a previous negative birth experience might be of greater importance than mode of delivery or obstetric complications in the experience of FOC (Lukasse et al., 2014; Storksen, Garthus-Niegel, Vangen & Eberhard-Gran, 2013).

Previous experience of miscarriage was significantly related to FOC in two studies (Raisanen et al., 2014; Saisto et al., 1999), as was prior infertility. One study found no significant difference in prevalence of FOC between women who had and had not experienced previous pregnancy loss (O'Connell et al., 2019). Raisanen et al. (2014) used the Finnish Medical Birth Register (MBR) to obtain their data, whilst the other studies relied on more subjective self-report questionnaires.

Trauma and abuse. Experiences of trauma unrelated to birth, and post-traumatic stress have been linked to FOC. In Rondung et al.'s (2018) study, where previous negative experiences in healthcare were accounted for separately, 61.7% of women with FOC reported general previous traumatic experiences that caused them intense fear, helplessness or horror. Lukasse et al. (2014) reported a strong association between post-traumatic stress and FOC. However, one study found that exposure to traumatic events was not associated with FOC (Soderquist et al., 2004). The nature of the trauma experienced was not clear in these studies, meaning a variety of traumatic experiences may have been included. This might offer an explanation as to why findings are not entirely consistent.

Two studies examined links between abuse and FOC and reported that experience of abuse was a significant associate of FOC. Heimstad, Dahloe, Lacche, Skogvoll & Schei (2006) found that women who reported physical and sexual abuse in childhood had higher levels of FOC than those who were not abused. This was only the case for women who had experienced abuse in childhood, not adulthood. Lukasse et al. (2010) used the Norvold Abuse Questionnaire, a validated instrument measuring emotional, sexual and physical abuse, and

reported similar findings. They found a graded response between FOC and the number of types of abuse women had experienced. They also reported that emotional abuse was most strongly associated with severe FOC.

Abusive and traumatic experiences in healthcare were reported as associates of FOC in two studies. Lukasse et al. (2014) found a significant association between experiences of abuse in healthcare and FOC in some countries, but not others. However, it is possible that the reported abuse was in relation to a previous pregnancy or birth. As might be expected, Rondung at al. (2018) reported that parous women were more likely to report previous trauma or negative experiences in healthcare.

Stress and fatigue. Stress and fatigue are linked to FOC, according to Hall et al. (2009). They reported that women with high levels of FOC were significantly more likely to experience increased daily stressors and fatigue than those with low and moderate FOC. Fatigue was measured with a validated measure (Multidimensional Assessment of Fatigue (MAF) scale), but stressors were identified using unvalidated questionnaires. Söderquist et al. (2004) also considered the role of stress in relation to FOC. Using the Stress Coping Inventory (SCI), they reported that 'low stress coping' was linked to FOC. When exploring manifestation of fears, stress symptoms had strong explanatory power for FOC in another study (Melender, 2002). However, Molgora et al. (2018) found the association between stressful experiences before pregnancy and FOC was not significant. What constituted a stressful experience differed between studies, as well as how proximal the participants were to the experience, which might explain the inconsistent findings.

Perceived social support. An association between FOC and perceived levels, and quality of, social support, has been reported in the literature. Most of the studies to report this finding have used questions specifically developed for their study to assess perceived social support. Hall et al. (2009) reported that women experiencing high levels of FOC were

significantly more likely to receive less help. In another study (where 'no social support' was defined as having no one to confide in besides a partner), 'no social support' was positively associated with severe FOC (Lukasse et al., 2014). Three further studies asked questions about social contact (Soderquist et al., 2004), social networks (Laursen et al., 2008), and the need for and availability of social support (Saisto et al., 2001). They all supported the suggestion that perceived lack of social support was an important and significant risk factor for FOC. Only one study, which used the Multidimensional Scale of Perceived Social Support (MSPSS), failed to find a significant relationship between social support and FOC (Molgora et al., 2018). It is possible that different definitions of support (e.g. partner support vs. general support) used in these studies could account for the inconsistent findings.

Two studies considered whether lack of informational support might be associated with FOC. O'Connell et al. (2019) used the Perinatal Infant Care Social Support Scale (PICSS) which measures structural and functional social supports in the context of perinatal infant care practices. They reported that women who received low informational support were more likely to report high levels of FOC. Toohill et al. (2014) reported similar findings using the Childbirth Knowledge Questionnaire (CKQ); that women who felt less informed had a greater tendency to report FOC. However, the latter measure reported low internal consistency in this study.

Toohill et al. (2014), used a brief five-item scale to measure aspects of support, such as verbal support provided by a partner specific to their current pregnancy and approaching birth. They observed that the majority of women in their study felt well supported by their partners, however, those who reported low support were more fearful. Three studies used the Dyadic Adjustment Scale (DAS) to measure relationship adjustment and found that FOC was significantly associated with lower dyadic adjustment (Molgora et al., 2018; Pazzagli et al., 2015; Saisto et al., 2001). Saisto et al., (2001) described how social support and marital satisfaction reported by both the woman and her partner were significantly associated with

severe fear of vaginal delivery; the more satisfied each was with the partnership, the less likely fear of vaginal birth was experienced. Pazzagli et al. (2015) also employed the Reciprocal Attachment Questionnaire (RAQ) and reported that increased insecurity in attachment relationships with a partner was significantly linked to FOC.

Cultural influences. Being exposed to 'horror stories' about pregnancy and childbirth has been linked to FOC. In their qualitative study, Fisher, Hauck & Fenwick (2006) reported that horror stories held great currency for women experiencing FOC. One woman with FOC talked about being exposed to such stories, saying,

> *"Well I think the biggest thing is being a first-time mum, a lot of people choose to be brutally honest about childbirth and they tell you all the horror stories, the ones you don't want to hear".*

Melender (2002) developed a set of questions based on the existing literature to elicit potential causes of FOC, some of which related to other people's previous experiences. 'Negative stories' had strong explanatory power for FOC. Furthermore, 'alarming information', which was commonly provided by healthcare and social welfare professionals, was considered a cause of fear.

A study conducted in the USA investigated how exposure to portrayals of risky, dramatic and medicalised births in the media influenced women's FOC. Vitek & Ward (2019) assigned participants to view a video clip of either a medicalised birth from reality TV, a midwife-attended birth from reality TV, or a neutral childbirth education clip. They found that childbirth attitudes varied across conditions, with participants in the medicalised birth condition reporting the highest levels of FOC. The type of birth viewed also influenced feelings about potential pregnancy. It should be noted that this study sampled nulliparous students only, so findings cannot be generalised.

Are psychosocial associates of FOC different for nulliparous and parous women?

Five of the papers in this review sampled only nulliparous women, two sampled only parous women, and twenty-four sampled both. Of the studies that sampled both, ten commented on the different psychosocial associates of FOC according to parity in the areas detailed below.

Mental health. Studies that reported on anxiety as an associate of FOC were inconsistent in their findings when comparing according to parity. Pazzagli et al. (2015) used the Symptom Checklist-90 (SCL-90) and STAI-Y to measure personal factors (i.e. psychological symptoms and distress, and state and trait anxiety) and found that the contributions of personal factors in predicting FOC differed according to parity. High state anxiety was associated with FOC in nulliparous women, whereas no personal factors were significantly associated with FOC in parous women. Zar et al. (2001) reported that nulliparous women had lower levels of trait anxiety than parous women. Contrary to this, Jokic-Begic et al. (2014) found trait anxiety was significantly associated with FOC in nulliparous women, but not parous women. Another study reported higher state anxiety in parous women with FOC when compared with nulliparous women with FOC (Hall et al., 2009), however the difference may not have been large enough to be clinically meaningful. Higher scores on the physical dimension of anxiety sensitivity were associated with higher levels of FOC in both nulliparous and parous women (Jokic-Begic et al., 2014).

Fewer studies considered differences according to parity when reporting on depression and FOC. However, three studies did find that there was an association between FOC and symptoms of depression in both nulliparous and parous women (Lukasse 2014; Raisanen et al., 2014; Toohill et al., 2014).

In relation to phobias and FOC, comparisons according to parity were made in one study. Rondung et al. (2018) reported that nulliparous women with FOC were more likely to report clinically significant levels of blood and injection phobia than parous women with FOC.

Self-efficacy and decisional conflict. The relationship between self-efficacy and FOC, according to parity, was only considered in one of the studies in this review (Schwartz et al., 2015). In their study, women who had high scores on the W-DEQ measure reported low self-efficacy, regardless of parity. One study considered decisional conflict according to parity (Toohill et al., 2014). Their findings suggested that difficulties in implementing decisions (based on DCS scores) contributed to FOC in both nulliparous and parous women but were most specific to nulliparous women.

Previous experiences of pregnancy and birth. One psychosocial associate that can only apply to parous women is a prior experience of childbirth. Studies have consistently found this to be the strongest associate of FOC in parous women (e.g. Lukasse 2010; Lukasse 2014; Melender, 2002). In their large population-based analysis of singleton births in Finland, Raisanen et al. (2014) reported an increased prevalence of FOC in women who had used in-vitro fertilisation (IVF), only in parous women.

Trauma and abuse. Three of the reviewed papers compared, according to parity, the relationship between FOC and trauma or abuse. A history of childhood abuse was significantly linked to experiences of severe FOC in nulliparous women. However, for parous women, after adjusting for confounding variables such as previous negative birth experiences and depression, there was no association between a history of childhood abuse and severe FOC (Lukasse, 2010). For both parous and nulliparous women, there was a strong association between post-traumatic stress, suffering from 'life-events' and FOC (Lukasse 2014). Another study found that traumatic and negative experiences in healthcare were more often reported by parous women than nulliparous women (Rondung et al., 2018).

Stress and fatigue. One of the studies that investigated the link between fatigue and FOC made comparisons according to parity. They reported significantly higher levels of fatigue and fewer hours of sleep in parous women than nulliparous women, however, it was noted that the difference found might not have been large enough to be considered clinically meaningful (Hall et al., 2009).

Perceived social support. Findings related to perceived social support and FOC, organised by parity, were limited. When comparing childbirth knowledge by parity, nulliparous women with FOC indicated less knowledge than parous women with FOC (Toohill et al., 2014), which is logical given that the latter have lived experience of childbirth. Pazzagli et al. (2015), using the RAQ and DAS, investigated the role of interpersonal factors in predicting FOC. They reported that for nulliparous women, FOC was associated with a compulsive care-seeking dysfunctional attachment pattern and quality of marital adjustment. For parous women, interpersonal factors and FOC were not significantly associated.

Other associates. A number of the psychosocial associates of FOC that were reported in the initial section of this review were not considered according to parity (e.g. self-esteem, stress, personality traits and cultural influences). The majority of studies sampled both nulliparous and parous women, so findings were generalised to both. Accordingly, it is not possible to infer how these psychosocial associates of FOC may or may not differ by parity.

Methodological Critique

Setting, recruitment strategy and sample

The majority of studies included in this review were conducted in Scandinavian countries (i.e. Sweden, Denmark, Finland), but Australia, North America, and other European countries (e.g. Ireland, Italy, Croatia) were also represented. Within these countries, healthcare systems vary; some have a publicly funded healthcare system (e.g. Ireland, Italy), whilst others

are predominantly privately funded systems (e.g. USA), or a combination of both (e.g. Australia, Greece). All but one of the studies recruited participants from healthcare settings, and all studies used non-probability sampling. A number of studies acknowledged that this was a limitation, as the potential for the participants to be un-representative of the population was increased. Many of the studies, particularly those that recruited women from private healthcare settings, reported that the sample represented older, white, middle-class women, so findings should be generalised to wider society with caution. Almost all of the women sampled were pregnant, therefore women who experienced FOC in the general population were not represented. Terminology used to describe parity varied across studies, with primiparous and nulliparous, and parous and multiparous, used interchangeably. A strength of many of the studies was the large sample sizes used. Use of regression analyses also meant that confounding variables were controlled for in a number of studies.

Materials and measures

The majority of studies employed the W-DEQ, an instrument specifically designed to measure fear of labour and childbirth. The W-DEQ is a 33-item questionnaire that can be scored from 0 to 165 (Wijma, Wijma & Zar, 1998). Definitions of FOC were inconsistent across studies; different descriptive terms were used (e.g. severe FOC, serious FOC, high level of fear, fear of vaginal delivery) and different cut-off points were used to define the same level of fear (e.g. 'high fear' was defined as W-DEQ score ≥ 71 in one study and W-DEQ score ≥ 66 in another). The Fear of Birth Scale (FOBS) and Childbirth Attitudes Questionnaire (CAQ) were also used to measure FOC. All of these measures are validated and reliable measures of FOC, however, they are all self-report questionnaires. Self-report measures increase the probability of response bias or social desirability bias influencing the findings. They are also not diagnostic instruments; clinical interviews are preferable but difficult to employ when sample sizes are large. Other measures used (e.g. to assess anxiety, self-efficacy, self-esteem)

are also self-report, and carry the same limitations with them. A small number of studies used single-item questionnaires developed by the researchers for the purpose of the research, reducing the validity of the findings.

Some of the studies were retrospective in design, which introduced the possibility of recall bias. This might be particularly relevant for studies that explored the influence of trauma on FOC, as the validity and reliability of retrospective self-reports of experiences of trauma have been queried (Hardt & Rutter, 2004).

Research design

Cross-sectional survey designs were used in the majority of studies. Exposures and outcomes were measured at one point in time, which allowed for estimations of prevalence of FOC, and investigation of the associations between exposures and outcomes. However, cross-sectional designs are limited in that they cannot infer a causal or reciprocal relationship. The two qualitative studies in this review used constant comparison (Glaser & Strauss, 1967) and content analysis (Krippendorff, 1989) to analyse their data. Their findings were presented clearly with themes and quotations and added some depth and richness to the literature.

Limitations of the review

Due to time and resource limitations, a single researcher carried out study selection and performed quality checks. There is therefore an increased risk of subjectivity in the studies included and excluded and in the quality ratings obtained.

Studies that were carried out in developing countries, or countries/regions where maternal and birthing care and sociocultural experiences of pregnancy likely differed to that of the UK, were excluded from this review. It was considered that FOC might be understood and experienced differently due to significantly different healthcare systems and/or cultural beliefs about childbirth in these countries/regions. However, this limited the scope of the review.

Whilst the aim of the review was to elucidate 'psychosocial associates' of FOC, the emphasis was on psychological factors, for example, constructs such as anxiety. The role of social variables such as poverty, class or ethnicity were not considered in this review, which was perhaps as a limitation of the search terms used.

This review synthesised studies which mainly concentrated on associations between variables. It is likely that associations found between variables (e.g. general anxiety and FOC) are to some extent a result of these variables overlapping conceptually. The studies in the review used diagnostic categories (e.g. FOC and tokophobia) to describe and conceptualise women's experiences of fear of childbirth. Whilst this can be helpful, particularly from a research perspective, it is not the only way to understand and conceptualise these experiences. With this in mind, a limitation of the review was that a more critical lens was not applied.

Discussion

The aim of this review was to explore psychosocial associates of FOC and investigate whether these might differ for nulliparous and parous women. The review found that FOC was associated with a number of psychosocial factors. The effect of parity for most of these psychosocial associates was unclear.

Anxiety appeared to be one of the key associates FOC. Although there was some disagreement as to whether state anxiety, trait anxiety, or both, were at play, almost all of the studies found a significant association between FOC and anxiety (e.g. Molgora et al. 2018). Anxiety sensitivity-physical concern was significantly associated with FOC (e.g. Spice et al., 2009), and there was some evidence for a link between phobia and FOC (Rondung et al., 2018). Similarly, the literature showed strong support for an association between depressive symptoms and FOC. This fits with findings from previous literature reviews (e.g. Dencker et al., 2019). It has been suggested that symptoms of depression could contribute to women having a negative view of their personal capabilities, and a belief that the world is unsafe and

unpredictable. These views and beliefs might then manifest in fear and uncertainty about childbirth (Toohill et al., 2014).

When comparing by parity, findings were contradictory, with no conclusive evidence to suggest that mental health problems differ for nulliparous and parous women. As the studies in this review used different measures (i.e. to explore anxiety, some measured both state and trait anxiety, some measured just trait anxiety, others measured just state anxiety), it is difficult to generalise these findings. The relationship between FOC, anxiety and depression appears to be a complex one, as evidenced by Storksen et al.'s (2012) finding that high levels of anxiety and depression were associated with higher levels of FOC, but the majority of women were neither anxious nor depressed.

The findings in this review suggest that low self-esteem and low self-efficacy are associated with FOC, and with more severe FOC. It is possible that women with high FOC experience a general lack of confidence in their ability to cope with difficult and demanding life events. In relation to parity, there was some evidence that self-efficacy was associated with FOC for both nulliparous and parous women. According to Bandura's self-efficacy theory (Bandura, 1977) there are four sources of self-efficacy information; performance accomplishment, vicarious experience, verbal persuasion, and visceral arousal. Performance accomplishment (previous experience of labour and birth for parous women) is an influential source of efficacy information because this experience provides the woman with the most authentic evidence of her abilities; a previous negative or traumatic birth experience could provide evidence that she is not able to birth 'effectively'. In nulliparous women, performance accomplishment is eliminated as a source of self-efficacy information. For these women, vicarious experiences, theoretically, would be the most powerful predictors of self-efficacy.

The findings in this review suggest a clear link between social support and FOC, with all but one study reporting an association. A lack of general social support and help (e.g. Hall

et al., 2009), informational support (e.g. O'Connell et al., 2019) and support from partners (e.g. Toohill et al., 2014) all increased FOC. Although most studies did not investigate this link according to parity, it was reported that nulliparous women with FOC indicated less knowledge than parous women with FOC (Toohill et al., 2014), which is a logical finding. Pazzagli et al. (2015) reported that for nulliparous women, FOC was associated with a compulsive care-seeking dysfunctional attachment pattern and quality of marital adjustment, but there was no association for parous women. Social support can help individuals to cope with stressful situations (Turner, Grindstaff & Phillips, 1990). Women who receive reduced emotional and social support are more likely to experience adverse pregnancy outcomes (Collins, Dunkel-Schetter, Lobel, Scrimshaw, 1993). It is possible that women experiencing FOC may get caught in a vicious cycle whereby a lack of social support worsens symptoms of depression, and these symptoms reduce their ability to engage with and maintain social support systems (Toohill et al., 2014).

One study reported a moderate, significant relationship between FOC and decisional conflict (Toohill et al. 2014). The authors hypothesised that indecision might be part of a vicious cycle of events similar to the one described above. There was an association for both nulliparous and parous women, but it was more specific to nulliparous women. In nulliparous women, higher decisional conflict might be compounded by the fact that the experience of childbirth is unknown, and in parous women, by the conflict of having already experienced a previous negative or traumatic birth.

Certain personality traits were found to be associated with FOC. Women with FOC were reported as being more short-tempered (more irritable and monotony-avoidant) than women not experiencing FOC (Ryding et al. 2007). Lower levels of optimism were linked with higher levels of FOC (Gouranti et al., 2015), as was increased vulnerability (Saisto et al., 2001), but a link with neuroticism was not conclusive (Saisto et al., 2001; Gouranti et al., 2015).

Cognitive theories of stress and emotion suggest that dispositional optimism influences individuals' expectations and how they appraise current and future events. Therefore, if dispositional optimism is reduced, women might be more likely to view childbirth as a more negative, fearful and threatening experience. Women who are less optimistic might expect that they will not cope well with childbirth and anticipate an unfavourable childbirth outcome (Gouranti et al., 2015). Women's vulnerability may be linked to mental illness, poor social support, and experiences of abuse, which have all been shown to be associated with FOC. None of the studies in this review compared personality traits according to parity, so it is not possible to deduce whether there are any differences.

Whilst findings were not entirely consistent across all studies, precipitating life events that seemed to be associated with FOC included previous traumatic (Söderquist et al., 2004) and subjectively negative experiences of pregnancy and birth (e.g. Lukasse et al., 2010), previous experiences of miscarriage and infertility (Saisto et al., 1999), previous experiences of trauma unrelated to childbirth (e.g. Lukasse et al., 2014), experiences of emotional, physical and sexual abuse in childhood (e.g. Lukasse et al., 2010) and experiences of abuse in healthcare (e.g. Rondung at al., 2018). Findings were mixed when considering a link between FOC and previous obstetric complications such as emergency caesarean section.

Experiences of trauma and negative experiences in healthcare were more often reported by parous women than nulliparous women (Rondung et al., 2018), and previous experience of IVF was only associated with FOC in parous women (Raisanen et al., 2014). Previous experiences of traumatic or negative birth can only be associated with FOC in parous women, where it appears to be the strongest associate of FOC (e.g. Lukasse 2010). Women who have had negative birth experiences have described a sense of not being present in the delivery room, having an incomplete childbirth experience, and feeling unsupported. The memory of the

experience was vivid and stayed with them, giving rise to feelings of fear, loneliness, lack of belief in their ability to give birth and reduced trust in healthcare (Nilsson et al., 2009).

One study found childhood emotional abuse to be most strongly associated with FOC (Lukasse et al., 2010). It has been suggested that emotional abuse experienced in childhood could contribute to the development of a cognitive vulnerability to depression (Haeffel et al. 2008). Women who suffer emotional abuse as a child may develop an understanding about themselves as incapable of performing well. This may lead to a cognitive appraisal of the upcoming birth as a situation they will not be able to manage, resulting in heightened FOC (Lukasse et al., 2010). After confounding variables were controlled for, a significant relationship between FOC and childhood abuse was only present for women having their first baby (Lukasse et al., 2010); when depressive symptoms, education, adult abuse and negative birth experience were assessed for their individual effects, each variable caused a significant association to disappear in parous women. This suggests that these factors override any potential effects of experiences of abuse on FOC.

On the whole, fatigue (Hall et al., 2009) and stress (e.g. Melender, 2002) were considered associates of FOC. Increased fatigue might account for lower stress tolerance. This might result in increased vulnerability in a woman, which has been shown to increase FOC. Higher levels of fatigue and fewer hours of sleep were reported in parous women when compared with nulliparous women, although the difference was small (Hall et al., 2009). This difference might be explained by parous women having more demands placed on them by existing children.

FOC was higher when women had been exposed to 'horror stories' (e.g. Fisher et al., 2006) and portrayals of risky, dramatic and medicalised births shown in the media (Vitek et al., 2019). This fits with Rachman's (1977) theory of fear acquisition, in which fears can be acquired via different pathways, including vicarious exposure and by indirect transmission via

information. It also fits with Bandura's theory of self-efficacy (Bandura, 1997), which suggests that vicarious experiences are powerful predictors of self-efficacy, which has shown to be reduced in women experiencing FOC. None of the studies compared by parity, so it is unclear how exposure or vicarious experiences might affect nulliparous and parous women differently.

'Vicious circle' of FOC

Whilst this review pointed to some differences between psychosocial factors associated with FOC according to parity, findings were mixed for most factors. It therefore seems reductionist to suggest a clear separation between nulliparous and parous women when it comes to associated psychosocial factors. Zar et al. (2001) put forward the possibility that a 'vicious circle' occurs in FOC. Nulliparous women with high levels of FOC might be more likely to experience fear during labour and cognitively appraise the approaching birth as threatening. This might increase the chances of having a negative or traumatic birth experience and reporting FOC following the birth or in a subsequent pregnancy. Therefore, FOC in parous women might not only be due to the experience of a previous negative birth, but actually the result of a complex process, made up of several factors interacting over time.

Clinical and research implications

The findings from this review suggest that women experiencing FOC have different psychological and social support needs to women not experiencing FOC. The psychosocial factors associated with FOC are diverse and complex; women experiencing FOC are a heterogeneous group. This inevitably makes assessing, formulating, and devising treatment approaches that are appropriate and effective more challenging. Therefore, an individualised, biopsychosocial perspective is suggested when working with women experiencing FOC. Routine screening for identified psychosocial associates, such as anxiety, depression and trauma, could support the development of an individualised formulation and treatment plan. Interventions that provide accurate childbirth information, focus on building self-esteem, self-

efficacy and optimism, reducing stress, managing anxiety, and improving mood, would likely prove beneficial. In addition, offering avenues for women to improve relationships and build social support would be valuable.

In order for services to be able to provide appropriate and timely interventions, early identification of FOC is important. It is therefore suggested that a FOC screening tool is used at early routine antenatal appointments. Furthermore, this review suggests that FOC is linked to feeling unsupported by services and healthcare professionals. Training and support for staff in these services may help them to provide more sensitive care to women experiencing FOC.

In order to develop and strengthen our understanding of FOC, future research should consider how FOC is defined and measured. Due to different definitions and measurements being used across the literature, validity and reliability of findings are currently questionable. Therefore, development of a universal measure of FOC would be beneficial. Where possible, future research should consider measuring variables prior to pregnancy, given that pregnancy itself triggers psychological reactions; this would increase validity.

As the majority of studies used cross-sectional designs, which are only able to assess at one point in time, it would be interesting for further research to develop a better understanding of how psychosocial factors associated with FOC change over time, particularly following intervention. A recent review has synthesised the current literature exploring the effectiveness of interventions for FOC (Hosseini et al., 2018), and it is encouraged that research in this area continues. Given the ever-increasing influence of media in current society, further investigation of how this is impacting on women's perceptions of pregnancy and birth is warranted.

This review highlights that women experiencing FOC are a heterogeneous group. It seems likely that the underlying mechanisms of FOC are complex and more research is needed to better understand the experiences of these women. Future research may therefore want to

explore women's lived experiences of FOC, with the aim of gaining a better qualitative understanding of the underlying processes and mechanisms at play. Only two of the studies in this review were qualitative in design. Whilst quantitative data allows for broader, more generalisable findings, it can lack the depth and richness that qualitative research can provide.

Conclusion

By synthesising existing research on psychosocial associates of FOC, and exploring differences according to parity, this review adds to the understanding of FOC. FOC was found to be associated with a number of psychosocial factors. The effect of parity for most of these psychosocial associates was unclear, supporting the suggesting that FOC could be understood through the concept of a 'vicious' circle; nulliparous women with high levels of FOC might be at increased risk of experiencing fear and appraising an upcoming delivery as threatening, increasing the likelihood of experiencing a negative birth and subsequent FOC. FOC in parous women might therefore not only be due to a previous negative birth experience, but actually the result of a complex process, with several factors interacting over time. Given that women experiencing FOC are a heterogeneous group, an individualised, biopsychosocial approach is recommended. Early identification of FOC through routine screening is suggested, along with implementation of interventions that provide accurate childbirth information, build self-esteem, self-efficacy and optimism, reduce stress, manage anxiety, and improve mood. Future research would benefit from exploring how psychosocial factors associated with FOC change following intervention, and the effects of the media on perceptions of pregnancy and birth. Future research exploring women's lived experiences of FOC, with the aim of gaining a better qualitative understanding of the underlying processes and mechanisms at play, is also warranted.

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Section B: Empirical Paper

"Like living with a monster": A Grounded Theory of women's journey to motherhood with primary tokophobia

Word count: 8265 (274)

A thesis submitted in partial fulfilment of the requirements of Canterbury Christ Church University for the degree of Doctor of Clinical Psychology and prepared for submission to the Journal of Reproductive and Infant Psychology

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Abstract

Objective: Primary tokophobia (intense fear of childbirth unrelated to previous birth trauma) can have huge implications for both mother and baby. Some efforts have been made to better understand women's experiences of tokophobia, however, gaps remain in the literature. This study aimed to further explore women's lived experiences of primary tokophobia and describe how identified themes relate to each other through a theoretical model.

Design: A non-experimental qualitative design was employed. A Constructivist Grounded Theory (GT) approach was used to generate and analyse data that was collected using semi-structured interviews.

Setting: NHS perinatal mental health teams and online tokophobia support groups.

Participants: Eight women who were experiencing, or who had experienced in the last five years, primary tokophobia.

Findings: A cyclical model was developed, representing conceptual relationships between nine superordinate categories: making sense; facing the fear; becoming lost in the terror; losing control; running out of time; finding a way to cope; surviving and reflecting; going through it alone; and changing fear. The categories were organised into three phases; understanding; experiencing; and appraising.

Key conclusions: This study is the first to provide a model of women's journey to motherhood with primary tokophobia. Findings tentatively suggest that primary tokophobia could be viewed through the lens of trauma, as a form of 'pre'traumatic stress.

Implications for practice: Key ideas of how the findings could be implemented are related to early intervention, peer support and professional input, and could shape and improve how services support women experiencing primary tokophobia.

Keywords: primary tokophobia, fear of childbirth, lived experience, Grounded Theory methodology, trauma

A note on terminology

This study uses the term 'tokophobia' to describe intense fear of childbirth, as this is the term that participants used when sharing their experiences. However, there is inconsistency in how tokophobia is defined in the literature: existing research relevant to this study has used other terminology, such as 'fear of childbirth (FOC)' or 'fear of delivery'.

Introduction

The experience of pregnancy and childbirth is multidimensional; it is typical for women to feel a range of emotions, from elation to horror (Larkin, Begley, & Devane, 2009). Fear is a normal and rational emotion to feel, given that childbirth is an experience that is connected to the existence of life. However, for some women this fear is so severe that it becomes overwhelming and debilitating and can be classified as tokophobia (Hofberg & Brockington, 2000). Tokophobia, from the Greek 'tokos' meaning childbirth and 'phobos' meaning fear, has been defined in a number of ways in the literature, including as "an unreasoning dread of childbirth" (Hofberg & Brockington, 2000) and a "severe fear of childbirth" (Raisanen et al., 2014). Women experiencing tokophobia often meet the DSM-V classification for a specific phobia (American Psychiatric Association, 2013). Due to the inconsistent definition of tokophobia, prevalence estimates vary, however a recent systemic review of the literature reported the overall worldwide prevalence of tokophobia to be 14% (O'Connell, Leahy-Warren, Khashan, Kenny & O'Neill, 2017).

Tokophobia is typically classified as being either primary or secondary; primary tokophobia referring to a phobic fear of childbirth in women who have not experienced pregnancy before, and secondary tokophobia referring to women whose fear develops after pregnancy or childbirth. The literature points to a number of psychosocial associates of FOC. These include, but are not limited to, anxiety and depression (Laursen, Hedegaard & Johansen, 2008), vulnerability (Saisto, Salmela-Aro, Nurmi & Halmesmäki, 2001), and lack of social

support (Toohill et al., 2014). Secondary tokophobia is usually in response to a previous traumatic pregnancy or birth and is therefore often conceptualised and treated as a specific form of post-traumatic stress disorder (PTSD) (NHS London, 2018). Some research has suggested that primary tokophobia could start as early as adolescence and could be associated with previous sexual abuse, or being witness to a traumatic birth, either in person or vicariously (Hofberg & Brockington, 2000; Alessandra & Roberta, 2013). However, the aetiology of primary tokophobia appears complex and remains unclear.

The impact of tokophobia on a woman's life can be significant. Thirteen percent of women report fear that is great enough to postpone or avoid pregnancy altogether (Hofberg & Brockington, 2001), often despite desperately wanting a baby. Women experiencing tokophobia sometimes contemplate or undergo a termination of pregnancy due to the extreme distress they feel (NHS London, 2018). Experiencing high levels of fear during pregnancy has been linked with an increased need for mental health care after birth (e.g. Hall et al., 2009; Rouhe, Salmela-Aro, Gissler, Halmesmäki & Saisto, 2011), obstetric complications (e.g. Adams, Eberhard-Gran & Eskild, 2012; Fenwick, Gamble, Nathan, Bayes & Hauck, 2009) and can have significant implications for relationships in the woman's life, including with her baby (Nicholls & Ayers, 2007; Parfitt, Pike & Ayers, 2013).

The current guidelines for the treatment of tokophobia suggest the input of perinatal mental health services, with a view to addressing the anxiety in a supportive manner. If after discussion and offer of support a vaginal birth does not seem possible, a planned caesarean section may be offered (NICE, 2011). There is some evidence to suggest that cognitive behavioural therapy (CBT) and psychotherapy can be helpful (e.g. Sjogren & Thomassen, 1997; Saisto & Halmesmaki, 2003). A recent systematic review synthesised findings of studies which had investigated education and hypnosis-based interventions for FOC (Hosseini, Nazarzadeh & Jahanfar, 2018). They found that both types of interventions were effective in

reducing FOC, however educational interventions seemed to have the greatest impact on reducing the fear.

Rationale

There have been some efforts to explore and understand women's experiences of tokophobia. A recent systematic review of the literature synthesised the findings of fourteen qualitative papers that had explored women's experiences of FOC. They were able to put forward a deepened understanding of women's experiences interpreted through the metaphor 'being at a point of no return'. Three key themes emerged from their review: to suffer consequences from traumatic births; to lack warranty and understanding; and to face the fear (Wigert et al., 2019). However, the existing qualitative studies were conducted mainly in Scandinavian countries; none were conducted in the UK. Women experiencing primary tokophobia have been under-represented in the literature, with most of the existing research placing primary and secondary tokophobia under the same umbrella of 'tokophobia'. Given that it is widely considered that the genesis is not the same in primary and secondary tokophobia, and there are separated clinically, exploring them separately seems important. Furthermore, whilst key themes have been summarised in the recent literature review, it is not currently clear how identified themes relate to each other. Developing a model grounded in women's lived experiences could help further theoretical understanding of the processes that women go through when entering motherhood with tokophobia.

Research questions

a) What are women's lived experiences of primary tokophobia?
b) How do women perceive, make sense of, and manage the tokophobia before, during, and after their pregnancy?
c) What are the links/relationships between emerging themes related to women's experiences of primary tokophobia?

Method

Design overview

A non-experimental qualitative design was employed. A Constructivist Grounded Theory (GT) approach (Charmaz, 2006) was used to generate and analyse data that were collected using semi-structured interviews. Considering the research questions that were being posed, this methodology was deemed most appropriate, as it offers a way to develop an explanatory framework in which the phenomenon under investigation might be understood (Willig, 2013). Furthermore, Grounded Theory is considered an appropriate methodology to use when a phenomenon has undergone limited research (Urquhart, 2013).

A constructivist epistemological stance was adopted in this study, where the contributions by the researcher and participants, and the context in which the research was carried out, were recognised as having influence on the development of the model.

Participants

Recruitment. Participants were recruited from;

a) An NHS perinatal mental health team (n=2). This team supports mothers who are experiencing, or who have previously experienced, severe mental health difficulties during pregnancy or up to a year after birth.
b) Online support groups for women experiencing tokophobia (n=6). Recruitment took place in two support groups on the social media platform Facebook, which women were voluntarily members of.

Six participants were primigravida and two were multigravida, but all had experienced tokophobia during their first pregnancy. All participants had accessed mental health services at some point in their journey, where they were given a diagnosis of primary tokophobia. Current practice in the UK is to use clinical judgement to make this diagnosis, therefore no

formal measures were used. Inclusion and exclusion criteria can be found in table 1. Participant characteristics and demographic information can be found in table 2.

Table 1. Inclusion and exclusion criteria

Inclusion	**Exclusion**
• Women over 18 years old • Women experiencing, or who had experienced within the last five years, primary tokophobia (intense fear of childbirth unrelated to previous birth trauma) • Women who had been pregnant and given birth in the UK	• Women under 18 years of age were excluded as other factors associated with teenage pregnancy may have made it difficult to gain a clear understanding of the meaning of primary tokophobia • Women who had never had a baby or were determined not to ever be pregnant. Although these women also experience primary tokophobia, the aim of this study was to explore the experiences of women who had lived through the fear, in order to better understand their journey • Women whose fear was related to a history of genital injury, as this would not be considered primary tokophobia • Women who were experiencing acute distress that might render the interview process unethical • Women who had been pregnant and given birth outside of the UK were excluded, due to the possibility that maternal and birthing care and sociocultural experiences of pregnancy could differ significantly

Number of participants. Rather than seeking category saturation as suggested by Charmaz (2006), the aim in this study was instead to reach 'theoretical sufficiency' as described by Dey (1999). This refers to the point where categories are able to adequately cope with new data without requiring further modifications. This was felt to be reached with eight participants; data collected in the later interviews fit within existing categories without the need for the addition or modification of categories.

Table 2. Participant characteristics and demographic information

Participant	Age	Ethnicity	Employment status	Marital status	Child(ren)'s age	Delivery method
P1	29	White British	Self-employed	Living with husband	1	Planned elective caesarean
P2	35	White British	Maternity leave	Living with husband	1	Planned elective caesarean
P3	37	White British	Employed	Living with husband	2	Planned elective caesarean
P4	39	White British	Employed	Living with husband	4, 2	Planned caesarean; planned elective caesarean
P5	34	White British	Employed	Living with partner	3	Planned elective caesarean
P6	36	White British	Full-time mother	Living with husband	1	Planned elective caesarean
P7	32	White British	Employed	Living with partner	Due in July 2020	Planned elective caesarean
P8	35	White British	Self-employed	Living with husband	3, 1	Planned elective caesarean; planned caesarean

Procedure

Recruitment from NHS settings. The research was presented to two multi-disciplinary perinatal teams. Staff were provided with an overview of the research aims and were given copies of the information sheet (Appendix D) and consent form (Appendix E). From January 2019 to March 2020, potential participants who met the inclusion criteria were identified by staff, provided with written information about the research, and given the opportunity to take part. Staff used their clinical judgement to inform their decisions about who to approach about the research, but were encouraged to use the inclusion criteria as a guide in order to reduce the possibility of selection bias occurring. Potential participants who showed an interest were contacted by the researcher where informed consent was gained.

Recruitment from social media platforms. From October 2019 to March 2020, recruitment posters were posted on two separate Facebook support groups for women experiencing primary tokophobia (Appendix F). Women who showed an interest were contacted by the researcher to ascertain whether they met the inclusion criteria. If so, they were provided with an information sheet and consent form. If willing to take part, informed consent was gained.

Interviews. Semi-structured interviews were used to explore participants' lived experience of primary tokophobia. The development of the initial interview schedule (Appendix G) was informed by principles suggested by Charmaz (2014) and was devised based on the research aims, but a degree of flexibility was also employed to allow for more spontaneous narratives to emerge (Brinkmann, 2014). Probes were used to elicit a deeper understanding of the participants' perspectives. As interviews progressed, questions were adjusted according to 'leads' that had emerged from the data, allowing for theory generation to occur (Charmaz, 2014) (Appendix H).

Interviews were conducted face-to-face at participant's homes (n=2) and via video link where home visits were not possible (n=6). Interviews were audio-recorded and transcribed.

Interviews ranged in length from 48 minutes to 113 minutes. Participants were fully debriefed at the end of each interview.

Data analysis. Data were analysed in line with Constructivist Grounded Theory methodology outlined by Charmaz (2014). Throughout the analysis process, constant comparison (Glaser & Strauss, 1967) was used to compare statements and incidents within and across interviews. Concepts were developed and raised to a more conceptual level through the use of memos written throughout (Appendix I).

Interviews were transcribed verbatim and fully anonymised. Three transcripts were analysed initially using line-by-line coding, in order to assign descriptive codes that remained as close to the data as possible (Appendix J). Gerunds were used where appropriate when coding, with a view to applying a process orientated lens to the data (Charmaz, 2014). Codes that appeared most frequently or appeared to hold most significance were funnelled into more directed, selective and conceptual focused codes (Glaser, 1978). As interviewing progressed, these focused codes were used to code further data that emerged and provide direction to the line of questioning in order to explore emerging themes (Draucker, Martsolf, Ross & Rusk, 2007).

Theoretical coding followed, with the development of analytic categories and subcategories that looked to encapsulate the data, make sense of them, and explain the relationships between categories (Glaser, 1978). Further interviewing and revisiting of transcripts led to the refinement of categories, subcategories and theoretical codes (Appendix K). An iterative process of comparing theoretical memos with codes, categories and raw data led to the development of a model grounded in participants' descriptions of their experiences (Appendix L).

Quality assurance methods. In order to ensure the quality of this research, a number of quality assurance strategies were used.

Consensus building. Throughout the analysis process, emerging codes and categories were discussed with research supervisors. This allowed space to explore different interpretations and help to ensure categories and theory development were representative of the raw data collected.

Reflexivity. The researchers acknowledged that their pre-existing knowledge and beliefs resulted in subjectivity. The primary researcher was a British female trainee clinical psychologist, who had personal experience of pregnancy and childbirth. With limited prior knowledge of tokophobia, the researchers embarked on the study interested in understanding what it was like to experience intense fear during such an emotional, unfamiliar, life-changing time, and what gave women the strength to do this. Employing reflexive strategies allowed for examination of how subjectivity might have influenced interpretations of the data, and make it explicit (Charmaz, 2014). A bracketing interview was conducted (Creswell & Miller, 2000), leading to the development of a positioning statement (Appendix M). Throughout the coding process, diagramming and memo-writing allowed for an open account of category and theory development. Personal reflections on the process of conducting the research were documented in a reflective diary (Appendix N).

Respondent validation. In line with a constructivist approach, participants were contacted and asked to provide feedback on the initial model that was developed (Appendix O). This allowed for validation of the findings. Feedback was received from six participants and was incorporated into the final theory.

Minimising potential interviewer bias. In order to minimise potential bias and limit the effects of social desirability and acquiescence, interviewer neutrality was employed as far as possible. A non-judgemental manner was used avoiding the use of verbal and non-verbal cues (e.g. nodding, frowning) that might be interpreted by participants as either approving or

disapproving. The interviewer refrained from expressing personal opinions or preferences, whilst still trying to establish and maintain rapport.

Ethical considerations. NHS ethical approval and Health Research Approval were obtained in May 2018 (Appendix P & Q), and approval from the Research and Development department of the NHS trust where recruitment took place was received in August 2018 (Appendix R). Informed consent was obtained prior to each interview being conducted, and participants were reminded of their right to withdraw from the study at any time. Participants were debriefed fully following each interview and provided with information about support services available to them. Following interviews, audio data collected were immediately transferred to a password-protected device accessed only by the researcher, then deleted once transcribed. Any identifying information was changed to maintain anonymity and confidentiality. Anonymised transcripts will be kept on a password protected CD and stored at the Salomons Centre for Applied Psychology in a locked cabinet for ten years, then destroyed.

Results

Model Summary

The theoretical model is titled *"Like living with a monster"* (P3). It represents conceptual relationships between nine superordinate categories: making sense; facing the fear; becoming lost in the terror; losing control; running out of time; finding a way to cope; surviving and reflecting; going through it alone; and changing fear. The categories are organised into three phases; understanding; experiencing; and appraising. Gerunds that most accurately captured the processes that participants described were used to name these phases. Movement between the phases represents the journey that participants described and is not linear or unidirectional. Some phases overlap and happen concurrently. The cyclical aspect of the model demonstrates how the journey is ongoing.

'Making sense' and 'facing the fear' occurred in the 'understanding' phase and were reciprocally enabling of each other. 'Facing the fear' crossed over into the 'experiencing' phase, where categories interacted with each other to create a description of how the fear was experienced and coped with: 'becoming lost in the terror' and 'losing control' were reciprocally reinforcing of each other, and participants described 'finding a way to cope' with what they were experiencing. The category 'running out of time' spanned across the phase and represented a temporal aspect that was described by participants. 'Finding a way to cope' crossed over into the 'appraising' phase and enabled a process of 'surviving and reflecting'. This in turn enabled the process of 'making sense'.

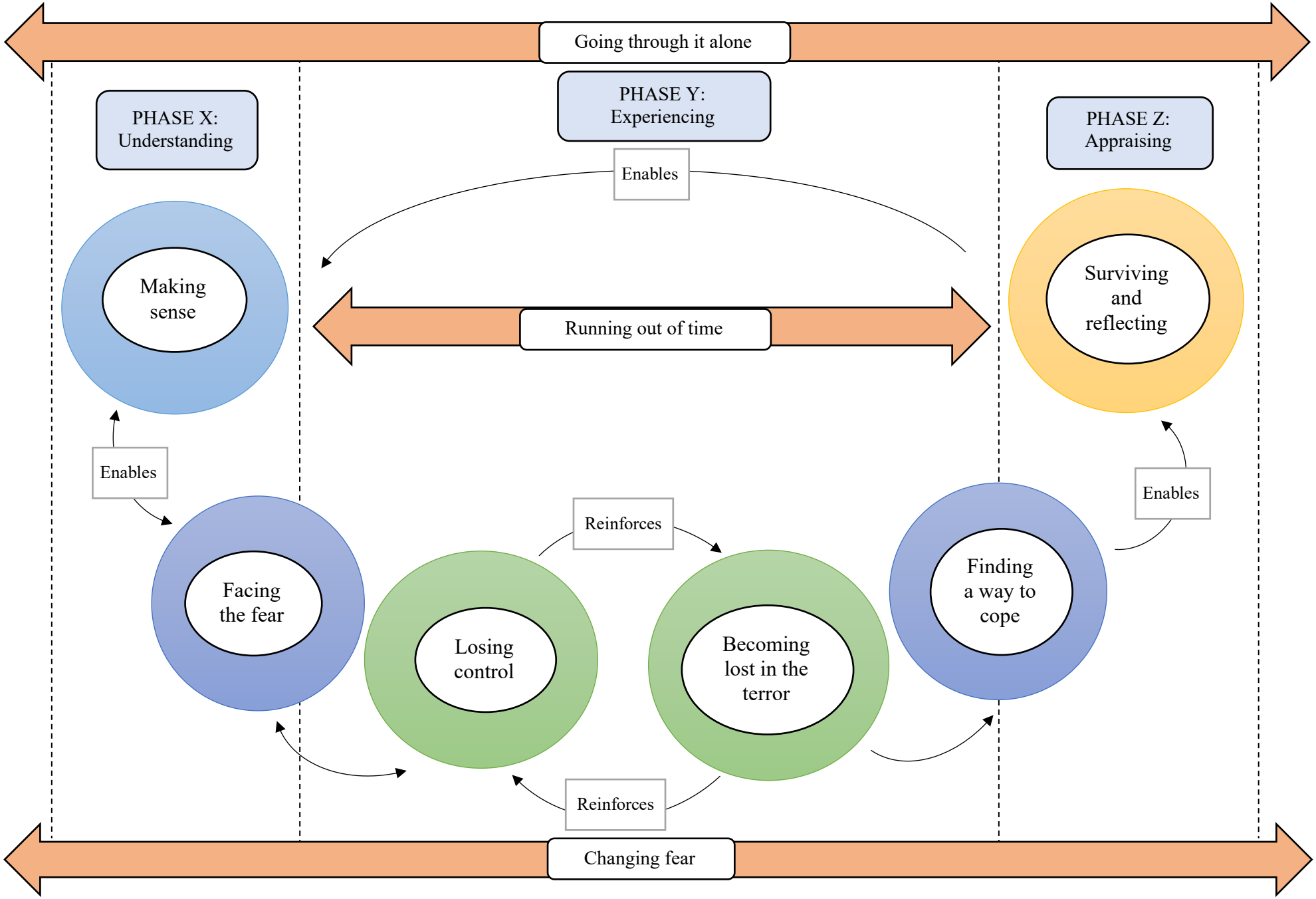
'Going through it alone' was an overarching category that permeated each phase. Similarly, the category 'changing fear' represented the evolvement of the fear, and the participant's changing relationship with the fear, throughout the journey.

Table 3. Categories and subcategories of a model of women's lived experiences of primary tokophobia

Categories	**Subcategories**
Making sense	Trying to make sense
	Prior traumatic and negative experiences
	Being at fault
Facing the fear	Becoming aware
	Taking on the fear
Becoming lost in the terror	Experiencing terror
	Fear being reinforced
	'Pre'-experiencing
	Being consumed by the terror
	Feeling like a different person
	Loss of connection
Losing control	Control

	Fearing the unknown
	Having to trust
	Relationship with their bodies
Finding a way to cope	Avoiding and hiding
	Support
	Allowing for hope
Running out of time	N/A
Surviving and reflecting	Reflecting on surviving
	Assessing the impact
	Looking to the future
Going through it alone	Feeling alone
	Feeling like an outsider
	Desire to be recognised and understood
	Shame
	Finding the words
Changing fear	N/A

Figure 1. "Like living with a monster": a GT model representing women's journey to motherhood with primary tokophobia



Phase X: Understanding

Participants went through a phase of 'understanding' their relationships with tokophobia. This phase preceded pregnancy for some participants, but not all. A reciprocal relationship occurred between the two categories in this phase, i.e. 'making sense' enabled 'facing the fear' and vice versa.

Making sense

Participants engaged in a process of **trying to make sense** of the fear. Tokophobia was described as a *"fear of pain" (P2),* a fear of "*dying" (P3),* a fear of something *"growing inside of me" (P6)* and a fear of *"losing control" (P8).* For some, the fear could be understood in stages:

> *"There's the fear of getting pregnant, there's the fear of being pregnant and then there's the fear of the delivery" (P4).*

Despite their best efforts, making sense of the tokophobia was difficult for most participants. Some felt closer to making sense of it than others:

> *"I understand why I was scared, so in that way, I've made sense of it" (P1);*
>
> *"I've never been able to ascertain like a particular reason" (P7).*

Legitimising and justifying the fears was a recurring theme that emerged. Some participants argued that there was a rational explanation for their fears, in that pregnancy and giving birth can be dangerous:

> *"Well is it irrational to be scared of something that does harm people?....It is the only way I could try to make sense of it" (P7).*

Some participants believed **prior traumatic and negative experiences** played a role in the fear. They described vicarious exposure to a traumatic birth through *"horror stories" (P7)* or in person:

> *"My mum went into premature labour with my sister at home when I was five years old and it was just me and her at home and still it just, I just remember seeing her in pain" (P6).*

Traumatic experiences in healthcare also played a role for some:

> *"I had major surgery when I was five years old… I felt the staff were horrible to me. You could call it abuse" (P2).*

One participant's fears seemed to be linked to losses she had experienced in her life:

> *"When you're lying in the theatre….you realise your granny died on the floor below"(P4).*

Prior traumatic or negative experiences left some participants with other phobias that were related to the tokophobia:

> *"I have a needle phobia…which I have always been aware of, since this surgery. I just didn't realise the rest of the implications of it…I didn't realise the whole thing was all linked" (P2).*

Some also reflected on experiences of anxiety in other areas of their lives:

> *"Quite a few things came up with other anxiety areas for me, and they said, it sounds like you have quite a lot of anxieties, childbirth being obviously a big one… I just had quite a lot of anxiety in my life" (P1).*

Many of the participants considered themselves as **being at fault.** They were left *"feeling like a failure" (P1),* feeling *"inadequate*" *(P2),* feeling like a *"bad mother" (P8)* and believing that there was "*something wrong with [them]" (P6).*

For some participants, the process of making sense involved an internalisation of the fear:

> *"I suppose it is making sense of it in a way, that tokophobia is…part of who I am" (P3).*

The process of making sense was not a static or linear one; it was ongoing, and participants wrestled with making sense of their experiences at different points throughout their journey.

Facing the fear

There was a point in each participant's journey when they came face-to-face with the fear. Some participants reached this point prior to becoming pregnant while others reached it once already pregnant. For all, there was an initial process of **becoming aware** of the fear and its influence over them:

> *"I knew I wanted kids, definitely, but how do I do this, because it's terrifying?" (P1);*
>
> *"I was fourteen weeks pregnant and I was honestly OK up until then… that's when my fear kicked in" (P6).*

There was a sense that the fear lay dormant under the surface, and could be ignored:

> *"I'd always dreaded the thought of it, even before I thought about starting a family. But because it wasn't a reality at that point, I never let it… I've never given it a huge amount of thought" (P8).*

Reaching a point in their lives where having a baby became more of a priority brought the fears into focus for some participants:

> *"And then as I got older, it became more… like relevant to my life I suppose. Which then made it feel bigger" (P7).*

The process of **taking on the fear** once aware of it came about differently for participants. For some, having a baby was "*so important*" (P1) to them that it gave them the strength to face the fear, some felt "*pressure"* (P5) to have a baby, and others reached a point where it felt like *"now or never"* (P7). Once pregnant, some participants battled with themselves over whether they felt able to take on the fear and continue with the pregnancy:

"I wanted to have a termination - that's what my head was telling me at fourteen weeks" (P6);

"Was I going to be able to go through this?... I considered crashing my car into a tree, with the aim of obviously maiming myself so badly that I lose the baby" (P5).

Phase Y: Experiencing

The 'experiencing' phase encapsulated categories that described what living with tokophobia felt like for participants, and how they found ways to cope with what they were experiencing. Most participants described that this phase was most 'live' when they were pregnant, but some felt they were also in this phase when thinking about the possibility of becoming pregnant. A temporal aspect, 'running out of time' permeated this phase.

Becoming lost in the terror

Participants described a process of "becoming lost in the terror". When in the grips of the tokophobia, they vividly described **experiencing terror:**

"It was like standing on the edge of a black hole of terror, and you didn't know what was in there, and somebody was trying to push me in. And I couldn't explain what it was exactly I was afraid of, because I didn't know what was going to happen, what it was going to feel like"(P3).

There was a shared experience of the **fear being reinforced** by media portrayals of childbirth, information found on the internet, and exposure to anything pregnancy or birth related:

"I literally this morning was on Facebook…her partner was talking about the birth of their little girl. And what a blood bath it was and how horrific it was and that was just the headline"(P3);

"They left me near a delivery suite window…it just sounded like kittens being killed. It was just the most horrific sound on earth" (P4).

Some participants described a form of **'pre'-experiencing**: a 'flash forward' to the horror that they anticipated was waiting for them. This was experienced as distressing imagery of "*harsh medical settings"(P3),* "*extreme blood loss"(P3)*, "*not being able to breathe*" *(P4)* and being in "*unbearable pain"* (P2), and recurring nightmares:

> *"I remember having nightmares before I was pregnant…I was suddenly pregnant and this thing was growing in me and it had to come out and all of a sudden it was bursting out…no pain relief, nothing like that" (P6);*
>
> *"I had nightmares when I was 14 of dying during vaginal birth. I bled to death in the dream" (P2).*

Participants described a sense of **being consumed by the terror**; that it was unrelenting, paralysing, ever-present and overshadowing any joy:

> *"Every day, every night is a struggle" (P2);*
>
> *"It was a paralysing fear, everything in my life ground to a halt…Everything else fell by the wayside" (P3);*
>
> *"It was always, always there" (P5);*
>
> *"It just felt like anxiety rather than any kind of celebration about being pregnant" (P8).*

One participant described tokophobia as *"like living with a monster…..it obscures it all"(P3).*

There was a strong sense of feeling "*trapped*" *(P1)* and feeling *"desperate*" *(P5)* to escape:

> *"you're stranded and you can't get away, I kept thinking that I could run now... No, you can't… run anywhere" (P4).*

Some participants were so consumed by the belief that they would not survive the birth that they made plans for what would happen after their death:

> *"I wrapped up all my finances, I put my life in order because I thought we were going to die and yet it's the furthest thing from what you want to do" (P3).*

The all-consuming terror left some of the participants **feeling like a different person:**

"I usually consider myself quite a logical, straightforward person...I don't know who I was. I don't recognise myself then. Just a different person" (P5);

"Losing who you are, so you become so unrecognisable" (P3).

One participant talked about wanting to *"just be me again"* (P3), while another participant described how the experience had changed them as a person:

"I feel completely changed by it...I just definitely don't feel how I did - I feel vulnerable by it" (P6).

Living with tokophobia resulted in a **loss of connection.** Participants longed to feel connected with their baby, but for many, the fear got in the way:

"Tokophobia is a total lack of connection… every night I would sit and read my baby a poem… not because I wanted to, but I thought I better do this… It was very mechanical… there was no connection" (P3);

"My mind wouldn't let me think of it as a little baby, it was just this alien inside of me" (P6).

A sense of being alone in the fear made participants feel isolated, and disconnected them from the world around them:

"It's isolating, and you feel like the only person in the world that feels like this"(P2);

"The only real connection I had with anybody else going through it was the one online Facebook group" (P8).

Losing control

Control was a theme that appeared frequently, with most participants describing how they feared being out of control:

"I cannot cope with the idea of going through it.. the loss of control, what if the same thing happened to me that happened to mum, we can't guarantee that wouldn't happen" (P1);

> *"the worst aspect was the thought of losing control…the thought of not having a choice" (P8).*

There was a strong desire to know what could and could not be controlled for:

> *"I just want to know what I do and don't have control over there...what do I have a choice over and what choices can I make to feel more in control…having a sense of control is what makes the difference" (P2)*

Planning an elective caesarean helped most participants to feel more in control:

> *"When I found out about the planned c-section…that's probably the best thing for me, when I was so worried and wanted something controlled" (P1).*

Participants described **fearing the unknown**; something they had little control over:

> *"The thing about the fear it's the unknown, isn't it. For me it's what's it going to be like when it starts moving, what's it going to be like when it kicks, and I can't stand it" (P6).*

There was a desire to be fully informed in order to feel *"prepared" (P3)* and *"avoid surprises" (P2)*. However, one participant described how being informed added to her fears:

> *"I like to know about things which then makes it worse… the things I find out aren't necessarily helpful" (P7).*

For some participants, the experience of losing control was linked with **having to trust** professionals involved with their care. Previous negative experiences in healthcare left some participants struggling to trust:

> *"Not trusting medical staff [maintained the fear]….everyone has to tell me what they're going to do before they're allowed to touch me" (P2).*

Continuity of care enabled trust to develop:

> *"Having a midwife I trust it was really helpful. Continuity of care is massive" (P2);*

> *"She was with me the entire journey, which was one of the things I really struggled with was trust. Trusting a professional was a big thing for me "(P3).*

Becoming pregnant brought the **relationship with their bodies** to the foreground for some participants. They described feeling *"repulsed" (P5)* and *"disgusted" (P6)* by what was happening in their bodies. A sense of losing control of their bodies was felt, both in terms of the inevitable changes that came with pregnancy:

> *"It wasn't just around the childbirth. It wasn't just around the end result with me. A lot of it was to do with how my body was going to change" (P8);*

And with the physical aspects of maternity care that were experienced as intrusive and exposing by some:

> *"I think one of my biggest fears was the fact that...I would have to take my underwear off to have the baby….for me it felt as strongly as, it was almost like actual assault in a way. I felt I didn't have an option" (P8).*

Some participants described feeling like they no longer had autonomy over their own bodies; that it had been taken over by something *"alien" (P6)* or that they were *"a prisoner in [their] own body" (5).* A sense of feeling *"used"(P5)* emerged, with one participant describing how she felt like*" just a vessel" (P8).*

Finding a way to cope

'Finding a way to cope' encompassed the ways in which participants managed and coped with the tokophobia. **Avoiding and hiding** were means of coping for a number of participants. By avoiding reminders of pregnancy and birth, participants were able to avoid coming face-to-face with that they feared:

> *"I couldn't be around anyone who was pregnant, I couldn't look at anybody with a pregnant belly…to me it was just to me out of sight out of mind" (P6).*

For some, avoidance started early, before they were fully aware of their fears:

> *"I've always avoided the baby aisle in the supermarket. Just didn't really think about it…. And it was only when someone else said that they did the same thing I thought, 'Oh, maybe it's a tokophobia thing. Maybe that's why'" (P2).*

Many participants waited as long as possible to disclose that they were pregnant, told as few people as they could, and avoided situations where they would have to acknowledge the pregnancy. Keeping the pregnancy and themselves hidden allowed them to cope by pretending that it was not happening:

> *"I avoided dealing with being pregnant by thinking I wasn't pregnant – telling myself I wasn't pregnant. I showered in the dark so that I wouldn't have to look at my stomach" (P6);*
>
> *"I kept my pregnancy secret from as many people as I could… My way of dealing with it was to pretend it wasn't happening, for the most part" (P5).*

Support, which came in different forms, helped participants to cope, and enabled them to feel like getting through the pregnancy and birth was *"achievable" (P6).* For some, therapeutic interventions such as "*CBT" (P1)* and *"hypnobirthing" (P4)* were valued. However, most found that therapeutic interventions did not help with managing the fear:

> *"Yeah, to be honest, for me, I didn't find the CBT that useful"* (P7).

Participants wanted to be supported with *"kindness" (P3), "warmth" (P1)* and *"reassurance" (P8),* and wanted someone to bear their distress with them and guide them through the journey:

> *"I felt I could openly speak, there was nothing I was saying to them that they were going "oh my god we can't listen to this" (P6);*
>
> *"There was something else missing of just someone guiding me through it and going, it's going to be fine, this is what's going to happen" (P1).*

Some participants hoped that professionals might be able to "*advocate" (P7)* for them. However, some felt that, despite people's best efforts, they did not always know how to support them:

> *"I think they tried…I think they walked on eggshells – I don't think they knew how to cope, know how to deal with me" (P6).*

For some, the support also came too late:

> *"It would be two to three weeks before your first appointment…. I was like, my due date is five weeks. So, it was absolutely pointless" (P4).*

Part of the process of coping for many participants was **allowing for hope**. Hope was found for some when thinking about the pregnancy and birth being over. Participants allowed themselves to look forward to what the future might bring and there was a shared sense that everything would be OK once the baby had arrived:

> *"I can't wait to not be pregnant…and to just be able to feel a little more normal I suppose. Enjoy the whole parenting as I think perhaps other people do… and not have the worry all the time" (P7);*
>
> *"In my head I thought I can just survive it… Cause I knew it could be OK once she was here" (P6).*

Some were able to enjoy some aspects of the pregnancy, in spite of the fear:

> *"There have been little bits I've enjoyed, like going and buying a few clothes" (P7).*

Running out of time

There was a temporal element to the experiencing of tokophobia: a sense that participants were 'running out of time' – the birth was approaching and there was nothing they could do to prevent it or escape it. One participant captured this when describing her experience:

"I think when you're pregnant it's like a countdown 'til you're going to die…you're on a conveyor belt and this conveyor belt is stopping because this baby is coming, it's time limited isn't it?" (P3).

Phase Z: Appraising

'Finding a way to cope' enabled participants to move into the 'appraising' phase, where they looked back on their experience and considered the impact of the tokophobia. This in turn helped them to make some sense of their experiences.

Surviving and reflecting

Participants described a process of **reflecting on surviving** *"[their] worst nightmare" (P5).* For most of the participants, the birthing experience was a positive and joyous one, which made them reflect on how their expectations had differed from reality:

"I actually had an amazing birth, I had an incredible birth" (P3);

"It was just so positive compared to what I thought it would be like, that I wish I didn't spend all that energy worrying" (P1).

Participants felt a strong sense of achievement and pride in themselves for facing and surviving their biggest fears:

"I was so proud of myself … I was glad I got through it" (P5).

Some described feeling invincible:

"Going through it and facing my fear… afterwards, I thought, I can do anything. I have just conquered my literal biggest fear in life… if I do that, there is nothing I can't do" (P1).

However, participants also went through a process of **assessing the impact** of their experiences with tokophobia. Some felt like they had lost time by *"delaying motherhood" (P4)* and felt a sense of loss related to their experience:

"I felt like my pregnancy had been taken away from me… there was a sense of loss of not being able to enjoy my pregnancy" (P8).

For some the experience put a strain on their relationships:

"It has really damaged our relationship…I find it quite unforgiveable, his lack of support and kindness" (P3).

Participants also considered how their fears might impact on their children:

"My daughter, I'm very scared that I'm going to pass this fear on to her" (P3).

As part of the process of appraising, participants talked about **looking to the future**. There was a strong, shared desire for increased awareness of tokophobia in society:

"There needs to be more awareness, because I'd never even heard of it before" (P2).

Participants felt passionate about changing the narrative around birth to be one that is more positive and more accepting of difference:

"People tell you horror birth stories, and I've never understood why anyone would do that…I just want to share my positive birth story" (P1);

"I think it's a real big misconception that there's only one way [to have a baby] when there are so many different ways" (P8).

For most participants, looking to the future included considering whether or not they would try to have another baby. All participants described how you never *"get over tokophobia" (P4).* Some participants felt sure that, despite surviving the first time, they could not go through the experience again:

"I couldn't live through ….I couldn't do it again "(P3).

Others felt conflicted:

"I keep coming back to it, and I keep thinking… it would be amazing to have a little brother or sister for him, and I'd love to be mum to another little one. But every time I

think about coming off the pill…the nightmares start again...and I'm thinking… I've got through it once. I can get through it again. But I still… can't take that step" (P5).

One participant who had gone on to have another baby explained that *"even on my second birth, the feelings were still there, I could just manage them in a different way" (P8).*

Going through it alone

This category spanned all phases and permeated the whole journey for all participants. They described **feeling alone** in their fear:

"I have never known anything so lonely" (P3).

Participants described **feeling like an outsider,** *"like [being in] a different world" (P3)*, and that there was *"nobody around [them] going through the same thing" (P8).* Participants shared a **desire to be recognised and understood**; many felt as though their fears were dismissed and not taken seriously, and that others did not understand what they were experiencing:

"I was trying to explain to her how I felt and what was going on in my head, and I basically got told, 'Every woman is scared about falling pregnant and becoming a mum. You'll get over it. Don't worry about it'"(P5).

The belief that others would not understand, or would make false assumptions, prevented participants from wanting to talk about their fears, which contributed to the sense of isolation:

"The worst thing about the fear is definitely the feeling that I can't tell other people. Whether that's because they genuinely wouldn't understand or just because I tell myself [they wouldn't]" (P7).

Participants also described feeling a sense of **shame.** Some experienced this shame as silencing, adding to the sense of being alone:

"I never told any of my friends when I was pregnant that I was experiencing what I was…I was so ashamed and so embarrassed" (P3);

"I was ashamed, I thought… why can't I just have a normal pregnancy" (P6).

Many participants felt shamed for not meeting society's expectations of how a pregnant woman should feel and act:

> *"You are expected to be happy…to glow. You are expected to sort of embrace it all and embrace motherhood, and it's all going to be lovely" (P5);*
>
> *"You're just bombarded constantly… if you haven't…delivered naturally you've not really delivered your child; you've not given birth" (P6)*

For some participants, **finding the words** to describe their experience was difficult, which contributed to them feeling misunderstood and silenced:

> *"I think…anxiety… I think that would be the best way to describe it... I still don't know how to explain it properly" (P5).*

Discovering the term 'tokophobia' gave participants a way to explain what they were going through. It also served to normalise their experiences, and reassure them that they were not the only women who felt this way:

> *"you're not going insane and other people feel this way, you're not alone because I felt really alone" (P6).*

Changing fear

Another category that spanned and permeated all phases was 'changing fear'. The fear was experienced as dynamic and fluid:

> *"It seemed to morph and grow. So, you'd sort of deal with one thing and the next thing would creep in, maybe they were just always there and once you dealt with it, it gave room for the other, for the other bits" (P3).*

Participants also described how, along their journey, the closeness to the fear changed:

> *"I think I've always had tokophobia, I don't think I realised it and I think it's sort of less of an issue because it doesn't affect me, I'm not pregnant, I won't get pregnant that's it now….I know it's there, it's up there and it rumbles on" (P3).*

Summary of main findings

The proposed model demonstrates how women fluidly move through a number of processes, and the ways in which these processes are connected. Participants described feeling terror, loneliness, uncertainty and loss. Prior negative experiences and beliefs appeared to play a role in the fear, and the journey involved processing whilst pregnant, and appraisal post-birth. Some of the key themes to emerge were fear of the unknown, seeking control, 'pre'-experiencing of the fear through nightmares and distressing imagery, and using avoidance as a coping strategy. The desire for others to understand their experience, as well as support them through it, emerged strongly.

Discussion

This study aimed to develop a model of women's lived experiences of primary tokophobia. Although each woman's experience is unique, the findings generated a theoretical model which captures the core experiences and how they relate to each other. Existing research has explored women's lived experiences of FOC, but this is the first proposed model to encapsulate and explain relationships between the themes described.

Many of the themes that emerged support findings from existing literature surrounding FOC. Participants described a journey to motherhood that was fraught with terror, loneliness, uncertainty and loss. Wigert et al.'s (2019) metasynthesis reported similar findings, with the main theme emerging as 'being at a point of no return'. Existing literature suggests that a perceived loss of control (e.g. Nilsson & Lundgren, 2009; Roosevelt & Kane Low, 2016) and fearing the unknown (e.g. Fisher, Hauck & Fenwick, 2006; Melender, 2002) are significant factors in the experiences of women with tokophobia; a finding that was echoed in this study. Participants in the current study considered avoidance as their only way to cope, something that was also reported in the existing literature (Nilsson & Lungren, 2009; Eriksson, Jansson & Hamberg, 2006).

The proposed model shares similarities with Iles & Pote's (2015) cognitive model of postnatal posttraumatic stress, including having prior negative experiences and beliefs, processing during the perinatal period, and appraising after the event. Many shared themes emerged including fear of the unknown, seeking control, and relying on maladaptive coping strategies, suggesting that the experiences of women with primary tokophobia are similar to the experiences of women with postnatal posttraumatic stress. Other factors associated with post-traumatic stress also emerged, including persistent re-experiencing in the form of nightmares and distressing imagery, persistent avoidance of stimuli associated with what is feared, negative cognitions, and increased arousal. The findings therefore lead to the proposition that primary tokophobia could be understood through the lens of trauma; as a traumatic stress response to an anticipated trauma. Childbirth can be a traumatic experience, but what makes childbirth different from other traumatic events is that giving birth is expected from when the pregnancy begins. While childbirth has some predictable elements, many aspects remain unknown, which leads some women to perceive the experience as threatening (Söderquist, Wijma, & Wimja, 2004). Early negative or traumatic experiences might make women more vulnerable to perceiving the forthcoming birth as threatening and as something to fear. Despite having never faced the feared object, the upcoming birth might provoke 'pre'traumatic stress symptoms; symptoms that are similar to those experienced following a traumatic event (Wijma, 2003).

These findings support some research that has pointed to the existence of 'pre'traumatic stress in women who fear childbirth (e.g. Söderquist, Wijma, & Wimja, 2004; Goutaudier, Bertoli, Séjourné & Chabrol, 2018). However, this existing research sampled women who may have been experiencing primary or secondary tokophobia. In the current study, by only sampling women who experienced primary tokophobia, the possibility that anticipated trauma

of childbirth could be the result of a potential PTSD related to a previous traumatic birth was removed. It is therefore an important contribution to the literature.

This study strengthened existing findings that support is a significant component of coping with tokophobia (Ramvi & Tangerud, 2011; Salomonsson et al., 2013). Having professionals and loved ones available and willing to listen, empathise, acknowledge distress and try to understand without judgement was important throughout the pregnancy and beyond; something that has been widely reported in the general perinatal mental health literature (e.g. Ford, Roomi, Hugh & van Marwijk, 2019; Iles & Pote, 2015). This could be understood through the concepts of psychological containment (Bion, 1962) and holding (Winnicott, 1945); women are looking for someone who can be present with them through their journey and provide a 'holding environment' that feels safe. This allows them to acknowledge and confront feelings that otherwise are likely to be experienced as overpowering and overwhelming. Feeling held and contained may then allow for reflection and meaning making to occur, as well as hope and a sense of strength to emerge.

Limitations and research implications

Due to the in-depth nature of Grounded Theory analysis and practical constraints of recruitment, the sample of participants in this research was restricted. The sample was not ethnically or socioeconomically diverse; all participants were white, British, middle class women. Results therefore cannot be generalised to all women, as experiences for women from different ethnic and socioeconomic backgrounds are likely to be different. Data were collected until 'theoretical sufficiency' was reached, however, the sample of participants was relatively small. Recruitment bias may have occurred; staff who referred participants are likely to have selected those who seemed most willing and best able to communicate their experiences. Similarly, self-selection bias is likely to have occurred, therefore it cannot be claimed that the findings represent all women who experience primary tokophobia. However, the findings do

offer a tentative model that can be developed; further research with a larger and more diverse sample would enrich and strengthen the findings.

Standardised measures were not used to determine a diagnosis of tokophobia; this is in line with current practice in the UK where clinical judgement is typically used as a measure. It was therefore not possible to determine the extent or severity of the symptoms of tokophobia that each participant was experiencing. It may be that the experience differs depending on the severity of the tokophobia, which could be investigated in future studies if a standardised measure, such as the W-DEQ, is used.

Participants in this study had faced their fear; it would be beneficial to explore the experiences of women who want a baby but have not felt able to try for a baby to investigate the barriers. Participants often referred to their partners, but there is very limited understanding of how fathers make sense of or manage a journey to parenthood alongside tokophobia. Exploration of this may help to inform family-based approaches.

Clinical implications

The tentative model presented provides a representation of the journey that women experiencing primary tokophobia go on in order to become a mother. It provides a holistic frame of reference for services and clinicians to better understand the processes that they go through; something that the women interviewed described as lacking, and as something they felt was vital in order to make their experience less distressing. Some suggestions of how the findings could be implemented are outlined below.

Early intervention. It was identified that women experiencing tokophobia often receive professional support too late in their journey for it to be helpful. This highlights the need for services to recognise and identify women experiencing tokophobia as early as possible, so that appropriate and effective care and support can be put in place. Screening for

tokophobia at initial booking appointments might be a way to do this; a recommendation that has been documented in the existing literature (e.g. Rouhe et al., 2009).

Given the suggestion that primary tokophobia could be understood as a 'pre'traumatic stress response, interventions could be informed by evidenced-based interventions for trauma. For example, trauma-specific psychoeducation and regular telephone tutoring for women at risk for postpartum PTSD has shown some efficacy (Rowe, Sperlich, Cameron, & Seng, 2014). Such prevention-programmes for women showing signs of fear prior to pregnancy might help to reduce the distress they experience and therefore positively impact on maternal antenatal well-being.

Peer support. Participants described their experiences as lonely and isolating. Some were able to access support through online forums, but more personal and containing support could be provided by establishing local peer support networks or employing peer support workers within perinatal services. Research suggests that having access to some form of peer and social support may reduce perceptions of isolation experienced by women during the perinatal period, particularly when the support networks are based upon a shared experience (e.g. Johnson et al., 1993; Fogarty & Kingswell, 2002; Dennis et al., 2009).

Professional input. Women's fears are related to the unknown and the unpredictable. It is therefore important that they are provided with clear, factual, unbiased information that allows them to feel as informed as possible, whilst countering the 'horror stories' that exacerbate the distress. Professionals should remain mindful of the societal stereotypes and expectations placed on pregnant women, and how these can impact on those who don't 'fit' with these. By challenging these stereotypes, they can help women experiencing tokophobia to avoid feelings of inadequacy and embrace being a 'good enough parent' (Winnicott, 1953).

Wherever possible, women should be encouraged and enabled to make their own choices and decisions about the care they receive, fostering a sense of empowerment and

control. Whilst this was a key recommendation in the 'Better Births' report (NHS England, 2016), the findings in this study suggest more work needs to be done to achieve this.

Findings from this study suggest that it is important for women experiencing tokophobia to form trusting professional relationships, and that this can be achieved through having the same professionals involved throughout their journey. Findings also suggest that it is important for women to feel held and contained. Clinical psychologists are well placed to be able to do this, and to provide guidance to other healthcare professionals to be able to do the same. A positive encounter with professionals can be seen as a way to restore a woman's trust in herself in relation to pregnancy and childbirth, which might result in a more positive experience and reduced suffering and distress (Nilsson & Lundgren, 2009).

Conclusion

Limited studies have explored women's experiences of primary tokophobia in the UK. This study provides a tentative model of women's lived experiences and the journey that they embark on to become mothers. The model demonstrates how women fluidly move through a number of processes, and the ways in which these processes are connected. The model shares similarities with models of PTSD, and it is proposed that primary tokophobia could be viewed as a form of 'pre'-traumatic stress. Despite some limitations, a number of valuable clinical implications emerged from this study which, if applied, could shape and improve how services support women experiencing primary tokophobia. Future research would benefit from considering diversity in the experience of tokophobia and explore the experiences of women who feel unable to try for a baby and partners going through this journey.

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Section C: Appendices of supporting material

Appendix A. Quality assessment tool for observational cohort and cross-sectional studies

	Fenwick et al. (2009)	Gourounti et al. (2015)	Hall et al. (2009)	Heimstad et al. (2006)	Jokic-Begic et al. (2014)	Laursen et al. (2007)	Lowe et al. (2000)	Lukasse et al. (2010)	Lukasse et al. (2014)	Melender (2002)
Was the research question or objective in this paper clearly stated?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the study population clearly specified and defined?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the participation rate of eligible persons at least 50%?	No, response rate was 43%	Yes (91%)	Not reported	Yes (54%)	Yes (68%)	No (30%) - however, 50% were not invited to participate due to GP not supporting recruitment	Yes (79%)	Yes (average 50%)	Not reported	Yes (68%)
Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	Yes	Yes, although selection bias likely	Yes, although selection bias likely	Yes, although selection bias likely	Yes, although selection bias likely	Yes, although selection bias likely	Yes (although time period not detailed)	Yes, although selection bias likely	Yes, although slightly different recruitment process between countries	Yes
Was a sample size justification, power description, or variance and effect estimates provided?	Yes (power description)	Yes (power description)	Yes (power description)	No	Yes (power description)	No	No	No	No	No

For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	Yes	No (cross-sectional design)	No (cross-sectional design)	Yes	No (cross-sectional design)	N/A	No (cross-sectional design)	No (cross-sectional design)	No (cross-sectional design)	No (cross-sectional design)
For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Yes (although self-report)	Yes (although self-report)	Yes (although self-report)	Yes (although self-report)	Partially (low reliability in ASI; self-report)	No (single questions used to measure - reliability and validity not considered)	Yes (although self-report)	Yes (although self-report)	Partially (self-report; variables such as abuse measured with single self-report questions)	No (unvalidated questionnaire developed specifically for study)
Was the exposure(s) assessed more than once over time?	Yes	No (cross-sectional)	No (cross-sectional)	N/A	No (cross-sectional)	Yes	No (cross-sectional)	No (cross-sectional)	No (cross-sectional)	No (questionnaire design)
Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participant s?	Yes (information collected from birth records)	Yes (although self-report)	Partly (Sleep measure was unvalidated)	Yes (partly self-report)		No (single question used to measure (validity and reliability not considered)	Yes (although self-report)	Yes (although self-report)	Yes (although self-report)	N/A

Were the outcome assessors blinded to the exposure status of participants?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Was loss to follow- up after baseline 20% or less?	No	N/A	N/A	Not reported	N/A	Yes	N/A	N/A	N/A	N/A
Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Yes (Multivariable logistic regression)	Yes (multiple linear regression analyses used)	Yes (hierarchical regression analysis used)	No	Yes (hierarchical regression analysis used)	Yes (logistic regression model used)	No	Yes (adjusted multiple logistic regression used)	Yes (logistic regression analysis used)	N/A
Additional limitations	**N/A**	Private clinic, only primiparous women so parity as an influence not investigated	Nonresponse bias, order effects, unvalidated measure of sleep	Relatively large non-response rate	Conducted in public healthcare setting; relatively homogenous sample	Different interviewers used; retrospective data used	Limited reporting of analysis	Retrospective reporting of abuse - recall bias	N/A	N/A

	Molgora et al. (2018)	**Nilsson et al. (2012)**	**O-Connell et al. (2019)**	**Pazzagli et al. (2015)**	**Raisanen et al. (2014)**	**Rondung et al. (2018)**	**Ryding et al. (2007)**	**Rouhe et al. (2011)**	**Saisto et al. (1999)**	**Saisto et al. (2001)**
Was the research question or objective in this paper clearly stated?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the study population clearly specified and defined?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Was the participation rate of eligible persons at least 50%?	Not reported	Yes (51%)	Yes (75%)	Not reported	N/A	Yes (80%)	Yes (99% and 89%)	Not reported	Not reported	Yes (70%)
Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	Yes, although selection bias likely	Yes	Yes	Yes, although selection bias likely	Yes	Yes, although selection bias likely	Yes, although selection bias likely	Yes	Yes	Yes
Was a sample size justification, power description, or variance and effect estimates provided?	No	No	No	No	No	No	No	No	Yes (power description)	No
For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	No (cross-sectional design)	N/A	No (cross-sectional design)	Yes	N/A	No (cross-sectional design)	Yes	N/A	No	No (cross-sectional design)
For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participant s?	Yes (although self-report)	No (unvalidated self-report questionnaire developed specifically for study)	Yes (although self-report)	Yes (although self-report)	Yes (ICD-10 codes used)	Yes (although self-report)	Yes (although self-report)	Yes (ICD-10 codes used)	Yes (data retrieved from hospital files)	Partially (low internal consistency on common symptoms measure; self-report)

Was the exposure(s) assessed more than once over time?	No (cross-sectional)	Yes	No (cross-sectional)	N/A	N/A	No (cross-sectional)	Yes	Yes	No	No (cross-sectional)
Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participant s?	Yes (although self-report and short version)	No (FOC measured with unvalidated questions devised for this study)	Yes (although self-report and short version)	Yes (although self-report and short version)	Yes (ICD-10 codes used)	Partially (self-report and moderate alpha co-efficient in measure)	Yes (although self-report)	Yes (ICD-10 codes used)	No (no FOC measure used, determined by researcher interview)	Yes (although self-report)
Were the outcome assessors blinded to the exposure status of participants?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Was loss to follow- up after baseline 20% or less?	N/A	Yes	N/A	No (high drop-out rate)	N/A	N/A	No (high drop-out rate)	N/A	N/A	N/A
Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Yes (stepwise multiple regression used)	Yes (multivariate logistic regression analysis used)	Yes (multinomial logistic regression used)	Yes (multiple regressions used)	Yes (logistic regression analysis used)	N/A	Yes (stepwise regressio n analysis used)	Yes (logistic regressio n analysis used)	Yes (logistic regression analyses used)	Yes (hierarchical regression analyses used)

Additional limitations	Sample reporting stress very high due to definition and timescale of stressful experience being wide	N/A	No power calculation, questionnaires completed only in second trimester	High drop-out rate	ICD-10 codes for FOC limits diagnosed cases to women with severe FOC	Limitations of cluster analysis	N/A	Did not analyse possible traumatic events; some MH problems are not treated with medication so not registered	N/A	Limitations not discussed in paper

	Schwartz et al. (2015)	**Soderquist et al. (2002)**	**Spice et al. (2009)**	**Storksen et al. (2012)**	**Storksen et al. (2013)**	**Toohill et al. (2014)**	**Vitek et al. (2018**	**Zar et al. (2001)**	**Zar et al. (2002)**
Was the research question or objective in this paper clearly stated?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes (hypotheses detailed)	Yes
Was the study population clearly specified and defined?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the participation rate of eligible persons at least 50%?	Yes (61%)	Yes (62%)	Not reported	Yes (70%)	Yes (63%)	Yes (61%)	Not reported	Not reported	Yes (82%)

Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	Yes, although selection bias likely	Yes (although time period not clear)	Yes (although time period not detailed)	Yes	Yes (although selection bias possible)	Yes (although selection bias possible)	Yes (although selection bias possible)	Yes (although time period not detailed)	Partially (year not given; selection bias possible)
Was a sample size justification, power description, or variance and effect estimates provided?	No	No	No	No	No	No	No	No	No
For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	No (cross-sectional design)	Yes	No (cross-sectional design)	No (cross-sectional design)	Yes	No (cross-sectional design)	No	Yes	Yes
For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	N/A	Yes	N/A	N/A	N/A	N/A	Yes (different types of media exposure)	Yes (levels of FOC)	N/A

Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participant s?	Partially (self-report; social support and knowledge scores measured using single item)	Yes (although self-report)	Partially (self-report; ASI social concerns subscale had low internal consistenc y co-efficient)	Yes (although self-report)	Partially (self-report of obstetric complications NRS used to measure overall birth experience - unvalidated, but similar scales have been considered reliable in other studies)	Partially (self-report; CKQ and SPSS measures had low internal consistency co-efficient so amended)	Partially (selected video clips - validated measures not possible)	Yes (although self-report)	Yes (although self-report)
Was the exposure(s) assessed more than once over time?	No (cross-sectional)	No	No (cross-sectional)	No (cross-sectional)	No	No (cross-sectional)	No	Yes (pre- and post-birth)	No
Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participant s?	Yes (although self-report)	Yes (although self-report)	Yes (although self-report)	Yes (although self-report)	Yes (although self-report)	Yes (although self-report)	Partially (self-report; some measures with good internal consistency used)	Yes (although self-report)	Yes (diagnostic interview)
Were the outcome assessors blinded to the exposure status of participants?	N/A	N/A	N/A	N/A	N/A	N/A	Not reported	Not reported	Yes
Was loss to follow- up after baseline 20% or less?	N/A	Yes	N/A	N/A	Yes	N/A	N/A	Yes (20%)	Yes (no drop-out)

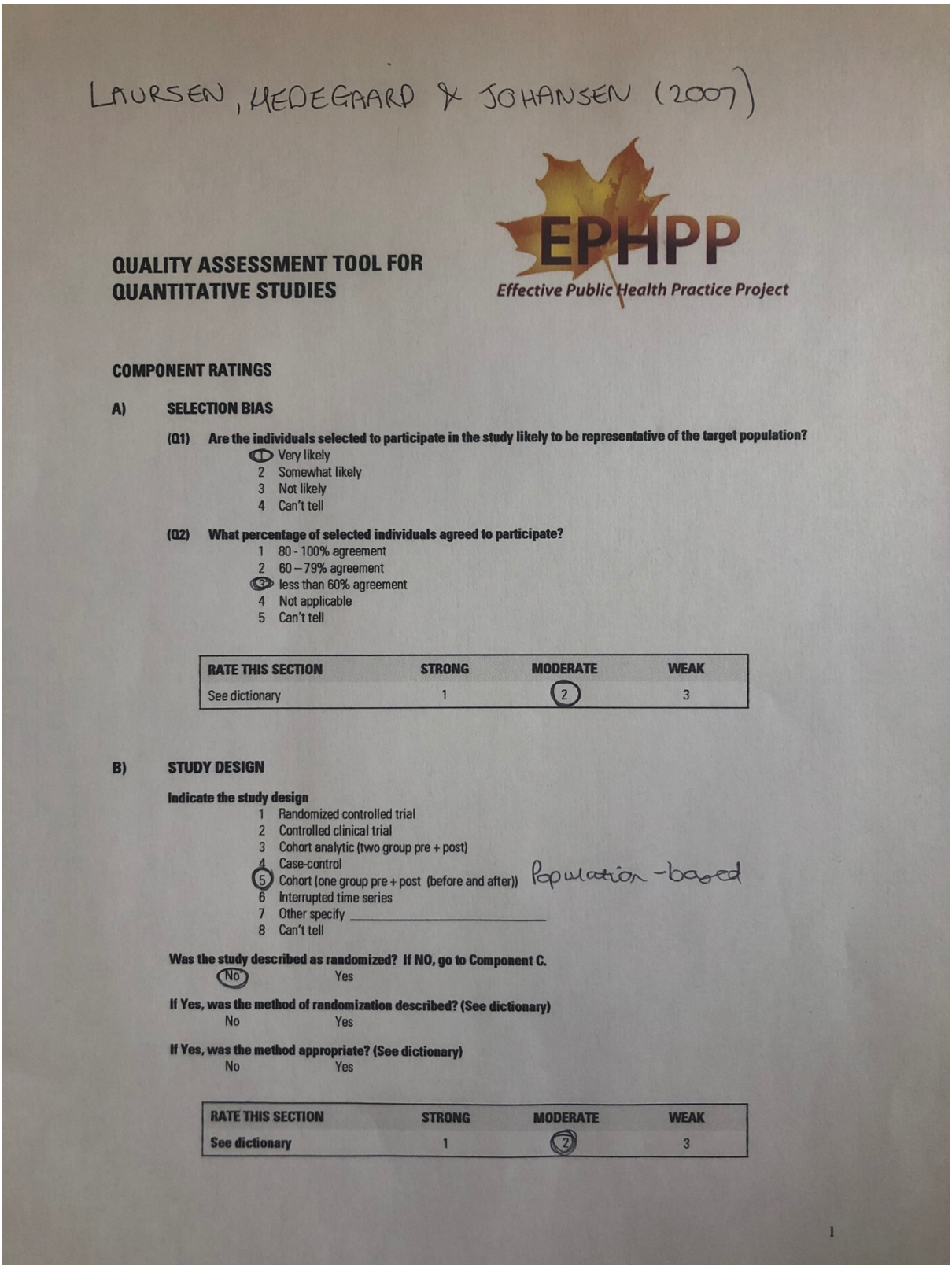
Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Yes (Pearson's r used)	No	Yes (regression analysis used)	No (discussed as a limitation of the paper)	Yes (logistic regression analyses)	Yes (multiple regression used)	Yes (significant factors controlled for in analysis)	No	No
Additional limitations	N/A	Limitations not discussed in paper	N/A	Higher cut-offs than recommended used on SCL-anxiety scale and EPDS measure, to increase specificity	Some data collected retrospectively - possible recall bias/ not all confounding variables considered	N/A	N/A	Ethical considerations not mentioned; limitations not discussed in paper	Limitations of small sample size discussed (i.e. too low for true prevalence rating)

Appendix B. Quality assessment checklist for qualitative research

	Fisher et al. (2006)	**Salomonsson et al. (2013)**
Study Design	Qualitative exploratory descriptive design	Qualitative
Was there a clear statement of aims of the research?	Yes	Yes
Is the qualitative methodology appropriate?	Yes (aimed to explore phenomenon)	Yes
Was the research design appropriate to address the aims of the research?	Yes (third phase of a study; exploratory)	Yes (part of a larger quantitative study)
Was the recruitment strategy appropriate to the aims of the research?	Partially (FOC for participants was subjectively determined)	Yes (although limitations of convenience sampling)
Was the data collected in a way that addressed the research issue?	Yes (telephone interviews asking about the fear)	Yes (semi-structured interviews)
Has the relationship between researcher and participants been adequately considered?	No (role of researchers not critically examined)	No (role of researchers not critically examined)
Have ethical issues been taken into consideration?	Partially (ethics committee approval gained, consent discussed, but debriefing not mentioned)	No (ethics committee approval not mentioned, consent not discussed, debriefing not mentioned)
Was the data analysis sufficiently rigorous?	Partially (analysis described but no mention of research supervision/ cross-validation)	Yes (analysis described in detail; cross-validation discussed)

Is there a clear statement of findings?	Yes (themes identified; quotations used to exemplify)	Yes (themes identified; quotations used to exemplify)
How valuable is the research?	Valuable (findings discussed in relation to current practice and relevant research- based literature)	Valuable (findings discussed in relation to current practice and relevant research-based literature)
Other limitations		Homogenous sample - nulliparous women

Appendix C. Example EPHPP rating



LAURSEN, MEDEGAARD & JOHANSEN (2007)

EPHPP
Effective Public Health Practice Project

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES

COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

(1) Very likely
2 Somewhat likely
3 Not likely
4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

1 80 - 100% agreement
2 60 – 79% agreement
(3) less than 60% agreement
4 Not applicable
5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	(2)	3

B) STUDY DESIGN

Indicate the study design

1 Randomized controlled trial
2 Controlled clinical trial
3 Cohort analytic (two group pre + post)
4 Case-control
(5) Cohort (one group pre + post (before and after)) Population-based
6 Interrupted time series
7 Other specify _____
8 Can't tell

Was the study described as randomized? If NO, go to Component C.

(No) Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	(2)	3

1

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

1 Yes
2 No
(3) Can't tell

The following are examples of confounders:

1 Race
(2) Sex
(3) Marital status/family
(4) Age
(5) SES (income or class)
(6) Education
(7) Health status
8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

(1) 80 – 100% (most)
2 60 – 79% (some)
3 Less than 60% (few or none)
4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	(1)	2	3

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

1 Yes
2 No N/A
3 Can't tell

(Q2) Were the study participants aware of the research question?

1 Yes
(2) No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	(2)	3

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

1 Yes
(2) No
3 Can't tell

(Q2) Were data collection tools shown to be reliable?

1 Yes
(2) No
3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	(3)

2

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

1 Yes
2 No
3 Can't tell
4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell
5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

1 80 -100%
2 60 - 79%
3 less than 60%
4 Can't tell

N/A

(Q2) Was the consistency of the intervention measured?

1 Yes
2 No
3 Can't tell

N/A

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

4 Yes
5 No
6 Can't tell

N/A

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

1 Yes
2 No
3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

1 Yes
2 No
3 Can't tell

N/A

GLOBAL RATING

COMPONENT RATINGS
Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	**SELECTION BIAS**	**STRONG**	**MODERATE**	**WEAK**	
		1	(2)	3	
B	**STUDY DESIGN**	**STRONG**	**MODERATE**	**WEAK**	
		1	(2)	3	
C	**CONFOUNDERS**	**STRONG**	**MODERATE**	**WEAK**	
		(1)	2	3	
D	**BLINDING**	**STRONG**	**MODERATE**	**WEAK**	
		1	(2)	3	
E	**DATA COLLECTION METHOD**	**STRONG**	**MODERATE**	**WEAK**	
		1	2	(3)	
F	**WITHDRAWALS AND DROPOUTS**	**STRONG**	**MODERATE**	**WEAK**	
		(1)	2	3	Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

1	STRONG	(no WEAK ratings)
2	(MODERATE)	(one WEAK rating)
3	WEAK	(two or more WEAK ratings)

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

(No) Yes

If yes, indicate the reason for the discrepancy

1 Oversight
2 Differences in interpretation of criteria
3 Differences in interpretation of study

Final decision of both reviewers (circle one):

1 STRONG
(2) MODERATE ✓
3 WEAK

Appendix D. Participant information sheet

An exploration of women's lived experiences of primary tokophobia

Information about the research

Hello. My name is Michelle Clark and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

Please feel free to talk to others about the study if you wish. Part 1 of this information sheet tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of this research?

I am conducting this research project as part of my doctorate, under the supervision of Professor Margie Callanan and Dr Kate Alexander. The purpose of this research is to explore the experiences of women who have primary tokophobia. The term 'tokophobia' was identified as a medical condition and used for the first time in 2000 to define an intense state of anxiety which leads some women to fear, and consequently to avoid, pregnancy and childbirth despite desperately wanting a baby. Primary tokophobia refers to when women who have not been pregnant before experience this intense fear of childbirth. We hope to gain a better understanding of how women make sense of their experiences, and how they manage their fear of childbirth. We hope that by hearing women's stories, we can shape and improve future research and clinical interventions for women experiencing childbirth-fear.

Why have I been invited?

You have been invited because you are someone who has been identified as having experienced primary tokophobia. Therefore, your view point will be greatly valued to help understand the process how this fear develops, and how people cope.

Do I have to take part?

No, if you would prefer not to take part, you do not have to. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?

If you agree to take part, you will be asked to sign a consent form. You will be given the option of taking part whilst pregnant, or after you have had your baby, or both. You will be invited to an interview where you will be asked to talk about your experiences of childbirth-fear. The interview will last approximately 30 minutes – 2 hours, at a time which is convenient for you. The discussion will be audio recorded so that all information is captured in your own words. These recordings will remain confidential and will be stored on a password-protected computer. The information gathered will be typed up, taking care to remove any personal information so that it remains anonymous, that is making sure that anything that identifies you will be taken out. Following this, the audio recording will be deleted. You will later be invited to have a telephone conversation to talk about the findings from the discussions. Any feedback you provide will be used to inform the final analysis. If English is not your first language, you will be asked if you would like an interpreter to join you for the interview.

Expenses and payments

We will not be able to reimburse you for any travel expenses, however you will be given a £10 shopping voucher for taking part in the research. This is our way of saying "thank-you" for participating in the research.

What are the possible risks and benefits of taking part?

I will ask you about your experiences of childbirth-fear. There is a chance that talking about this sensitive and emotional topic may elicit some feelings. However, you will not be expected to talk about anything you do not want to talk about. If you are feeling upset or uncomfortable, you can stop the interview at any time. If there are any concerns during or after the interviews, there will be professionals available to speak with you and to consider further support services. The benefit of taking part is that you will be contributing to research that aims to better understand women's experiences of intense fear of childbirth. You may also gain personal benefit from discussing your journey with another person. Whilst we cannot promise the study

will help you in this way, the information we get from this study will help improve perinatal care for women experiencing childbirth-fear.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

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

Part 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time, without giving a reason. You will be asked whether any information gathered from you up to that point can still be used in the study; you may, of course, wish to say no to this, and that will be fine.

Complaints

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me (Michelle Clark) and I will get back to you as soon as possible. If you are still unhappy and wish to complain formally, you can do this by contacting Dr. Fergal Jones, Research Director, Salomons Institute for Applied Psychology, Canterbury Christ Church University fergal.jones@canterbury.ac.uk.

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 Canterbury Christ Church University, but you may have to pay your legal costs.

Will information from or about me from taking part in the study be kept confidential?

Yes: taking part in the study, and the data collected from you will be kept confidential. Only Michelle Clark and her supervisors (Dr Kate Alexander and Prof. Margie Callanan) will have access to your anonymised audio recording and the anonymised transcript. The audio recording will be deleted as soon as it has been transcribed. Until then, it will be stored securely on an encrypted USB, that is a memory stick with very strong password protection, then a secure server. After completion of the study, data collected from you will be kept on a password protected CD and stored at the Salomons Centre for Applied Psychology in a locked cabinet for 10 years, then destroyed.

As previously mentioned, if you require the support of an interpreter, they will sign a consent form adhering to the confidentiality agreement.

The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were to become concerned about your safety or the safety of someone else.

What will happen to the results of the research study?

The initial results of the study will be written up. I will then contact you to invite you to discuss the findings and provide comments and feedback. The final results of the study will be written up into a report, and then published on the University's web site, and also, hopefully, in professional journals. The report will include anonymised quotes from the interviews. No one will be able to identify you in the write up of the report and you are welcome to receive a copy of the final report. A brief summary of the report will be written and available for interested participants.

Who is organising and funding the research?

Salomons Centre for Applied Psychology, Canterbury Christ Church University are supporting the organisation and funding of the research.

Who has reviewed the study?

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 HRA Research Ethics Committee.

What happens if you would like more information about the study?

You will be able to contact me, or my supervisor, to discuss the study during its duration. If you would like to ask any questions or receive more information about the study then please contact one of us on 01227 927070. You can leave a message for me on this 24 hour voicemail phone line. Please say that the message is for me (Michelle Clark) and leave a contact number so that I can get back to you.

Researcher

Michelle Clark
Salomons Centre for Applied Psychology
Canterbury Christ Church University
1 Meadow Road
Tunbridge Wells
Kent
TN1 2YG
Tel: 01227927073

Lead Supervisor

Prof. Margie Callanan
Salomons Centre for Applied Psychology
Canterbury Christ Church University
1 Meadow Road
Tunbridge Wells
Kent
TN1 2YG
Tel: 01227927073

PALS - Independent Contact

Patient Advice and Liaison Service

Swandean

Arundel Road

Worthing

West Sussex

BN13 3EP

Tel: 0300 304 2198

Thank you for taking the time to consider participating in this research. Please do not hesitate to contact us if you have any questions.

Appendix E. Participant consent form

Participant consent form

Participant Identification Number: _____

Title of Project: An exploration of women's lived experiences of primary tokophobia

Name of researcher: Michelle Clark

1. I confirm that I have read and understood the information sheet dated _____ for the above study. I have had the opportunity to ask the researcher questions and have had these answered satisfactorily. ☐

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

3. I agree to take part in an interview, as explained in the information sheet. ☐

4. I agree for my interview to be audio recorded and understand the recording will be destroyed as soon as the interview is typed up. ☐

5. I agree that the anonymised findings (including quotes) from this study will be published as a doctoral thesis and possibly published in a research journal. ☐

6. I consent for my pseudonymised interview transcript to be shared with the study supervisors. ☐

7. I understand that if I make a disclosure of risk to myself or others, information may need to be shared with appropriate services. ☐

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

9. I would like to receive a copy of the summary of findings of the research. ☐

Name of participant	**Date**	**Signature**
Name of person taking consent	**Date**	**Signature**

Appendix F. Recruitment poster

Are you currently pregnant and experiencing primary tokophobia (intense fear of childbirth)?

OR

Have you experienced primary tokophobia and had a baby in the last 5 years?

Researchers at Canterbury Christ University are conducting a research study exploring **women's lived experiences of primary tokophobia.**

If the answer to either of the questions above is **YES**, you are **aged 18+**, and you would like to **share your experiences**, you may be eligible to take part in the study. Participation would involve a researcher asking you questions about your experiences of tokophobia, and how you make sense of it. This interview would last 30 minutes to 2 hours, and interviews could be conducted at home or via SKYPE if convenient for you.

If you take part, as a thank you for your time, you will receive a £10 shopping voucher.

If you would like to take part, simply **email** **m.m.clark754@canterbury.ac.uk** with your **name** and **contact number**. You will then receive a call to discuss the study and arrange a time for the interview to take place.

Appendix G. Initial interview guide

- Introduce researcher
- Outline research and ask if there are any questions after reading the information sheet
- Inform participant about limits of confidentiality
- Go through consent form

Questions about development of fears

Can you recall when you first became aware of your worries and fear of childbirth?

Was there a specific event/incident?

Do any images come to mind when you think about your fear of childbirth?

Were/are there people around you who experienced a similar fear?

What are/were your thoughts? How did you feel?

What maintained/maintains the fear (are there things you avoid)?

Did you google or social media anything that impacted on your worries?

Questions about making sense of the fear

What does your fear of childbirth mean to you?

What is the worst aspect of the fear?

How have you made sense of it?

What ideas/thoughts have you seen reflected in social media/magazines etc.? What messages do you think they give to women about birth?

What are the consequences for you?

How does it feel to be told you have 'tokophobia'?

How did the health care professionals you talked to respond? Were they helpful/not helpful in making sense of what you are/were experiencing?

What was your understanding of tokophobia prior to accessing services?

How have your loved ones/ people around you reacted when you've told them about your fear (if you have)?

How do you make sense of women who do and don't experience the same fears that you do?

How do you think your fear of childbirth has impacted on you as a person/on your role as a mother/mother-to be?

Does your anxiety relate to any previous sense of being unsafe in the world, or anxiety about your body?

Questions about managing/coping

Is there anything that you feel helped you to relieve/minimise the fear? How sustainable has this been/was this?

When you have difficult feelings or worries related to your fear, what do you do?

What do you think might have helped you cope more effectively?

What do you hope/wish for in the future?

Is there anything else you would like to tell me that I have not asked about?

General prompts

- Can you tell me more about that?
- What do you mean by that?
- What makes that feel important?
- What are your thoughts/feelings about that?

End of interview

- Thank participant for their time and contribution
- Debrief participant and provide information about support services
- Inform participant abut next stages of the research

Appendix H. Final interview guide

- Introduce researcher
- Outline research and ask if there are any questions after reading the information sheet
- Inform participant about limits of confidentiality
- Go through consent form

Questions about development of fears

Can you recall when you first became aware of your worries and fear of childbirth?

Do any images come to mind when you think about your fear of childbirth?

Were/are there people around you who experienced a similar fear?

What maintained/maintains the fear (are there things you avoid)?

Are there different stages to the fear? e.g. what is the fear related to? Getting pregnant, being pregnant, birth?

Did you google or social media anything that impacted on your worries?

Questions about making sense of the fear

What is the worst aspect of the fear?

How have you made sense of the fear?

What ideas/thoughts have you seen reflected in social media/magazines etc.? What messages do you think they give to women about birth?

What do you think society's expectations are for pregnant women?

How does it feel to be told you have 'tokophobia'?

How did the health care professionals you talked to respond? Were they helpful/not helpful in making sense of what you are/were experiencing?

What was your understanding of tokophobia prior to accessing services?

What kind of psychological input did you receive?

How do you think others perceive your fear?

How do you think your fear of childbirth has impacted on you as a person/on your role as a mother/mother-to be?

What enabled you to have another baby? (if applicable)

Does your anxiety relate to any previous sense of being unsafe in the world, or anxiety about your body?

What are the consequences of the tokophobia for you?

Do you feel a sense of loss in relation to the tokophobia?

How has the fear changed over time?

Questions about managing/coping

What enabled you to cope?

Is there anything that you feel helped you to relieve/minimise the fear? How sustainable has this been/was this?

What do you think might have helped you cope more effectively?

What do you hope/wish for in the future?

Is there anything else you would like to tell me that I have not asked about?

General prompts

- Can you tell me more about that?
- What do you mean by that?
- What makes that feel important?
- What are your thoughts/feelings about that?

End of interview

- Thank participant for their time and contribution
- Debrief participant and provide information about support services
- Inform participant abut next stages of the research

Appendix I. Example memos

Example memos are presented below. They demonstrate the process of code refinement, exploration of relationships between categories, and theory development.

Memo 1

This memo captured initial ideas about the relationships between fear of the unknown, control and trust.

A recurring theme that is emerging is the link between tokophobia and a fear of the unknown. The whole process is a terrifying unknown (e.g. what will it feel like when baby kicks? How will my body change? Will I change my mind and it will be too late? How will I get the baby out?) These thoughts seem to always be there; there is no escape from them. And there is no way to becoming 'knowing' other than to face the fear. Not being able to prepare for the unknown removes any sense of being in control -

"it was like standing on the edge of a black hole, and you didn't know what was in there, and somebody was trying to push me in. And I couldn't explain what it was exactly I was afraid of, because I didn't know what was going to happen, what it was going to feel like, or anything, but it was that. It was just a big black hole of terror that was stood right in front of me that I was trying to be pushed into. It was awful."

For one participant, secrets harboured about medical procedures when she was a child made her feel as though there was something terrible to fear. If not, why was she not told about it? There was also a sense of not being able to escape as a child – having no choice or control over what was going to happen, which was then reflected in her experience of pregnancy.

Feeling uninformed breeds fear and destroys trust – *"Nobody told me what was happening"*

Not knowing leads participants to imagine the worst care scenario, creating images that are hugely distressing.

Memo 2

As interviewing and coding continued, the memo above was further developed, eventually leading to the concept of an 'experiencing' phase.

The sense of terror is palpable. The terror feels so intense and all-consuming that they become lost in it; it takes over their lives and the sole focus becomes surviving. For some, surviving

feels unlikely; there is a genuine belief that they will die. The fear changes them – who am I? This is not me - *"I am normally a rational person".*

An image that keeps coming to mind is being trapped at the bottom on a dark pit – it is terrifying, lonely and it feels like there is no way out. Nobody can reach them, leading to a loss of connection from the world, their baby, and themselves. Participants talk about feeling segregated, unable to share how they feel with loved ones, unable to engage with the pregnancy, unable to bond with their baby, despite desperately wanting to feel the love and excitement that others do. The connection is missing, but they continue to go through the motions anyway, because what other choice do they have? All joy and excitement is stolen from their experience, only to be restored after birth. Life and love is on hold.

The experience of terror seems to be strongly linked with a sense of losing control – it feels like there is no control over the terror which has taken over their lives, and the sense of being out of control adds to the terror. A reinforcing cycle? There is also no control over time – they are counting down to facing their biggest fears.

It seems like a process or phase is occurring – going through it? Experiencing the fear at its worst? Something that captures this time in their lives when they are taken over by the terror.

Memo 3

This memo captured thoughts about the functions of avoiding and hiding, and the relationship with coping.

Participants talk about avoiding things that are a reminder of pregnancy. They talk about not wanting to see their bump, other women's bumps, baby clothes etc. They talk about keeping busy as a way of avoiding thinking about the pregnancy and pending birth. They also want to avoid talking about it – they avoid family gatherings, places where they might be asked about the pregnancy. There is a sense that talking about it and seeing it makes it real. The only way to cope and survive is to not acknowledge it and pretend it is not happening; "*bury my head in the sand"*. I picture them holding their breaths and closing their eyes until it's over -

"You don't get past it. You grit your teeth and you live through. That's all you can do. That's all I could do."

I wonder if they're scared of what might happen if they allow themselves to confront the thoughts/feelings?

Linked to avoiding, participants talk about hiding. There's a sense of wanting to be invisible, to disappear until the pregnancy is over. Unwanted attention that comes with pregnancy, such

as touching the bump, heightens their awareness when all they want to do is hide from it. It also allows them to take back some control that they feel they have lost, i.e. they decide to whom and when they disclose their pregnancy or fears -

"It is also a way for me to feel some control – I decide what to disclose and how the conversation goes."

Some participants talk about shame, and how hiding serves as a defence against judgement, both from others and themselves -

"Hiding also helps me to defend from anticipated judgement. If people don't know what I am thinking and feeling, they can't judge me. If I don't acknowledge how I am feeling and instead 'bury me head in the sand', I can also avoid the shame and judgement I have for myself."

Avoiding and hiding keeps the fear at bay to an extent but prevents them from being able to talk about it or share how they are feeling. They lock their thoughts and feelings away, distancing themselves from others, which only compounds the experience of loneliness and isolation. So although it feels like the only way to cope, it probably makes the experience worse.

Memo 4

This memo related to the idea that there was a process of moving closer or further away from the fear over time. It also led to the development of the core category.

The fear seems to change, coming in and out of focus, depending on the stage of the journey. The fear is described as a "*monster"* that lives within. It can be tamed and ignored until the time comes to face up to it. Then it takes over everything and can only be tamed again once the baby is out. The monster never leaves, it morphs and changes (there are layers to the fear; peel back one and another emerges), then lies dormant under the surface. There is a sense of having to survive it, then adjust to the fact that the monster will never leave completely – learning to live with it. This idea of 'living with a monster' seems to capture how the experience is being described.

The fear is *"deep rooted"* – despite surviving it one time, participants talk about being sure they cannot do it again as the fear would re-emerge (the monster would come out of hibernation?) Is it harder to find the strength to face the monster a second time?

Appendix J. Example coded transcripts

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Appendix K. Categories, subcategories, focused codes and example quotations

Categories	Sub-categories	Focused codes	Example quotations
Making sense	Trying to make sense	Understanding tokophobia as a fear of pain Understanding tokophobia as a fear of inevitable death Understanding tokophobia as a fear of losing control Linking tokophobia to a fear of something taking over my body Understanding tokophobia in stages Difficulty making sense of the fear Struggling to understand why this happened to me Rationalising my fears as being legitimate (birth is dangerous) Wanting to prove my fears are legitimate Believing that my feelings are reasonable	"There's the fear of getting pregnant, there's the fear of being pregnant and then there's the fear of the delivery" (P4) "I understand why I was scared, so in that way, I've made sense of it" (P1) "I don't really know what I felt like, you know? It's hard to know what my real feelings were and why" (P2) "I don't think… I kind of got my head around it in the slightest" (P6)
	Prior traumatic and negative experiences	Linking fear with traumatic medical experiences Linking fear to vicarious exposure to negative birth experiences Linking fear with experiences of loss Experiencing other phobias as a result of prior negative experiences Experiencing other anxieties	"I've never been able to ascertain like a particular reason" (P7) "well is it irrational to be scared of something that does harm people? I don't know. It is the only way I could try to make sense of it" (P7)
	Being at fault	Blaming myself Having something lacking in me Feeling like a failure Feeling inadequate Feeling like a bad mother	"Everyone loves to share a bad story, don't they? Everyone loves to share the extreme, the worst-case scenario" (P7) "just learning about mum's really difficult birth and afterwards" (P1)

		Something being wrong with me Understanding tokophobia as being part of me	"I was very aware that my mum had got a side effect of my delivery" (P4) "My mum went into premature labour with my sister at home when I was five years old and it was just me and her at home and still it just, I just remember seeing her in pain" (P6) "So I had major surgery when I was five years old… So during this time, I felt the staff were horrible to me. You could call it abuse" (P2) "When you're lying in the theatre….you realise your granny died on the floor below" (P4) "I can have very happy feelings about being a mum and having a baby, but I'm not happy about being pregnant" (P7) "I think it's always been there, always been terrified of hospitals, needles, nurses, interventions, any kind of physical sort of thing" (P3) "I have a needle phobia…which I have always been aware of, since this surgery. I just didn't realise the rest of the implications of it, and other things I've had, I didn't realise the whole thing was all linked." (P2) "Quite a few things came up with other anxiety areas for me, and they said, it sounds like you have

			quite a lot of anxieties, childbirth being obviously a big one… I just had quite a lot of anxiety in my life" (P1) "I suppose it is making sense of it in a way, that tokophobia is who I am, part of who I am" (P3) "I'm like, a tokophobic" (P4)
Facing the fear	Becoming aware	Knowing I want a baby, but feeling paralysed Being aware of fear from a young age Being able to ignore the fear when not pregnant Pregnancy bringing the fear into focus Awareness of fear developing after becoming pregnant Becoming aware of the extent of the fear Being surprised by the extent of the fear	"I knew I wanted kids, definitely, but how do I do this, because it's terrifying?" (P1) "I became pregnant and it never fully hit me - I was fourteen weeks pregnant and I was honestly OK up until then… I felt a flutter in my stomach and that is when I just completely, like, lost the plot and that's when my fear kicked….my fear went into overdrive" (P6)
	Taking on the fear	Trying to become pregnant Coming to terms with being pregnant Feeling under pressure to face the fear Making the decision to tackle the fear Feeling time pressured to have a baby Knowing I want a baby giving me the strength to face the fear Questioning whether I can continue with pregnancy	"I think I realised it was a serious problem…when I got the positive pregnancy test and the realisation that I was going to have to somehow go into a hospital and be touched and have treatments "(P3) "I'd always dreaded the thought of it, even before I thought about starting a family. But because it wasn't a reality at that point, I never let it… I've never given it a huge amount of thought" (P8) "And then as I got older, it became more-I don't know, more like relevant to my life I suppose. Which then made it feel bigger" (P7)

			"I wanted to have a termination - that's what my head was telling me at fourteen weeks - when I knew that - I can't go on" (P6) "Was I going to be able to go through this? What was I going to do? I considered crashing my car into a tree, with the aim of obviously maiming myself so badly that I lose the baby. And the sane part of me now thinks about what I was doing and what I was thinking about at the time and going, that's just – and if anybody else told me that, I would be horrified, absolutely horrified, but at the time, that felt like an option" (P5)
Becoming lost in the terror	Experiencing terror Fear being reinforced 'Pre'-experiencing Being consumed by the terror	Feeling terrified Feeling petrified Terror being visible Being in a constant state of panic Media portrayals of birth reinforcing the terror Information on internet reinforcing the fear Exposure to pregnancy and birth reinforcing the fear Imagining unbearable pain Imagining extreme blood loss during birth Imagery of cold medical settings Recurring nightmares related to fear All-consuming nature of the fear Unrelenting nature of the fear Feeling paralysed by fear	"It was like standing on the edge of a black hole, and you didn't know what was in there, and somebody was trying to push me in. And I couldn't explain what it was exactly I was afraid of, because I didn't know what was going to happen, what it was going to feel like, or anything, but it was that. It was just a big black hole of terror that was stood right in front of me that I was trying to be pushed into" (P3) "I was vibrating with fear and they said they'd never seen anything like it" (P4) "you could see the terror in my face, it's so real" (P6)

		Living with the ever-present fear Feeling trapped Feeling stuck Focusing only on surviving the pregnancy Being aware that the fear is always on my mind Struggling to see a way to overcome the fear Fear feeling enormous Fear taking over my life Fear taking over my thoughts and actions Fear getting in the way of my happiness Fear limiting me Living with belief that death is imminent Making preparations for my death Feeling unable to plan/prepare for the future Unable to see a future Feeling unable to function Putting my life on hold Feeling helpless Feeling desperate to escape Experiencing psychosomatic symptoms Feeling like I will never be happy again Having panic attacks Fear being overwhelming	"I literally this morning was on Facebook…her….partner was talking about the birth of their little girl. And what a blood bath it was and how horrific it was and that was just the headline"(P3) "They didn't see on my notes again that I'd got tokophobia and they left me near a delivery suite window and I could heard delivery suite, and to me, it just sounded like kittens being killed. It was just the most horrific sound on earth" (P4) "I remember having nightmares before I was pregnant just like, um, a fear I was suddenly pregnant and this thing was growing in me and it had to come out and all of a sudden it was bursting out you know you know - no pain relief, nothing like that" (P6) "I still was scared of the image of lying on this bed…not knowing what is happening, fear, lights, the atmosphere, everything being quite medical and surgeons everywhere. I'd say mainly that room I would get scared of" (P1)
	Feeling like a different person	Questioning who I am Feeling "alien" Wanting to return to my "old self" Feeling changed as a person Losing myself Becoming unrecognisable Becoming a different person Wanting to "just be me"	"Every day, every night is a struggle" (P2) "It was a paralysing fear, everything in my life ground to a halt and the only thing I could focus on was, I'm never going to get this baby out, we're both going to die. Everything else fell by the wayside" (P3)

	Loss of connection	Wanting to feel connected with my baby Wanting to connect through a shared experience Feeling distant from others Feeling isolated Feeling segregated Feeling disconnected from my baby Missing an emotional connection Feeling unable to engage with the pregnancy Fear affecting my ability to bond	"I just had this impending sort of doom and I just yeah just couldn't cope on any level, I just, I couldn't eat, I couldn't sleep, I couldn't think, I couldn't do anything" (P6) "It was always, always there" (P5) "It just felt like anxiety rather than any kind of celebration about being pregnant" (P8) "like living with a monster.....it obscures it all"(P3) "you're stranded and you can't get away, I kept thinking that I could run now. I could run. No, you can't fucking run anywhere" (P4) "I think when you're pregnant it's like a countdown till you're going to die, like I genuinely believed my baby and I weren't going to survive this. To the point that I wrapped up all my finances, I put my life in order because I thought we were going to die and yet it's the furthest thing from what you want to do" (P3) "I usually consider myself quite a logical, straightforward person, and sort of the 12 months that we were trying and then that I was actually pregnant for, I don't know who I was. I don't recognise myself then. Just a different person" (P5)

			"Losing who you are, so you become so unrecognisable" (P3) "I feel completely changed by it – I don't know if I've changed because I'm a mother now but I just definitely don't feel how I did - I feel vulnerable by it" (P6) "Tokophobia is a total lack of connection, definitely was my experience… every night I would sit and read my baby a poem… not because I wanted to, but I thought I better do this…. It was very mechanical… I did it but there was no love or excitement or that's not the right word love isn't the right word, but there was no connection" (P3) "my mind wouldn't let me think of it as a little baby it was just this alien inside of me and it just disgusted me" (P6) "I guess that's it's isolating, and you feel like the only person in the world that feels like this"(P2) "I was always around friends and then I became completely housebound…I didn't want to see anybody so I was coping with it on my own" (P6) "The worst aspects were probably the effect that it had on my relationship at the time. My other half…I couldn't explain to him how I was feeling, and I couldn't explain why I felt that way" (P5)

			"The only real connection I had with anybody else going through it was the one online Facebook group" (P8)
Losing control	Control	Losing control Fearing being out of control Being unable to guarantee that things won't go wrong Feeling controlled by the fear Wanting to know what I can and cannot control Wanting to be able to choose what happens to me Wanting to be involved with planning my care Having ability to choose taken away Not trusting that I am in control of my own decisions Having elective caesarean helping me to feel in control	"I cannot cope with the idea of going through it, the pain is the biggest fear, the loss of control, what if the same thing happened to me that happened to mum, we can't guarantee that wouldn't happen" (P1) "the worst aspect was the thought of losing control. It was around dignity hugely, and the thought of not having a choice" (P8) "I just want to know what I do and don't have control over there. And I fully appreciate there are some things you just can't control, and that's okay, but I need to know what those things are and then what do I have a choice over and what choices can I make to feel more in control. And definitely having a sense of control is what makes the difference" (P2)
	Fearing the unknown	Fearing the unknown Fearing the unpredictable Wanting things to feel familiar Wanting to avoid any surprises Wanting certainty in a situation that is full of uncertainty Anticipating what each stage might feel like Wanting to feel fully informed Wanting to feel as prepared as possible Knowing everything can make it worse	"when I found out about the planned c-section…that's probably the best thing for me, when I was so worried and wanted something controlled" (P1)
	Having to trust	Trusting professionals being difficult based on previous experiences Professionals getting things wrong Professionals having to earn my trust	"I just remember my midwife suggesting it even before I did, and the second that her and the consultant turned around and said, we think that having an elective section is going to be the best thing for your health, the second they said it, I just

		Feeling let down by services Developing trust with professionals helping with the fear Having to trust and rely on others Fearing that professionals will not stick to their word Continuity of care allowing trust to develop Having trust allowing me to feel safe	remember this feeling of thank god. Something I can plan for, that's not unpredictable, is going to happen" (P8) "It was just this huge unknown thing where I just didn't understand how I could just have the baby" (P1)
	Relationship with their bodies	Feeling repulsed by changes in my body Feeling disgusted by changes in my body Worrying about being physically exposed Not wanting to be touched Wanting to maintain my dignity Feeling like a prisoner in my own body Feeling like my body is being used Hating feeling the baby move Avoiding thinking about my tummy getting bigger Feeling like my body is being taken over by something 'alien' Losing control of my body Having no choice over what happens to my body Pregnancy changing the rules about who has access to my body	"the thing about the fear it's the unknown, isn't it. For me it's what's it going to be like when it starts moving, what's it going to be like when it kicks, and I can't stand it" (P6) "they informed me when they were about to do it. They informed me when it was done. They told me, like, 'You've been covered again. You're fine.' Again, I can't feel that, but I needed to know" (P2) "I wanted to know as much information as possible so I don't have any surprises" (P2) "I like to know about things which then makes it worse… the things I find out aren't necessarily helpful" (P7) "Not trusting medical staff [maintained the fear]….everyone has to tell me what they're going to do before they're allowed to touch me" (P2) "Having a midwife I trust it was really helpful. Continuity of care is massive" (P2)

			"She was with me the entire journey, which was one of the things I really struggled with was trust. Trusting a professional was a big thing for me" (P3) "It wasn't just around the childbirth. It wasn't just around the end result with me. A lot of it was to do with how my body was going to change" (P8) "I didn't like to be touched, to being naked, having to get my skin out it's just things that I would never ever, ever have done" (P3) "I think one of my biggest fears throughout the whole thing was the fact that actually, I would have to take my underwear off to have the baby, and that just built up and built up….for me it felt as strongly as, it was almost like actual assault in a way. I felt I didn't have an option" (P8)
Finding a way to cope	Avoiding and hiding	Avoiding baby imagery Avoiding negative birth stories Avoiding looking at my bump Avoiding being around pregnant women Hiding my fears from others Keeping my pregnancy a secret for as long as possible Pretending to myself that it is not happening Distancing myself allowing me to hide Allowing myself to think about the fear making it worse Avoiding as a means of protection	"I stopped watching a lot of TV because all of a sudden, everyone on TV seemed to be pregnant, and I couldn't watch that "(P5) "I couldn't be around anyone who was pregnant, I couldn't look at anybody with a pregnant belly. I didn't want to be around anybody at these antenatal classes or whatever. I couldn't do any of that – to Me it was just to me out of sight out of mind" (P6) "I avoided dealing with being pregnant by thinking I wasn't pregnant – telling myself I wasn't

		Blocking out my fears Keeping myself distracted to avoid the fear Coping by staying in the moment	pregnant. I showered in the dark so that I wouldn't have to look at my stomach" (P6)
	Support	Valuing support Crediting professionals for enabling me and my baby to survive Wanting to be shown warmth Valuing being treated with kindness Support enabling me to cope Feeling lucky to receive professional support Other's wanting to help, but not knowing how to Valuing continuity of care Professionals going above and beyond to help me Support making the process feel achievable Having someone who can bear my distress with me Having a negative experience with CBT Finding hypnobirthing helpful Feeling like someone has 'got my back' Feeling unsupported Searching for reassurance that I will be OK Feeling reassured hearing similar experiences Wanting someone to advocate for me Wanting someone to guide me through this process Taking comfort from fears being normalised Support coming too late	"I've always avoided the baby aisle in the supermarket. Just didn't really think about it, just didn't do it and then don't go there, just pick a different aisle. Don't want to look at the baby products and stuff. And it was only when someone else said that they did the same thing I thought, 'Oh, maybe it's a tokophobia thing. Maybe that's why'" (P2) "It almost felt like I wanted to hide. So, I didn't particularly want to announce the pregnancy" (P8) "I had to sleep, I had to go to bed, I just didn't want to speak - I just went under the covers" (P6) "I kept my pregnancy secret from as many people as I could anyway. My way of dealing with it was to pretend it wasn't happening, for the most part" (P5) "Yes, so the CBT wasn't as such for the fear of the birth, but it did help I think, generally, contributing towards everything as a whole" (P1)
	Allowing for hope	Allowing myself to hope Allowing myself to think about the future Knowing I will be OK once baby arrived Looking forward to becoming a mother Feeling love for my baby	"Yeah, to be honest, for me, I didn't find the CBT that useful" (P7)

		Enjoying some aspects	"There was something else missing of just someone guiding me through it and going, it's going to be fine, this is what's going to happen" (P1) "I felt I could openly speak, there was nothing I was saying to them that they were going "oh my god we can't listen to this" (P6) "I feel she will, I suppose, advocate for me a little bit if she knows what I would like" (P7) "I think they tried…I think they walked on eggshells – I don't think they knew how to – I don't think they knew how to cope, know how to deal with me" (P6) "I can't wait to not be pregnant, I can't wait for this bit to be finished and to just be able to feel a little more normal I suppose. Enjoy the whole parenting as I think perhaps other people do. Yeah. Just to be able to enjoy it and not have the worry all the time" (P7) "In my head I thought I can just survive it. You know if I can just do what I need to get through it and get a section. Cause I knew it could be OK once she was here" (P6) "There have been little bits I've enjoyed, like going and buying a few clothes" (P7)

Running out of time	N/A	Running out of time Feeling time pressured Travelling on a conveyor belt towards the inevitable Counting down to baby having to come out Not having enough time to get over my fear Reaching milestones bringing me closer to the end	"I think when you're pregnant it's like a countdown 'til you're going to die…. the furthest thing from what you want to do. It's not like feeling suicidal, it's this terrifying fear that something, you're on a conveyor belt and this conveyor belt is stopping because this baby is coming, it's time limited isn't it?" (P3) "I call it a ticking tok" (P4)
Surviving and reflecting	Reflecting on surviving	Feeling happy that I survived Reflecting on my birth experience as positive Reflecting on difference between expectation and reality Acknowledging my strength Feeling proud of myself Succeeding despite the fear Feeling a sense of achievement Appreciating the gift of motherhood Feeling invincible Focusing on the good that came from my experience Becoming more aware of who I am Being changed No longer being ashamed Regretting time wasted on worry	"I actually had an amazing birth, I had an incredible birth" (P3) "It was just so positive compared to what I thought it would be like, that I wish I didn't spend all that energy worrying" (P1) "I was so proud of myself and I was so happy when she was born and I was glad I got through it" (P5) "Just going through it and facing my fear has definitely… afterwards, I thought, I can do anything. I was like I have just conquered my literal biggest fear in life and I remember before thinking, if I do that, there is nothing I can't do" (P1)
	Assessing the impact	Fear affecting my loved ones Experience putting a strain on my relationship Delaying motherhood – losing time Feeling a sense of loss Not being able to have a bigger family Losing a part of myself Worrying about the impact on my children	"The worst aspects were probably the effect that it had on my relationship at the time" (P5) "it has really damaged our relationship and he knows that, but I find it quite unforgiveable, his lack of support and kindness" (P3)

	Looking to the future	Hoping for increased awareness of tokophobia Contemplating whether I could do it all again Knowing that I could not go through this again Being aware that the fear does not go away Wanting to protect my daughter from this fear Wanting to change the narrative of birth to a positive one Feeling passionate about affecting change Wanting to share my story to help others Wanting to reduce stigma	"My daughter, I'm very scared that I'm going to pass this fear on to her" (P3) I felt like my pregnancy had been taken away from me… there was a sense of loss of not being able to enjoy my pregnancy (P8) "There needs to be more awareness, because I'd never even heard of it before" (P2) "People tell you horror birth stories, and I've never understood why anyone would do that…I just want to share my positive birth story" (P1) "there is still this stigma, with having a planned c-section" (P1) "I think it's a real big misconception that there's only one way [to have a baby] when there are so many different ways" (P8) "This is why I'm really passionate and proactive about talking about tokophobia because I have never known anything so lonely. I never had anybody tell me that they have experienced this" (P3) "I wanted to help people that were really fearing birth" (P8)

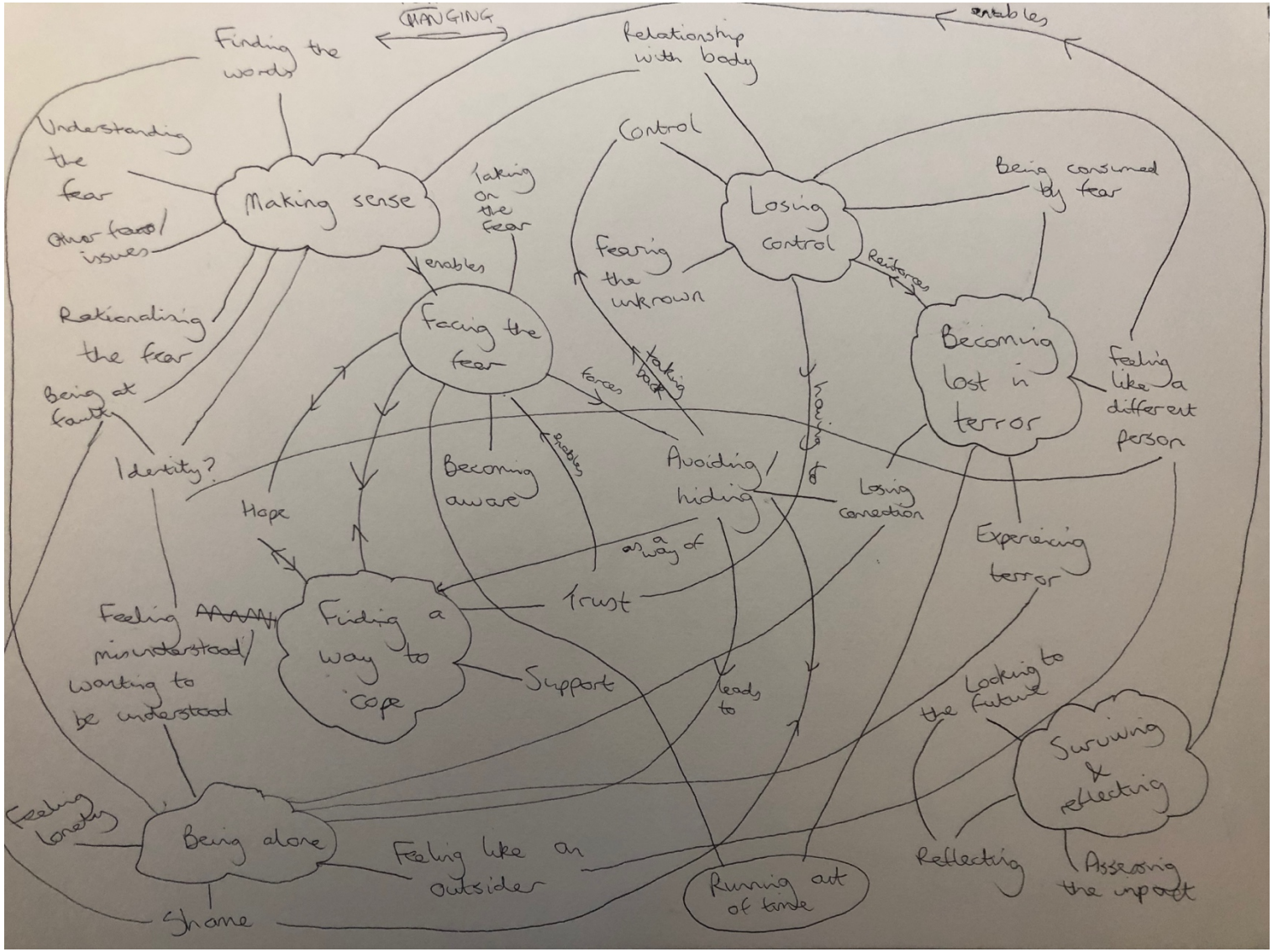
			"I couldn't live through ….I couldn't do it again" (P3) "I keep coming back to it, and I keep thinking, oh, that would be – it would be amazing to have a little brother or sister for him, and I'd love to be mum to another little one. But every time I think about coming off the pill or – yeah, even just coming off the pill again, the nightmares start again, and I find myself awake at 2 o'clock in the morning, on my phone, googling things, and I'm thinking, "What are you doing? You don't need to do this. You know you can do this." I've got through it once. I can get through it again. But I still can't take that – I can't take that step" (P5) "even on my second birth, the feelings were still there, I could just manage them in a different way" (P8)
Going through it alone	Feeling alone	Feeling lonely Feeling abandoned Others don't understand what I am going through Being in a place that others could not reach Going through this experience alone	"I felt so alone" (P5) "I have never known anything so lonely" (P3) "like [being in] a different world, like a different language (P3)
	Feeling like an outsider	Feeling like an outsider Nobody around me experiencing the same fears Wanting to be accepted Wanting to feel 'normal' Not identifying with other pregnant women	"nobody around me going through the same thing" (P8) "I was trying to explain to her how I felt and what was going on in my head, and I basically got told,

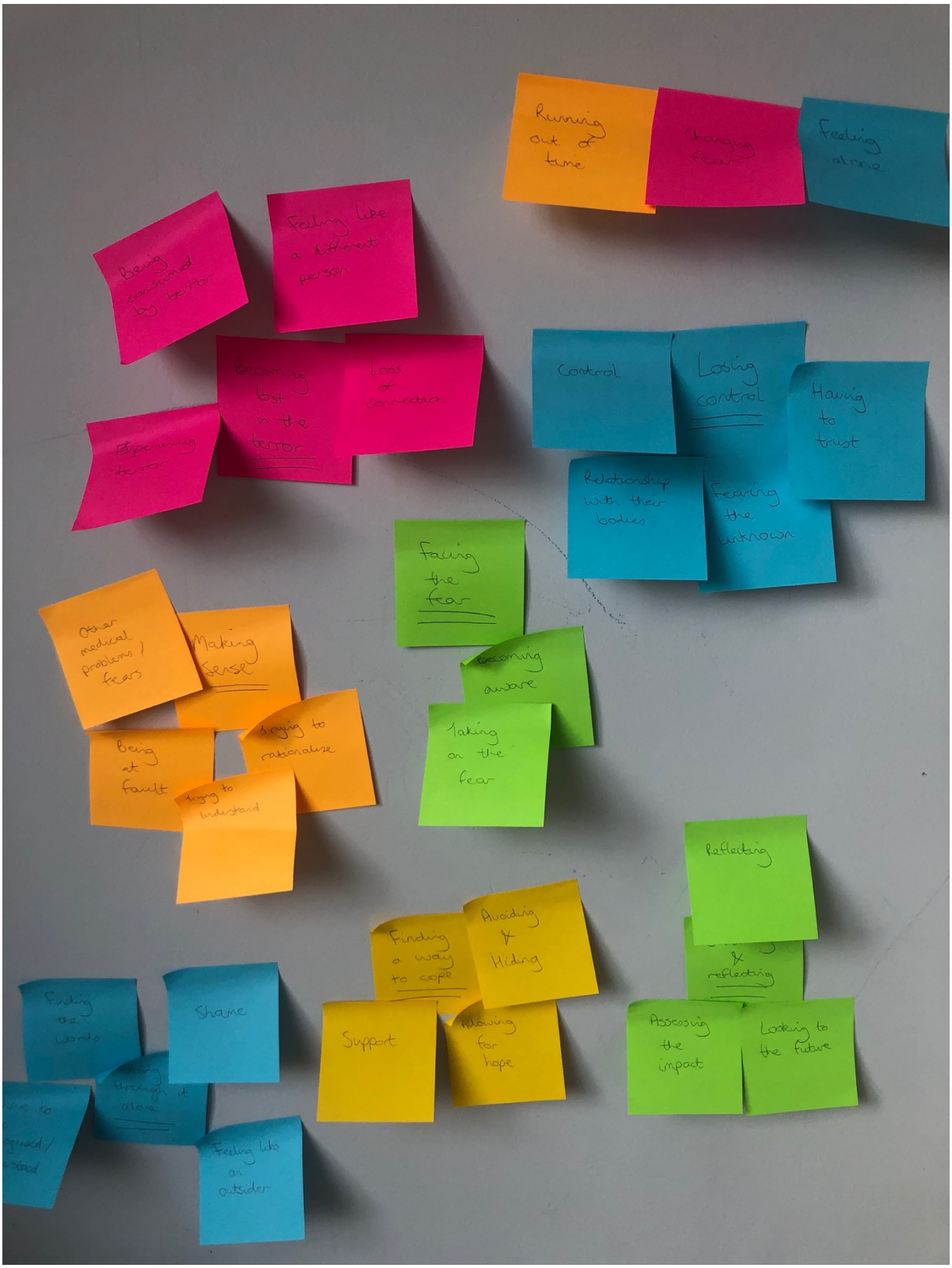
		Being different to other pregnant women Feeling less than other women Comparing my experience to other 'normal' pregnancies	'Every woman is scared about falling pregnant and becoming a mum. You'll get over it. Don't worry about it.' And I was discharged, and that was that (P5)
	Desire to be recognised and understood	Seeking validation that my fears are normal Wanting recognition that my fear is real Experiencing others as not taking my fears seriously Wanting to be taken seriously Having to fight to get my voice heard Wanting to feel understood Feeling misunderstood Others making false assumptions Predicting that others will not understand Wanting others to understand the sacrifices I have made Having my feelings dismissed Feeling like someone believes me Feeling ignored Looking for others with a shared experience	Yeah and the worst thing about the fear is definitely the feeling that I can't tell other people. Whether that's because they genuinely wouldn't understand or just because I tell myself [they wouldn't]" (P7) "I never told any of my friends when I was pregnant that I was experiencing what I was, I just couldn't find the words. I was so ashamed and so embarrassed" (P3) "I was ashamed, I thought I can't be normal ,why can't I just have a normal pregnancy" (P6) "You are expected to be happy. You are expected to glow. You are expected to sort of embrace it all and embrace motherhood, and it's all going to be lovely" (P5)
	Shame	Feeling shamed Feeling ashamed Feeling embarrassed to disclose my fears Anticipating judgement Fearing judgement Avoiding judgement Feeling stigmatised for my birth choices Feeling silenced by fear of judgement Not meeting society's expectations of a pregnant woman Feeling guilty	"You're just bombarded constantly… if you haven't…delivered naturally you've not really delivered your child; you've not given birth you know" (P6) "But I was worried about what other people would think, and I was worried, like I say, what the midwives would think, whether they would take the

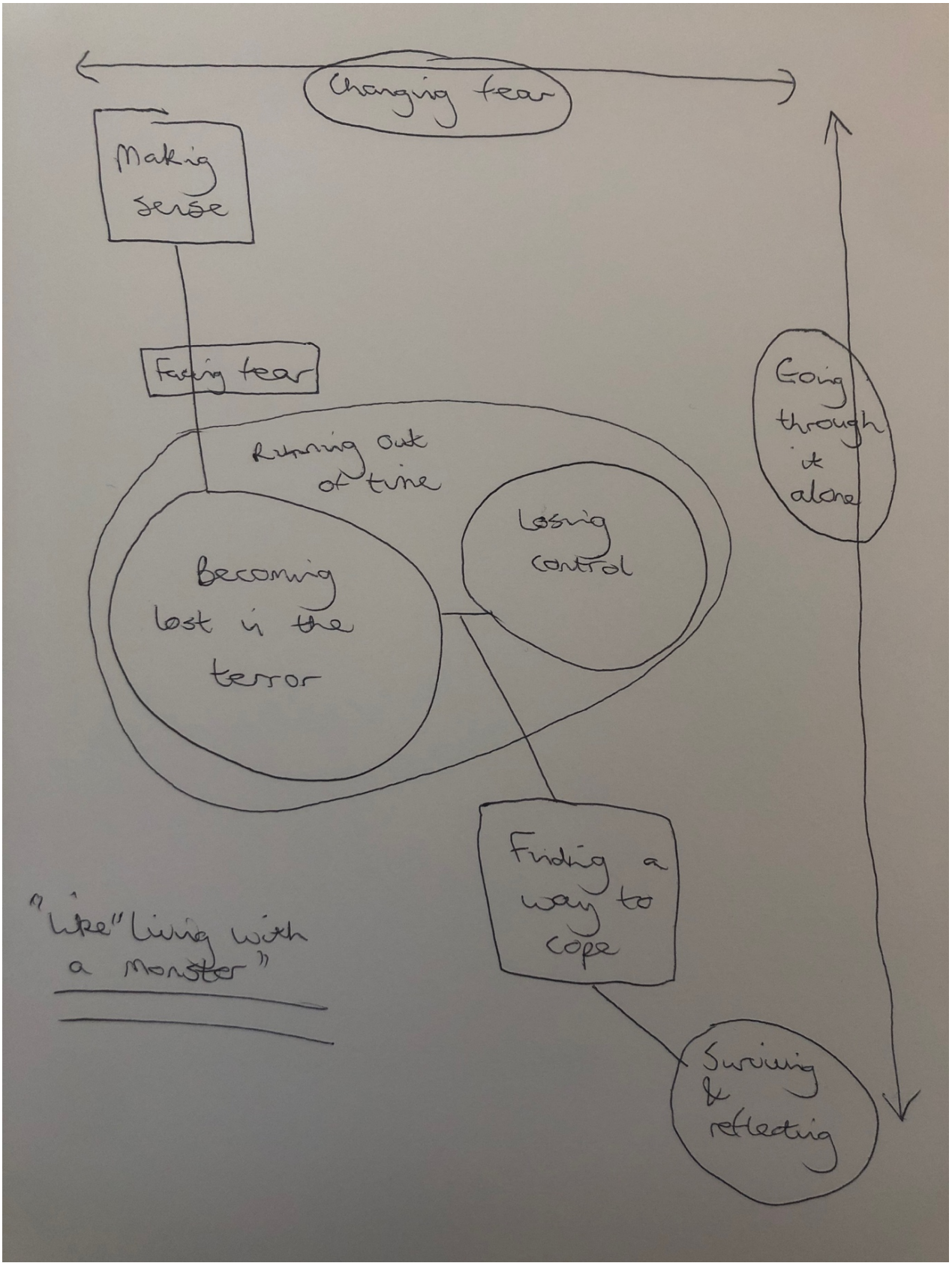
	Finding the words	Being made to feel like I'm not as good as other mothers Being afraid to disclose the extent of my fears for fear of repercussions Finding it difficult to explain my experience Difficulty finding the right words to explain my fears Receiving a diagnosis that can help explain my experience Discovering the term tokophobia Finding a label that fits Being given a label was normalising Label being pointless if nobody has heard of it	baby off me as soon as it was born because I was a danger to it" (P5) "Everybody automatically assumed, and even the GP in that first appointment, she automatically assumed I want to harm my baby and sent me to a social worker rather than it being how I actually was feeling about growing the baby" (P8) I think…anxiety… I think that would be the best way to describe it. But I don't know whether that would describe all of it, if you see what I mean. I don't know if that would describe the full extent of how I was feeling at the time (P5) "It's just so bizarre realising that there are others out there"(P4) "you're not going insane and other people feel this way, you're not alone because I felt really alone" (P6)
Changing fear	N/A	The fear changing over time Fear morphing and growing Moving from one aspect of the fear to the next Fear having layers Closeness to fear changing over time	"This is what I found really cruel about tokophobia it seemed to morph and grow. So, you'd sort of perhaps deal with one thing and the next thing would creep in, maybe they were just always there and once you dealt with it, it gave room for the other, for the other bits" (P3) I think I've always had tokophobia, I don't think I realised it and I think it's sort of less of an issue

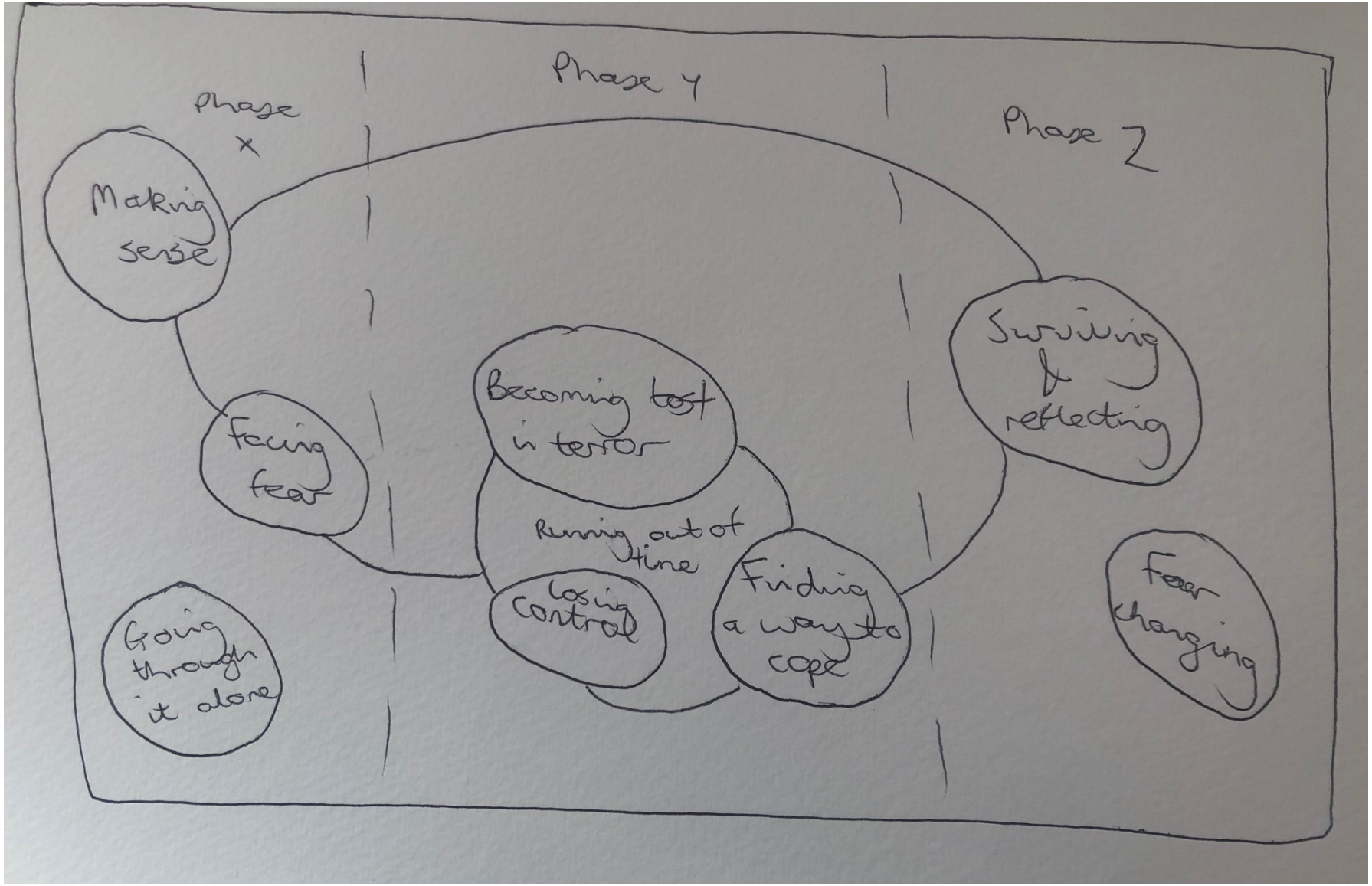
			because it doesn't affect me, I'm not pregnant, I won't get pregnant that's it now….I know it's there, it's up there and it rumbles on (P3)

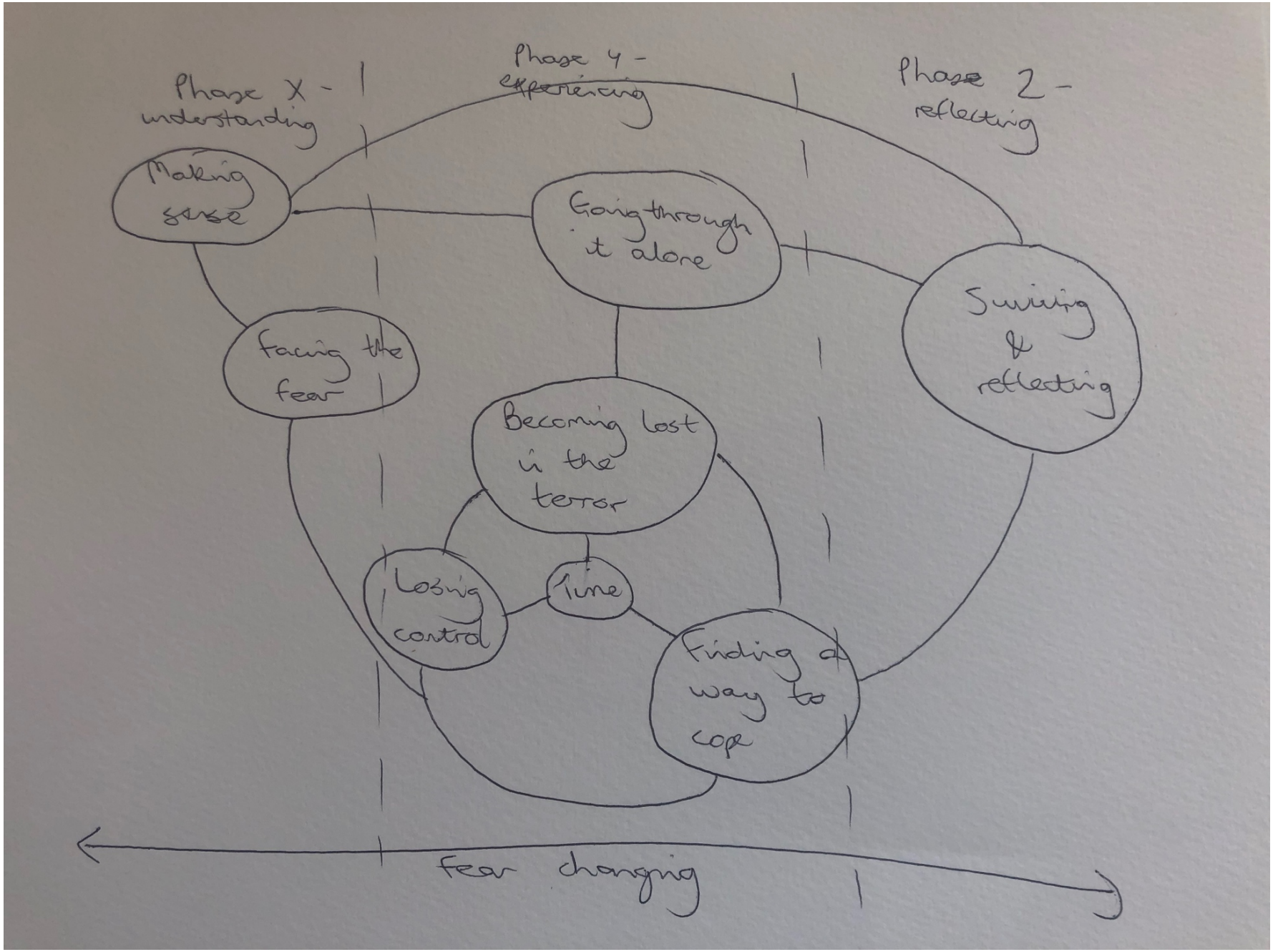
Appendix L. Theory development process

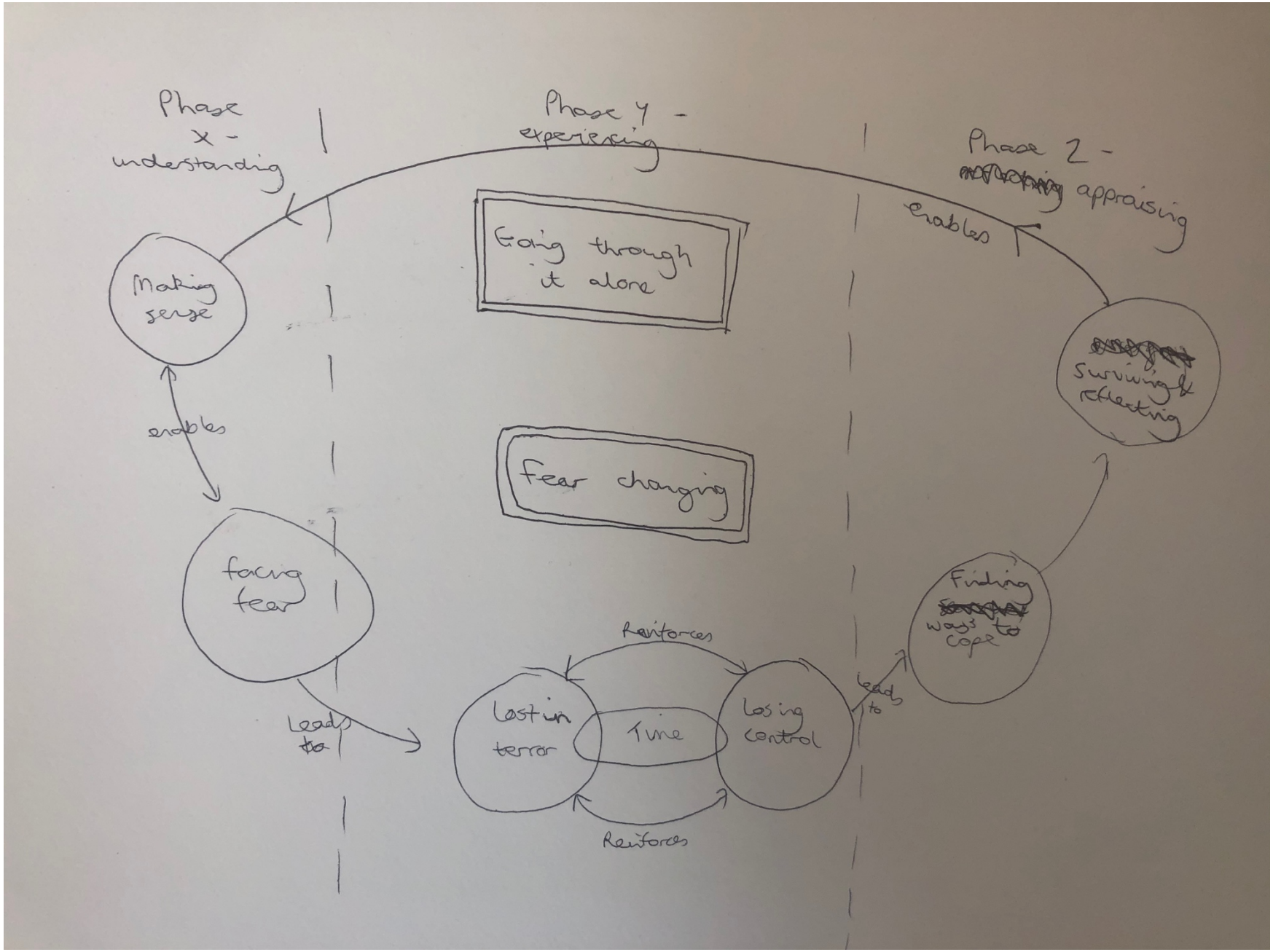



Running out of time
Changing fear
Feeling alone
Being consumed by terror
Feeling like a different person
Becoming lost in the terror
Loss of connection
Experiencing terror
Control
Losing control
Having to trust
Relationship with their bodies
Fearing the unknown
Facing the fear
Other medical problems / fears
Making Sense
Becoming aware
Being at fault
Trying to rationalise
Taking on the fear
Trying to understand
Reflecting
Finding a way to cope
Avoiding & Hiding
& reflecting
Finding the words
Shame
Support
Allowing for hope
Assessing the impact
Looking to the future
Feeling like an outsider


Changing fear
Making sense
Facing fear
Running out of time
Becoming lost in the terror
Losing control
Going through it alone
Finding a way to cope
Surviving & reflecting
"Like" Living with a monster"


Phase X
Phase 4
Phase 2
Making sense
Facing fear
Becoming lost in terror
Running out of time
Losing control
Finding a way to cope
Surviving & reflecting
Fear changing
Going through it alone


Phase X - understanding
Phase 4 - experiencing
Phase 2 - reflecting
Making sense
Going through it alone
Surviving & reflecting
Facing the fear
Becoming lost in the terror
Losing control
Time
Finding a way to cope
Fear changing


Phase x - understanding
Phase 4 - experiencing
Phase 2 - appraising
Going through it alone
Making sense
enables
enables
Surviving & reflecting
Fear changing
facing fear
Finding ways to cope
Reinforces
Lead to
Lead to
Lost in terror
Time
Losing control
Reinforces

Appendix M. Positioning statement

I am a 32-year-old white British female trainee clinical psychologist. I have two young children, one of whom was born during the research process. Whilst I did not experience any mental health difficulties during my pregnancies, I did at times question whether my thoughts and feelings about pregnancy and childbirth were in line with 'the norm'. Over the course of the bracketing interview, I realised that my views about a 'normal' pregnancy were shaped by experiences of people close to me, and representations in the media. I became aware that I hold strong feelings about my own childbirth experiences, which differed greatly from each other, for a number of reasons. Prior to commencing this study, I had never heard of tokophobia. I knew of a couple of people who had expressed fears about birth, but not to the extent that it was overly distressing or preventing them from having a baby. I embarked on this study interested to hear what it was like to experience intense fear during such an emotional, unknown, life changing time, and what gave women the strength to do this.

Appendix N. Abridged reflective research diary

07/08/18	I have just had my letter of access through from the Trust, which I'm very happy about. I was keen to get all the approvals sorted as soon as possible so I'll be ready to go. I'm now on maternity leave until next year but would like to keep the momentum going if possible. Perhaps in a few months I can start thinking about recruitment.
10/10/18	I have been busy with the children, but research has been on my mind lately. I contacted my external supervisor to check in and talk about potentially coming in to meet the team and talk about the research. She suggested coming to a triage meeting, but it's an hour and a half drive. I had big plans to keep up momentum whilst on maternity leave, but perhaps that was too optimistic. I will have to get childcare for the morning to attend the meeting. Hopefully it will be worth the trip and I can get the team on board to help with recruitment.
23/11/18	Had an email from my external supervisor – apparently she has been trying to contact me but emails have been bouncing back. She has suggested that I contact the team leaders individually to arrange to attend triage meetings. She suggested I go weekly, which is not feasible with the children and the distance. I'm hoping that once they put a face to a name, I can email them on a regular basis so they keep my research in mind.
14/01/19	Finally managed to attend a triage meeting. I was given 15 minutes to talk about the research, and let the team know how they can help. Everyone seemed interested, which made me feel hopeful. They have quite a few referrals that might be suitable, so fingers crossed some of them will be interested in taking part. I met with my supervisor separately too. She was keen for me to get started with recruitment, so hopefully together we can get things moving.
05/02/19	I attended another triage meeting today, with a different team. They have fewer referrals as they cover a smaller area, but there's still a possibility some of their referrals will be suitable for the project. There were lots of people at the meeting,

	which was a bit intimidating, but it's much easier to talk about something you are interested in!
04/04/19	My external supervisor suggested I go to a network meeting this week. I was given a slot to talk about the research, which was good, although it felt as though they wanted to hear about the results, and I haven't done a single interview yet! Made a few contacts, and someone from Maternity Voices Partnership was really interested. She thought she might be able to help with recruitment, so I will keep in touch with her. It was really interesting to hear about other things going on in perinatal mental health – it made me feel glad that my research is in an area I feel passionate about.
24/04/19	One of the midwives contacted me today with the details of two women who are interested in taking part in the research. I feel relieved, excited and anxious all at the same time! I'm going on holiday next week, so will try to arrange interviews before I go.
27/04/19	Conducted my first two interviews today. Both were at their homes. They were so lovely and were so open about their experiences. I've been thinking about how brave they are to put themselves out there and share their stories. They both felt strongly that people need to know more about tokophobia – that's why they agreed to take part in the research. I'm feeling spurred on now and motivated to make this a meaningful and useful piece of research. I'm also intrigued about what will emerge.
18/05/19	I've been on holiday, so nothing much as happened. I want to start transcribing the interviews soon, just have to find the time.
12/06/19	I returned from maternity leave last week. I'm glad to be back, but also sad my maternity leave has come to an end. It's also made me realise I have to start focusing on recruitment – I really don't want to get behind and make the process more stressful than it needs to be.

05/07/19	Received an email from one of the midwives today with a potential participant. She is currently pregnant, so will be slightly different from the interviews I have already done. I have been thinking about the different themes that might emerge – I imagine the experience might feel quite different with the birth still pending. Hopefully I can meet with her in the next few weeks.
30/07/19	I have tried contacting the woman who was interested in taking part, but she's now not replying to my messages. Going to leave it with her, as I don't want to put pressure on and chase her. Maybe she has changed her mind. Feeling a bit disappointed, but also completely understand.
31/07/19	I have been worrying a bit about recruitment. I am attempting to be proactive and think about other potential routes for recruiting participants. I spoke to both of my supervisors about recruiting online, and what I would need to do (ethics wise) to make this possible. It will add more work now but will hopefully make recruitment easier in the long run.
28/08/19	I submitted an amendment to the NRS committee this week to add online recruitment. It's been quite a lot of work to get all of the documents together. Hoping it gets approved.
26/09/19	I was contacted by a team member at the perinatal team about a potential participant earlier this week. However, after assessment, they did not think she was suitable. I'm feeling disappointed – I've still only completed two interviews. I'm not sure why more potential participants are not being put forward – perhaps I should go and visit the teams again.
07/10/19	I received a favourable ethical opinion from the NRES committee which means I can start advertising the research online. Feeling motivated again and hopeful that this will really help get things moving in the right direction.
21/10/19	I have now been able to complete three interviews, so I am going to start the transcribing and coding process. Feeling quite apprehensive about it – I have

	been reading the Charmaz book, but it still feels a bit unknown. Hopefully it will become clearer once I get started.
20/11/19	I have finished coding my first interview. The process took some time but did get a bit easier towards the end. I sent some of the coding to my supervisor to see if I was on the right track. She reassured me that I was extracting from the data, which gave me a bit more confidence. I found myself struggling to know if I should code content or process. After speaking to my supervisor and re-reading the initial coding chapter of Charmaz's book, I thought I would just move through it quickly and try not to overthink it. This seemed to help, but I did find I had to keep going back to amend codes. I suppose I should get used to this though, as I will be doing lots of looking back over the codes when I'm doing constant comparison. I'm feeling partly relieved that I've started the coding process, but also daunted by how long it took to do one interview. I'm also worrying about how I am going to make sense of all of these codes – all 465 in this one interview! I am telling myself to just trust the process and see where it takes me….
02/12/19	Completed another interview. I've started to think about theoretical recruitment, and where the interviews so far are leading me. I need to do some more coding but it's taking so long.
07/12/19	Two of the interviews over video messenger have been quite emotional. I would have preferred to do them face to face, but it's just been too tricky recruiting from the NHS site. The women I have spoken to are glad to be able to share their story, and they really want to raise awareness of tokophobia. I hope I do their stories justice. I have found myself thinking about my own experiences of pregnancy and birth. It is such a unique and personal journey, but I can relate to some of what participants are talking about, especially in relation to expectations of what it is to be pregnant and to be a mother.

26/01/20	I've been concentrating on Part A for the last month or so. Feeling a bit better that that is taking shape, but it's meant I've neglected Part B. It's so hard juggling it all and keeping on top of it. I'm feeling apprehensive about the next few months – it still feels like I'm a million miles away from being able to pull together a theory from the data I've collected.
01/03/20	So here we are in March, with the deadline looming next month. I'm deep into coding. I find myself getting lost in the stories, and I think I'm starting to piece together some links in my mind. It's interesting how the experiences of the women I've interviewed are similar in so many ways, yet they talk so much about feeling lonely and isolated in their experiences. It has made me consider how important social networking sites must be for these women, to be able to feel less alone. I'm trying to stop myself from thinking ahead too much, but I am still apprehensive about how I am going to bring all of this data together. I can't yet picture how a theory might develop out of this but trying to trust the process.
06/03/20	As I've progressed with coding, I've been having to remind myself to keep an open mind and stay close to the data. I can see how easy it would be to skip over things that don't fit with the focused codes that have emerged from earlier interviews. I've had to go back a few times to check I haven't fallen into this trap.
16/03/20	I have an initial model which I think captures the process that the participants have described. I'm trying to write it up enough so that it makes sense, then will send to my supervisors to get their thoughts. I have had to keep going back and rethinking whether the codes fully capture what is going on (e.g. phase Z was initially 'reflecting', but later became 'appraising'). It has struck me that the experiences described have qualities akin to PTSD. I have tried to capture ideas like this in my memos as I go.

Appendix O. Participant validation

The following email was sent to participants with a copy and explanation of the proposed model. Feedback is presented below -

"Hello [participant],

I hope you are your family are keeping well at this strange and worrying time.

Thank you so much for participating in an interview about your experiences of primary tokophobia. I am getting back in touch as I have now analysed the data from your interview, alongside interviews from other participants, and would like to get your feedback on the proposed results.

You will see attached a model that has been developed – can I ask what you think to this model? Does it make sense to you? Does it reflect the experiences that you shared with me when we spoke?

Any feedback would be much appreciated – I want to ensure that the model captures the experience of primary tokophobia as closely as possible. You are welcome to email me back or call me on [……...]. If you would like me to talk the results through with you, please let me know and we can arrange a time to talk.

Thank you again for your time and input – it is very much appreciated.

Many thanks,

Michelle Clark

Trainee Clinical Psychologist"

Example feedback

"Hi Michelle, that makes sense. It's a diagram of the last 10 years of my life basically. From [participant]"

"Hi Michelle,
Thank you for sending me back this information. I resonate with everything in page 1 in some way.
I did feel a 'running out of time' sense in that a) I really wanted to have children and not leave it late and b) once I was pregnant, it was a bit of a scary countdown to knowing that I will have to face my fears.
And I did also feel alone in the journey as a) no one could do this for me, even my closest family, as much as they were trying to support me and b) I also didn't know any other women with Tokophobia in general. It would have been brilliant to have known other women who had it, and had gone through it, and were absolutely fine to talk about it afterwards….
All the best, [participant]"

Appendix P. NHS ethics approval letter

This has been removed from the electronic copy.

Appendix Q. HRA approval letter

This has been removed from the electronic copy.

Appendix R. Research and development approval letter

This has been removed from the electronic copy.

Appendix S. NHS ethics committee and HRA end of study form

DECLARATION OF THE END OF A STUDY

(For all studies except clinical trials of investigational medicinal products)

To be completed in typescript by the Chief Investigator and submitted to the Research Ethics Committee (REC) that gave a favourable opinion of the research within 90 days of the conclusion of the study or within 15 days of early termination. For questions with Yes/No options please indicate answer in bold type.

1. Details of Chief Investigator

Name:	Michelle Clark
Address:	1 Meadow Road, Tunbridge Wells, TN1 2YG
Telephone:	01227 927070
Email:	m.m.clark754@canterbury.ac.uk
Fax:	N/A

2. Details of study

Full title of study:	"Like living with a monster": A Grounded Theory of women's journey to motherhood with primary tokophobia
Research sponsor:	Canterbury Christ Church University
Name of REC:	London – Surrey research Ethics Committee
REC reference number:	18/LO/0545

3. Study duration

Date study commenced:	07/08/18
Date study ended:	01/04/20
Did this study terminate prematurely?	*No* *If yes, please complete sections 4, 5, 6, & 7.* *If no, please go direct to section 8.*

4. Recruitment

Number of participants recruited	
Proposed number of participants to be recruited at the start of the study	

If different, please state the reason or this	

5. Circumstances of early termination

What is the justification for this early termination?	

6. Temporary halt

Is this a temporary halt to the study?	*Yes / No*
If yes, what is the justification for temporarily halting the study? When do you expect the study to re-start?	*e.g. Safety, difficulties recruiting participants, trial has not commenced, other reasons.*

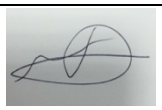
7. Potential implications for research participants

Are there any potential implications for research participants as a result of terminating/halting the study prematurely? Please describe the steps taken to address them.	

8. Final report on the research

Is a summary of the final report on the research enclosed with this form?	*Yes* *If no, please forward within 12 months of the end of the study.*

9. Declaration

Signature of Chief Investigator:	
Print name:	Michelle Clark
Date of submission:	17/04/20

Appendix T. End of study/summary letter to ethics panel/HRA/R&D Department

"Like living with a monster": A Grounded Theory of women's journey to motherhood with primary tokophobia

Objective:

Primary tokophobia, a phobic fear of childbirth in women who have not experienced pregnancy before, can have huge implications for both mother and baby. Some efforts have been made to better understand women's experiences of tokophobia, however, gaps remain in the literature. The purpose of this research was to further explore women's lived experiences of primary tokophobia and describe how identified themes relate to each other through a theoretical model.

Method:

Eight semi-structured interviews were conducted with women who were pregnant or had given birth in the last five years and were experiencing/had experienced primary tokophobia. Interviews explored women's lived experiences of primary tokophobia, how they made sense of the fear, and how they coped. Participants were recruited from an NHS perinatal service and from online support groups. Grounded Theory methodology was used to analyse the interview data. Respondent validation of initial findings was sought from participants.

Main findings:

A cyclical model was constructed representing women's journey to motherhood with primary tokophobia (see model). The theoretical model is titled *"like living with a monster"* (P3). It represents conceptual relationships between nine superordinate categories: making sense; facing the fear; becoming lost in the terror; losing control; running out of time; finding a way to cope; surviving and reflecting; going through it alone; and changing fear. The categories are organised into three phases; understanding; experiencing; and appraising. Gerunds that most accurately captured the processes that participants described were used to name these phases. Movement between the phases represents the journey that participants described and is not linear or unidirectional. Some phases overlap and happen concurrently. The cyclical aspect of the model demonstrates how the journey is ongoing.

'Making sense' and 'facing the fear' occurred in the 'understanding' phase and were reciprocally enabling of each other. 'Facing the fear' crossed over into the 'experiencing'

phase, where categories interacted with each other to create a description of how the fear was experienced and coped with: 'becoming lost in the terror' and 'losing control' were reciprocally reinforcing of each other, and participants described 'finding a way to cope' with what they were experiencing. The category 'running out of time' spanned across the phase and represented the temporal aspect that was described by participants. 'Finding a way to cope' crossed over into the 'appraising' phase and enabled a process of 'surviving and reflecting'. This in turn enabled the process of 'making sense'.

'Going through it alone' was an overarching category that permeated each phase. Similarly, the category 'changing fear' represented the evolvement of the fear, and the participant's changing relationship with the fear, throughout the journey.

Implications:

This study provides a tentative model of women's lived experiences and the journey that they embark on to become mothers. The model demonstrates how women fluidly move through a number of processes, and the ways in which these processes are connected. The model shares similarities with models of PTSD, and it is proposed that primary tokophobia could be viewed as a form of 'pre'-traumatic stress.

The proposed model provides a holistic frame of reference for services and clinicians to better understand the processes that women with primary tokophobia go through; something that the women interviewed described as lacking, and as something they felt was vital in order to make their experience less distressing. Recommendations for service development include early identification and intervention for women experiencing tokophobia, and development of peer support networks in the community or within services. Consideration was given to how interactions with services and clinicians could be improved to provide support and interventions that are normalising, empowering and containing. The findings could be strengthened with further research considering diversity in the experience of tokophobia and exploration of the experiences of women who have not felt able to try for a baby, and partners going through this journey.

Dissemination:

The findings from this study will be presented to the NHS perinatal teams where recruitment took place. A written summary of findings will be disseminated to all participants who were involved. It is intended that the study will also be submitted for publication in the Journal of Reproductive and Infant Psychology.

Appendix U. Study summary email and report for participants

"Like living with a monster": A Grounded Theory of women's journey to motherhood with primary tokophobia

Dear [participant],

Thank you for taking part in a research study about your experiences of primary tokophobia. I wanted to send you a summary of the findings, now that the study is complete. The findings will be presented to the perinatal teams in the NHS Trust that were involved with the study. It is hoped that this research will help services and clinicians to better understand the processes that women with primary tokophobia go through, and put in place effective interventions and support. The research paper will also be sent to the Journal of Reproductive and Infant Psychology with the aim of having it published.

I want to thank you again for bravely sharing your story with me – your contribution has been invaluable to the research.

If you have any questions at all, please do not hesitate to contact me at m.m.clark754@caterbury.ac.uk. If you have any concerns about the study that you would rather discuss with somebody else, please contact Dr Fergal Jones, Research Director, Salomons Centre for Applied Psychology, at fergal.jones@canterbury.ac.uk.

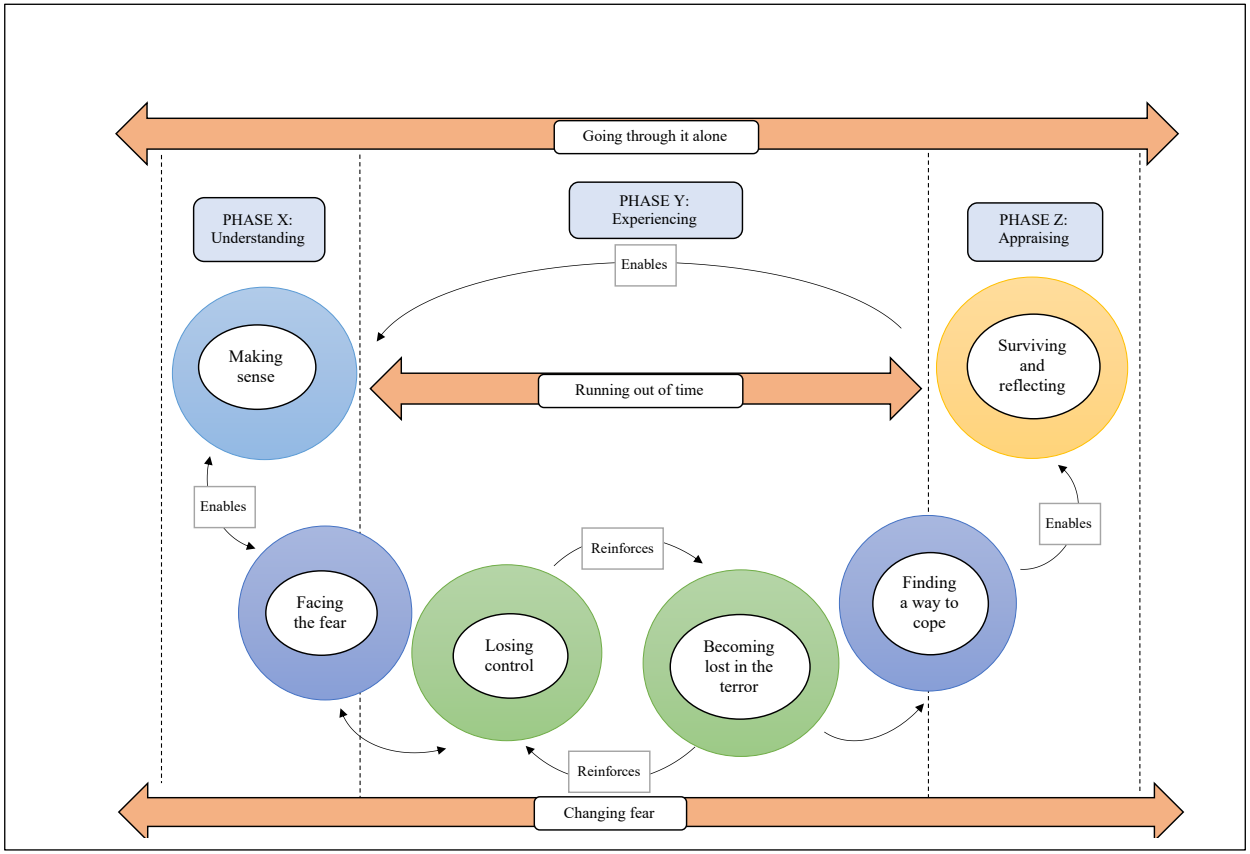
Thank you again,

Michelle Clark
Trainee Clinical Psychologist
Salomons Centre for Applied Psychology Canterbury Christ Church University

"Like living with a monster": A Grounded Theory of women's journey to motherhood with primary tokophobia

What did we do and why?

- Women who were experiencing, or who had experienced in the last five years, primary tokophobia, took part in this research.
- We hoped to gain a better understanding of primary tokophobia by hearing women's stories. We wanted to better understand how women make sense of their experiences and find ways to cope.
- Eight women were interviewed about their experiences.
- Interviews were typed up and analysed to create an overall understanding of what was being described.
- A model, made up of categories and subcategories, emerged which was intended to represent these described experiences.



Categories	Subcategories
Making sense	Trying to make sense
	Prior traumatic and negative experiences
	Being at fault
Facing the fear	Becoming aware
	Taking on the fear
Becoming lost in the terror	Experiencing terror
	Fear being reinforced
	'Pre'-experiencing
	Being consumed by the terror
	Feeling like a different person
	Loss of connection
Losing control	Control
	Fearing the unknown
	Having to trust
	Relationship with their bodies
Finding a way to cope	Avoiding and hiding
	Support
	Allowing for hope
Running out of time	N/A
Surviving and reflecting	Reflecting on surviving
	Assessing the impact
	Looking to the future
Going through it alone	Feeling alone
	Feeling like an outsider
	Desire to be recognised and understood
	Shame
	Finding the words
Changing fear	N/A

An overview of the model

- 'Making sense' and 'facing the fear' occurred in the 'understanding' phase and were reciprocally enabling of each other.
- 'Facing the fear' crossed over into the 'experiencing' phase, where categories interacted with each other to create a description of how the fear was experienced and coped with: 'becoming lost in the terror' and 'losing control' were reciprocally reinforcing of each other, and women described 'finding a way to cope' with what they were experiencing.
- The category 'running out of time' spanned across the phase and represented a sense of 'time running out' that was described.
- 'Finding a way to cope' crossed over into the 'appraising' phase and enabled a process of 'surviving and reflecting'. This in turn enabled the process of 'making sense'.
- 'Going through it alone' was an overarching category that was present in each phase. Similarly, the category 'changing fear' represented the evolvement of the fear, and women's changing relationship with the fear, throughout the journey.

What does all of this mean?

- This study provides a tentative model of women's lived experiences and the journey that they embark on to become mothers. The model shows how women fluidly move through a number of processes, and the ways in which these processes are connected. The model shares similarities with models of Post-Traumatic Stress Disorder (PTSD), and it is proposed that primary tokophobia could be viewed as a form of 'pre'-traumatic stress.
- The proposed model provides a holistic frame of reference for services and clinicians to better understand the processes that women with primary tokophobia go through; something that the women interviewed described as lacking, and as something they felt was vital in order to make their experience less distressing. Recommendations for service development include early identification and intervention for women experiencing tokophobia, and development of peer support networks in the community or within services. Suggestions are made about how interactions with services and clinicians could be improved to provide support and interventions that are normalising, empowering and containing.

Appendix V. Author guidelines for journal

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