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# AN INTERNATIONAL STUDY OF FEAR OF CHILDBIRTH AND TOCOPHOBIA WITH APPLICATION IN AN IRISH MATERNITY SETTING

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# LIST OF ABBREVIATIONS

| ABBREVIATION | TERM |
|---|---|
| aRRR | Adjusted Relative Risk Ratio |
| BMI | Body Mass Index |
| CASP | Critical Appraisal Tool |
| CAQ | Childbirth Attitudes Questionnaire |
| CBT | Cognitive Behavioural Therapy |
| CI | Confidence Interval |
| CS | Caesarean Section |
| DSM | Diagnostic and Statistical Manual of Mental Disorders |
| FOC | Fear of Childbirth |
| FOBS | Fear of Birth Scale |
| GAD-2 | Generalised Anxiety Disorder Questionnaire Part 2 |
| GP | General Practitioner |
| ICD | International Classification of Diseases |
| IQR | Inter-Quartile Range |
| MeSH | Medical Subject Headings |
| NICE | The National Institute for Health and Clinical Excellence |
| OR | Odds Ratio |
| PPI | Patient and Public Involvement |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analysis |
| PTSD | Post Traumatic Stress Disorder |
| RCT | Randomised Controlled Trial |
| RRR | Relative Risk Ratio |
| UCC | University College Cork |
| UK | United Kingdom |
| WHO | World Health Organisation |
| W-DEQ A | Wijma Delivery Expectancy Questionnaire Part A |

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# DEDICATION

This thesis is dedicated to my parents, Peter and Anne O'Connell
who provided love, support, positivity and encouragement all my life.

# DECLARATION

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.

Analysis performed in this thesis was conducted accurately and without bias by Maeve O'Connell with the exception of the meta-analysis, where Dr Ali S Khashan performed the analysis using Stata software version 13.1 after the relevant data were extracted and prepared.

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university. The work, upon which this thesis is based, was carried out in collaboration with a team of researchers and supervisors who have been acknowledged in the thesis text. The library may lend or loan this thesis on request.

**Signed:** _____

Maeve Anne O'Connell

**Date:**

# THESIS ABSTRACT


## Background and aims:

It is normal for women to face childbirth with a degree of apprehension. Women can experience levels of fear from low to severe, phobic fear termed tocophobia. Tocophobia is a severe fear of childbirth which is debilitating for women during pregnancy and can impact their health and well-being. Most women with tocophobia request a Caesarean Section (CS) since they have a phobia of vaginal birth. The last three decades have seen an increased emphasis on fear of childbirth as an important women's health issue both in research and clinical practice. However, to date, there has been little agreement on the concept and definition of what tocophobia is, how best to measure fear of childbirth and consequently, prevalence.

Moreover, there is a dearth of research in relation to fear of childbirth in Ireland; with the majority of research performed in Scandinavia. Various interventions have been trialled, but there is little information about how women experienced the interventions and how the intervention could be improved. Thus, the objective of the present thesis is to provide an in-depth investigation of this (relatively new) research phenomenon and to add to what is known about interventions which have been trialled.

## Structure and methods:

An initial literature review of all published research on tocophobia was performed to establish the paucity of research in the field and identify recommendations for research. This original search of the literature was conducted in September 2014 and the findings were subsequently published. The literature review findings are presented in Chapter 2. Following on from the literature review, the research questions were identified and a number of research studies were planned and conducted.

Firstly, having established a lack of consensus on the worldwide prevalence of tocophobia, a systematic review and meta-analysis were conducted to perform a robust systematic review of the definitions of tocophobia and provide an estimated global pooled-prevalence (Chapter 3). An update of the meta-analysis was performed before the submission of this thesis and is included at the end of Chapter 3.

Secondly, a cross-sectional study (n=882) was carried out in a major tertiary hospital in the South of Ireland using a convenience sample to determine the prevalence and associated risk factors of tocophobia (Chapter 4). Multivariate multinomial logistic regression was used to identify associated risk factors for high fear of childbirth. Within the cross-sectional study, a cohort analysis (n=389) was performed to investigate the association between fear of childbirth and pregnancy outcomes. Simple linear regression was employed to investigate the relationship between high fear of childbirth and pregnancy outcomes and findings are presented in Chapter 5.

Thirdly, a meta-synthesis of women's experiences of interventions for fear of childbirth in the perinatal period is presented in Chapter 6. Finally, in Chapter 7, a discussion of the thesis findings, strengths, limitations and conclusion is presented, as well as, recommendations for future research.

## Results:

*Literature Review:*

The literature review found tocophobia defined as a severe fear of childbirth which is very debilitating for women in pregnancy. The fear is so strong that mothers may have a physical response when faced with their fear. CS is the usual perceived solution. Physical, social and cultural causes, presentation and characteristics of women with tocophobia were attributed. Both and short and long term consequences of tocophobia

were found. Importantly, tocophobia may be associated with other maternal mental health disorders such as anxiety and depression. The research on tocophobia originated in Sweden, therefore the majority of research has been performed in Scandinavia to date. While there have been various European studies, there was a dearth of research in UK and Ireland.

Finally, in terms of management, there is no definitive treatment for tocophobia, but in some countries, such as Norway and Sweden, there is counselling available routinely. A good assessment of the individual is important as the management depends on the cause and severity of the fear. Good communication with the woman is vital and an interdisciplinary approach may help to provide early psychological support to her. In some cases a woman may need a CS, in other cases, women may go on to have a vaginal birth if other specific requests help, such as an early epidural or a female or known birth attendant (continuity of carer).

*Systematic review and meta-analysis:* Thirty-three studies were included in the systematic review, of which 29 were included in the meta-analysis. The majority of research was carried out in Scandinavia. There is a lack of consensus on definition of tocophobia leading to vast ranges of prevalence estimates. The pooled-prevalence estimate was 14% with considerable heterogeneity noted (99.25%) using a random-effects model and appears to have increased since 2000. Heterogeneity could not be explained despite comprehensive *a priori* subgroup and sensitivity analysis. Thus results should be interpreted with caution.

*Prevalence and associated risk factors:* The prevalence of tocophobia (W-DEQ A≥85) was 5.3% in this study. A further 31.4% of pregnant women in the study experienced high fear of childbirth (W-DEQ A 66-84). There was a prevalence of tocophobia (W-

DEQ A≥85) of 7.4% in nulliparous and 4.3% in multiparous women, but this difference was not statistically significant ($p<0.07$). Single marital status, low perceived informational support and EPDS>10 were found to be significantly associated with high fear of childbirth in a multivariate analysis. Using a cut-off of 2.5 in the four W-DEQ A Subscales, 35.6% scored above the cut-off in Negative Emotions, 29.4% in Lack of Positive Emotions, 9.9% in Social Isolation and 7.8% in Moment of Birth.

*Tocophobia and pregnancy outcomes:* The finding that there was no association between severe FOC and birthweight, birthweight centile and gestational age is reassuring. Moreover, there was no statistical difference in the labour and delivery outcomes; epidural use, Caesarean Section and induction of labour in women with severe FOC versus those without. A likely association was noted between severe FOC and APGAR score at one minute. However the number of women in this group (severe FOC) was small (n=18), therefore further research studies should be undertaken.

*Meta-Synthesis of women's experiences of interventions for fear of childbirth:* There is very little published qualitative research on women's experiences of interventions for FOC. No previous meta-synthesis was found in a search of the literature. Therefore this meta-synthesis aimed to create a new interpretation of women's experiences of interventions for FOC in the perinatal period. Six studies incorporating the views of 118 nulliparous women from Norway and Swden were included in the meta-syntesis. Interventions they experienced included team midwifery, Cognitive Behavioural Therapy (CBT) via the internet, art therapy and midwife-led counselling. Four included continuity of midwifery care model as a component of the intervention.

A new analytical framework was used to present the process of progressing from fear to “Ownership of childbirth” through the interventions. “Facing the fear” by “Acknowledging the fear” and “Identifying the fear” were crucial steps for women when engaging with interventions. Women cannot move beyond FOC unless they first acknowledge it and identify the nature of the fear. Once this was achieved, women needed to gain control, and they did this by developing their sense of “Internal agency”. By “Growing in self-belief and feeling empowered”, women could self-manage the fear with some knowledge, support and skills, but could be disempowered if clinical staff were not understanding or engaged, which may be related to the underpinning ethos of care. Women described “Feeling empowered” or conversely, disempowered during the birth process. When women took an active part in the birth, they viewed the outcome more positively overall. Partners also needed to be understanding of FOC and supportive in the birth process. “External factors” were important as partners or clinicians who were unsupportive or who did not engage were a barrier to the effectiveness of the intervention.. Finally, “Managing the fear with a sense of security” was described. Developing a trusting relationship with the caregiver and a belief in their competence helped women progress from fear to “Ownership of childbirth” and “Cope in the uncertainty”. Feeling safe was crucial for women with FOC. This was facilitated by being supported to cope with the uncertain outcome of labour, and feeling emotionally prepared. The interventions helped women to “Re-frame the emotions about childbirth”. After the interventions, women perceived their upcoming birth more positively and that they could expect supportive care.

The overarching theme “Ownership of Childbirth” was the outcome for most women following engaging with the various interventions.

## Conclusions:

This thesis identified the need for more research about fear of childbirth worldwide since the majority of research has been conducted in Scandinavia previously. Prior to this, there was no global estimate of the prevalence of tocophobia, and little was known about fear of childbirth in Ireland. No consistent definition of tocophobia was found and there is no definitive treatment. A pooled prevalence suggests that as many as one in six women worldwide may experience tocophobia, and the prevalence appears to have increased over the last decade. Furthermore, subgroup analysis was conducted where possible, in the various continents, a prevalence of 23% was found in Australian studies, 11% in studies in America, 25% in Asia, and 8% in Europe.

In this thesis, it was established that the prevalence of tocophobia in an Irish sample of women was comparable with international prevalence (5%), but high FOC was relatively common when compared with other countries (37% versus 20%). Fear of childbirth was more common in first-time mothers, but this difference was not statistically significant.

In the prevalence study, the associated risk factors were similar to the findings of previous research studies; single marital status, low perceived informational support and depression. Similar to previous studies, high FOC was more prevalent in nulliparous women. In addition to investigating the severity of the fear, analysis was performed using new W-DEQ A subscales. Using these subscales may be beneficial to guide a discussion identifying the nature of the fear and gain more information about the cause of the fear. Importantly, over half of nulliparous women scored above the cut-point in the subscale ‘Negative Emotions’ which related to women’s self-efficacy in the ability to give birth. This factor may respond well to strategies such as discussing

the individual's fears, answering questions, information-giving, birth preparation and learning practical skills and approaches for coping during labour.

The pregnancy outcomes study found no significant difference in mean birthweight, mean birthweight centile or mean gestational age in women with severe FOC versus women without in the second trimester. Furthermore, there were no statistical differences in the use of epidural analgesia, induction of labour or CS in women with severe FOC versus those without. There was a slight association between Apgar scores and FOC, but the findings were reassuring on the whole.

The meta-synthesis identified a dearth of qualitative research investigating women's experience of interventions for FOC worldwide. A rich analysis of how women experience engaging with interventions for FOC was achieved through the meta-synthesis. These findings are important as they help us to gain an understanding of women's experiences of interventions. There is a need to undertake qualitative evaluation of interventions in the future. The findings of this thesis will be of interest to researchers with an interest in fear of childbirth or perinatal mental health globally, obstetricians, midwives and women. To date, interventions have lacked input from women and qualitative evaluation. Future trials of interventions should involve women in the design of the study. More research in this area is necessary to provide evidence-based care for women with FOC.

# CHAPTER ONE.

# INTRODUCTION

# 1.1 INTRODUCTION

## 1.1.1 Motherhood, a psychological transition

Pregnancy and motherhood is a major life transition which can be challenging for women, particularly for first-time mothers (1, 2). From a social perspective, childbearing (from conception until after the birth of the infant), is a major life event in which women have a period of psychological transition. However, despite research, little is known about the extent of this change and the overall impact on the mother. It is normal for a mother to experience some concern about her well-being and the well-being of the fetus during pregnancy. This apprehension is commonly experienced by women and tends to fluctuate in the different stages of pregnancy (3).

The first trimester is a time when women are adjusting to their new state and may be a period of uncertainty where women may frequently tend to worry about miscarrying (1). During the second trimester, fetal movement begins, and the mother begins to visualise the baby and forms a bond. The woman begins to develop her identity as a mother and may reflect on her own relationship with her mother. As she moves into the third trimester, most women begin to consider childbirth and wonder if they have the ability to give birth. Throughout this period, the birth may be viewed with trepidation and women may worry about the outcome of childbirth, about injury to the baby or herself (1).

Most women begin to prepare and to become impatient to meet their baby, moving on to the next phase of their life, motherhood (1). Some women may experience emotional or psychological challenges in the perinatal period which disturb the transition to motherhood and bonding and attachment with her infant. Anxiety, depression, fear of childbirth, and birth trauma may upset this process of attachment.

### 1.1.2 Becoming a mother in Ireland

Changes in social context influence how mothers navigate the transition from being a woman without a child to being a mother. Over the last thirty to forty years, in Ireland, the social context of becoming a mother has changed, with the lifting of the marriage bar in 1973, meaning women can continue to work after marriage, and the legality of purchasing contraception in 1980, meaning women have more choice in the decision to become a mother. The result of this was that becoming a mother occurred slightly later in life (the average age of birth of first child was 31.0 in 2016 (4), while in 1981, it was 28.9 (5). In Ireland, the average number of children per family is 1.38 which is unchanged since 2011. However, it was 2.00 in 1991 (4).

In Ireland, women who were pregnant outside of marriage faced societal stigma up until the late 1990s. Due to the dominance of the Catholic Church in Ireland, women were sent to religious orders to work in industrial laundries if they were suspected of sexual activity outside of marriage, or were pregnant and unmarried. Some women were shunned and lost contact with their families. The last laundry closed quite recently, in 1996. The latest Irish census saw the decline in those who identified as Roman Catholic (92% in 1991 v 78% in 2016) and, congruently, a rise in those with no religion (1.8% in 1991 v 10% in 2016) (4).

Moreover, Ireland has a history of committing atrocities to women in childbirth. Within hospitals, a brutal surgical procedure, symphysiotomy was frequently used on women giving birth in Ireland, usually performed without consent. In this procedure (also known as pelviotomy), the cartilage of the pubic symphysis is separated and it was carried out in place of Caesareans in Ireland, leading to long term health problems for women (6). Attitudes towards women and sexuality have changed and Irish society has become more open since the Millenium.

There is a mixed public/ private health care system in Ireland, free care is available in the antenatal period and for up to six weeks postnatal for those ordinarily resident. In 2016, 82% of women opted for shared care (7). There is private Obstetric care available at all 19 units nationwide for a fee, and there is one fully private unit. The prevalent model of care is Obstetric-led, with the result that most births in Ireland occur in hospitals today. Correspondingly in 2016, 99% of women were booked hospital admissions (7). In fact, Ireland has one of the lowest homebirth rates in the world (approximately 200 per year-0.2%) (8). In comparison, the rate in England is 2.2% and 0.7% in the USA (8).

Traditionally in Ireland, the mother would not have their partner present at the birth, relying on the midwife and perhaps a female family member for support in labour. However nowadays, when giving birth in hospital, unlike other countries which allow at least two people with the labouring mother, most Irish hospitals allow just one support person to stay. Usually, this is the other parent, despite good evidence from a Cochrane Review involving 15,000 individuals from 17 countries, that support in labour and childbirth for women from a person other than their partner, (perhaps a doula), is beneficial for emotional support and information about labour progress (9). These benefits included more spontaneous births, shorter labours, less likely use of analgesia or have a CS, and more likely to be satisfied with their birth (9). The review described concerns that lack of continuous support may lead to a negative birth experience and poor quality of care, due to institutional routines in modern obstetric care (9). Improving women's experience by supportive care during labour may lead to improved self-efficacy and control during labour and birth, reduced need for obstetric intervention and superior physiological labour processes (9). Thus, this particular

nuance of Irish maternity culture may influence women's expectations and experience of the labour and birth process.

Irish obstetricians pioneered a timeline for labour, the partogram, and championed the active management of labour, which had a ripple effect globally. Birth has become progressively medicalised in the Western World, in parallel, clinical practice has become more risk-averse; it has been suggested that this has led to a culture of fear (10, 11). Furthermore, there is a growing organisational culture of fear driven by practices that are influenced by 'risk'(10, 11). The concept of the 'paradox of timid prosperity' as described by Taylor-Gooby (2000) is cited where anxiety has increased rather than reduced despite an increase in safety in giving birth in the Western world (10). Findings from a qualitative study on fear of childbirth in Northern Ireland indicated that most couples perceived medical interventions as a resource for a safer birth (12). However, The Lancet series "Too much too soon, too little too late" recognises that in many high-income countries too many unnecessary medical interventions are performed, sometimes incorrectly, and sometimes the adverse risks of these interventions are not explained to women (13).

Overuse of interventions can be associated with morbidity, while other interventions, which are known to benefit women, such as having a supportive birth companion are under-used. Furthermore, in 2018, the World Health Organisation (WHO) released a guideline (14) with key recommendations for labour to ensure a positive birth experience, that each labour is unique and do not all progress at the benchmark of 1cm per hour of cervical dilatation, this is unrealistic for some women. WHO recognises that this is important in order to reduce the increasing number of CS (14). Crucially, the WHO highlighted that childbirth needs to go beyond simply 'having a healthy baby' and aim to ensure a 'good birth' for all women (14).

In comparison to the majority of OECD countries (apart from a few), Ireland differs in that abortion is not currently available, which is relevant because women have no choice but to remain pregnant. Article 40.3.3 also known as the Eighth Amendment, stated that 'the state acknowledges the right to life of the unborn and, with due regard to the equal right of the mother, guarantees in its laws to respect, and as far as practicable, by its laws to defend and vindicate that right'(15). However, in 2018, a Referendum to repeal the eighth amendment was successful, which means that soon the legislation will be changed so that abortion before 12 weeks gestation will no longer be a criminal offence, and in addition, women will have the right to refuse treatment in pregnancy (15). Up to now, the right to life of the fetus was equated with the right to life of the mother. Thus, decisions in relation to pregnancy were therefore in the hands of health care professionals rather than women themselves.

The case of Miss Y was a tragic example of this. A woman who had travelled to Ireland for Asylum, following brutal violence in her country of origin, was pregnant following rape. She was living in Direct Provision, and access to travel for a legal abortion in the UK was extremely prohibitive, difficult and expensive. Thus, she was ultimately forced to keep the pregnancy, despite expressing suicidality. After she went on hunger strike, doctors informed her that they would terminate the pregnancy if she ate, she resumed eating, reached viability, and was subsequently delivered by CS. Thus, cases such as this which were in the public eye may have implications for how the mother attains her identity and views the childbearing process overall. Extreme cases like these influence how mothers in Ireland perceive childbirth and it is likely that pregnancy and birth are perceived as a 'risky' event, in which mothers do not have control over their own body and decisions about childbirth.

To date, the majority of research on fear of childbirth has been undertaken in Scandinavia. The first published study was performed in Sweden in the early 1980s (16) reporting that 6% women experienced fear of childbirth, but prior to this, there was no attention paid to fear of childbirth in research or clinical practice.

Despite growing interest in the field, we still have a limited understanding of the phenomenon, although we now know that it is extremely complex. Up to now, it has not been explored in Ireland. Therefore, this doctoral thesis will aim to add to the current body of knowledge on fear of childbirth and investigate the phenomenon of tocophobia in an Irish setting.

### 1.1.3 Fear of childbirth in Policy and Reports in Maternity Care

Due to physiological and psychosocial changes, women are at the highest risk for developing mental health issues in pregnancy than at any other time in life (17, 18). Mental health issues may be new onset and severe, and in women who previously experienced perinatal mental illness, relapse is possible in subsequent pregnancy (17-19). The most commonly experienced psychiatric disorders are anxiety and depression, ranging from mild to severe (19). There has been less research attention on mental health in the antenatal period than the postnatal period historically (18-20). Current Irish policy recommends preventive treatment and action plans as they may help to stop onset and relapse (17, 19).

An international position paper published in 2017 stressed the need for a perinatal mental health speciality with a focus on recognising at-risk mothers during pregnancy and in the postnatal period to prevent primary and secondary mental illness (21). In addition to ensuring that parents have access to experts in the field to address their concerns, recognising, identifying and treating mental illness in the perinatal period

may result in significant economic savings (21). In this position paper, the absolute lack of perinatal mental health services in Ireland was highlighted in particular as an example, while globally no country has come near to meeting the needs of mothers and infants (21). Where services do exist, they are not accessible to all women due to poor funding leading to lack of availability, and stigma persists in relation to accessing mental health services (21). Recognising and supporting women with fear of childbirth who may have vulnerable mental health is important to prevent further deterioration in the perinatal period.

The specialist perinatal mental health model of care in Ireland was launched in November 2017 and recognised tocophobia under the umbrella of anxiety disorders relevant in the perinatal period (22). It is crucial to acknowledge that women with tocophobia are more likely to have anxiety and depression, and may also have overlapping co-morbid mental health issues (23-25). This document for the proposed clinical pathway for perinatal mental health in Ireland highlights the importance of providing emotional and psychological support with equal value to physical health for women in the perinatal period and recognising the need to prevent and detect any mental health issues (22). There is no specific information about women with tocophobia in Ireland in this document (22). It is proposed that women with tocophobia under the new model would be referred to the new specialist perinatal mental health team as an outpatient (22).

This new proposed perinatal mental health model is in accordance with the overall aim of the WHO Mental Health Action Plan (2013-2020) which is to promote mental well-being, prevent mental disorders, provide care and enhance recovery for individuals with mental disorders (26). More specifically, the WHO recognises the significance of maternal mental health in Millennium Development Goal 5 and Sustainable

Development Goal 3 focuses on ensuring healthy lives and promoting well-being of all at all ages, which is essential for women and infants to thrive (26).

Recruitment into the perinatal mental health teams has commenced. Limerick is the first county to implement the Irish model of care for perinatal mental health, with a good uptake of the service so far. However, no care pathway has been developed for women with fear of childbirth in Ireland yet.

Globally, many maternity services provide specialised care for women with fear of childbirth due to growing evidence of the marked negative impact on women's health and well-being. Services that do exist for women with fear of childbirth vary in availability and in type of care offered, with various health care professionals leading the service (27, 28).

In terms of screening, the National Institute for Health and Care Excellence (NICE; CG192) proposed using the two-question Generalised Anxiety Disorder (GAD-2) questionnaire in order to identify anxiety disorders in pregnancy and in the postnatal period. This recommendation is based on expert consensus, rather than evidence, due to concern related to the prevalence of anxiety disorders (29). However, there is a lack of evidence as to the accuracy of the GAD-2 in diagnosing and identifying anxiety disorders in pregnancy. A UK study (n=545) found that GAD-2 may create false positives, therefore may not be the best option for use in maternity services (30). Furthermore, this tool would not recognise women with fear of childbirth, since anxiety is a different construct.

In Sweden, the Fear of Birth Scale (FOBS) has been adopted in a number of clinical settings as a screening tool, stimulating a discussion between the clinician and the mother about fear of childbirth. It is short and user-friendly, consisting of a two-

question VAS (31). This tool underwent psychometric testing with success (32, 33) and findings from a qualitative study conducted in Sweden suggests that the FOBS is acceptable by women (34). A cut-off greater than 60 on the FOBS indicates that the woman may benefit from further investigation, and a clinical assessment using an interview is recommended to explore the cause or root of the fear . This tool may be the most practical option for opening a discussion about fear of childbirth with pregnant women.

Women may request CS as a way to reduce the perceived risks related to childbirth. Tocophobia is included in Section CG192 of the NICE Guidelines (29) and is recognised as a possible reason for planned CS, which must be performed after 39 weeks. However, it is recommended that this decision is carried out following obstetric and perinatal mental health assessment, due to increased risk of new-born respiratory difficulties following CS. According to CG192, if an obstetrician is unwilling to perform the CS, for this reason, they should refer the woman to an obstetrician who will (29). In the Irish model of care document (22), there is no reference to a discussion about the planned mode of birth for women with tocophobia. Nonetheless, women in Ireland already accessed planned CS at maternal request based on CG192.

At present in Ireland, a specific service does not yet exist, and there has been little research into the phenomenon of fear of childbirth on the island of Ireland. Therefore, there is a need for this research.

### 1.1.4 Defining fear of childbirth and tocophobia

It is important to recognise that worry, anxiety and fear are separate constructs. Worry is normal; women may worry about a situation but verbalise a possible solution, anxiety is usually future-oriented with an imagined negative situation which persists over time, whereas fear is future-oriented with no possible solution and characterised by avoidance behaviours. Fear exists on a continuum from normal worry and anxiety, which may be protective, since the automatic response to worry about health is to seek help or advice (35), to rumination (more chronic worrying), to extreme phobic fear leading to avoidance. Women are significantly more likely to suffer from anxiety disorders than men, and, may be particularly vulnerable to developing anxiety disorders or relapsing during the perinatal period (36). Although fear is a separate emotion to anxiety, fear of childbirth is classified broadly with anxiety disorders (30). Women may have Pregnancy Specific Anxiety (PSA) where they have particular anxiety related to pregnancy separate to fear of childbirth or PSA and fear of childbirth may overlap (37). "Fear of childbirth has been recognised as a psychological domain in its own right" (38).

Fear of childbirth exists on a spectrum from low to high fear, with a phobic fear at the top end of the spectrum. Levels of fear may be low, moderate, severe or phobic. When women have low fear, this can be seen as having normal worries associated with pregnancy, where women cope with everyday life and prepare for the birth of their baby (3). Some women experience a moderate fear which does not affect her mental health, but which she may have difficulty self-managing and seek support (3). Severe fear and phobia fear differ in that severe fear affects the woman's daily life and bond with her baby, whereas phobic fear results in women who are so afraid that they avoid

pregnancy or are phobic about the mode of birth (3). Since there is no optimal measure of fear of childbirth, it is difficult to assess when a fear becomes a phobia.

The term tocophobia derives from the Greek origin ‘tokos’ and ‘phobos’ -literally meaning fear of contractions and has become synonymous with fear of childbirth (FOC), increasingly used in maternity settings for mothers who request CS with no medical indication. However, there is a lack of a consensus on a definition for tocophobia, and the term appears to be used for a range of psychological difficulties experienced by women in the perinatal period. In general, phobias are extremely common, affecting approximately 9% of people (39). This specific phobia differs from others. Unlike other phobias, the individual must face their worst fear, since giving birth is unavoidable when pregnant.

Since fear of childbirth is a separate psychological domain to anxiety, there are various specific validated questionnaires used to assess and measure fear levels. This thesis assessed the various measurements for fear of childbirth and found that the most common tool currently used in research is the Wijma Delivery Expectancy Questionnaire version A (W-DEQ A) (40). This questionnaire has successfully been translated into many languages and undergone rigorous psychometric analysis. The original authors suggested a cut-off greater than or equal to 85 to define severe fear of childbirth and greater than or equal to 66 to define high fear. However, various subsequent studies used different cut-off scores to define high or severe fear. More recently, researchers have been looking more deeply into how to investigate the cause, as well as the severity of the fear. In addition, a tool should be clinically useful and acceptable for use in an outpatient setting by women and midwives. Since the W-DEQ A consists of 33 questions, with some reverse scoring required, it may be considered complex and time consuming for clinical use, although it is used in practice at present

in Scandinavia. A study in the US highlighted the issue of literacy, stressing that the English literacy requirement needed to complete the W-DEQ A was higher than average (41).

Earlier, I described the FOBS, a two question VAS, with a cut-off greater than 60 used to define FOC, which is also commonly used (32, 33). Some other questionnaires exist but are less commonly used, such as the Childbirth Attitudes Questionnaire (CAQ) (42). The Delivery Fear Scale has been used to assess fear during labour (43). In some countries, fear of childbirth has been allocated an International Classification of Diseases (ICD-10) classification code since women have attended specialised phobia clinics. Therefore, in terms of defining fear of childbirth, the use of the ICD-10 code is restrictive since it is limited to women who had treatment for fear of childbirth in secondary care.

Tocophobia may be diagnosed by a psychiatrist using a structured clinical interview, but there is no evidence of the psychological mechanisms or psychopathology. Thus a diagnosis may be subjective (30). It is more likely that a woman may be diagnosed with a Generalised Anxiety Disorder or specific phobias such as fear of blood, needles or hospitals than tocophobia. In extreme cases, psychiatrists can use a structured clinical interview for DSM-IV (SCID-1) to specifically identify tocophobia. However, access to perinatal psychiatrists is extremely limited in maternity care worldwide (21), so this is not usual.

In a UK study by Nath et al, women were interviewed by a psychiatrist using this criterion (n=545) (30, 44), the cases of tocophobia were extremely rare (0.03%), with 17% having Generalised Anxiety Disorder and 8% having a Specific Phobia. A small Italian study of nulliparous women by Calderani et al (n=106), published in 2019 (after

I submitted this thesis) set out to compare the W-DEQ A≥85 with a structured clinical interview by a psychiatrist using the DSM-5 criteria and found that the W-DEQ A≥85 had sensitivityof 100% at this cut-off with a high specificity (93.8%) (45). The prevalence in this study was 14%, which is quite high given the small sample size. This could be related to the high prevalence of women in the study with a lifetime history of psychiatric disorders (n-=25). This evidence suggests that even when structured clinical interviews using pre-specified criteria performed by psychiatrists, it is open to interpretation and the results are subjective, but suggests that the W-DEQ A is a valuable tool for screening women.

Over the last five years, my understanding of the subject changed, due to the growing interest and thus, the growing body of knowledge on this topic. At the outset of my PhD, I set out to investigate 'tocophobia' in pregnant women. In the first part of this thesis, the literature review, it was established that tocophobia is not clearly defined; thus the first aim of this doctoral thesis was to examine the literature in relation to how tocophobia is defined by conducting a systematic review. In addition, a meta-analysis was performed to determine a global pooled-prevalence estimate.

However, as discussed, it became apparent that it is normal for pregnant women to have some level of fear of childbirth, and that true 'tocophobia' itself is quite rare. So, although there is a continuum of fear of childbirth from low to high fear with tocophobia at the top end, the terms 'tocophobia' and 'fear of childbirth' are used interchangeably in the literature and in practice. It is not known when fear becomes a phobia and this is difficult to measure. Thus, as my PhD progressed, I decided that my PhD should investigate the spectrum of fear of childbirth, rather than limit the focus to 'tocophobia'. Therefore, following on from the meta-analysis, the prevalence study

used the best measure of FOC available at present, the W-DEQ A (40). The cut-off W-DEQ A≥85, while commonly used, is not an exact science, as there has been critique of this tool, therefore W-DEQA≥85 is referred to as 'severe fear of childbirth' in the thesis. Moderate and high levels of FOC are also reported, as well as the W-DEQ A subscales to examine the nature in addition to the severity of the fear.

As a point of clarification, in the literature review and systematic review I focussed on the term 'tocophobia' only, but, in the latter chapters of this thesis, I concentrated on the spectrum of 'fear of childbirth' to encompass all women experiencing high to severe and possibly phobic levels of fear. The terms have been used interchangeably since it is not clearcut. Both terms are used in the title of the thesis to enhance the searchability of the thesis for those with an interest in the field.

### 1.1.5 Fear of childbirth in Ireland

There has been difficulty in defining fear of childbirth, and various measurement scales with various cut-offs exist; prevalence reports have differed. Worldwide, up to 80%, pregnant women have some fears about childbirth (46). Approximately 20% of women have high fear and further 6-10% women have severe fear of childbirth (47). A large study of 6 European countries (Belgium, Iceland, Denmark, Estonia and Norway) (n=6870) (48) reported a prevalence of 11.2%. There was no previous meta-analysis conducted. Therefore the next aim of this thesis was to conduct a systematic review and meta-analysis of the global prevalence of tocophobia in pregnant women. Following on from this systematic review, no Irish prevalence study was located; therefore, there was a need to conduct an Irish prevalence study.

In a search for studies about fear of childbirth in Ireland, only one study based in Northern Ireland was located (12). The aim of the descriptive qualitative study (12)

was to explore fear of childbirth and its impact on birth choices among women and their partners using a purposive sample of 19 women and their partners (n=38). While the study has merit, a number of methodological considerations need to be taken into account. The main weakness of the study is that the sample did not specifically consist of couples who expressed fear of childbirth, but rather women deemed to be of obstetric 'low-risk'. Secondly, the study used thematic content analysis to analyse the data but presented some results as statistics which is not consistent with the type of data collected. The sample size of the study was large given that it is qualitative, a smaller sample size would have allowed for richer data analysis. A major drawback of the use of a large sample is that not all participants are represented in the quotes and some participants have more than one quote included in the results. The risk of a large sample when conducting qualitative research is that results may be superficial and lack depth (49). A better study would stop data collection upon saturation of concepts or when new themes stop emerging (49). Three concepts; 'riskiness', 'ways of coping' and 'being a good parent' were found. Findings of the study indicated that medical interventions were chosen as way to cope with the uncertainty of childbirth rather than midwifery support (12). These findings are useful, despite the limitations acknowledged, given the lack of knowledge in relation to fear of childbirth in Ireland. There were no quantitative studies located in the search. Thus, there is a need for information about fear of childbirth in Ireland.

### 1.1.6 Risk factors and reasons for fear of childbirth

Women with fear of childbirth commonly experience other psychological difficulties such as depression and anxiety (50-54). A Norwegian study (n=1642) found that while presence of anxiety and depression increased prevalence of fear of childbirth, most women with fear of childbirth did not have anxiety or depression. Two other

Scandinavian studies found associations with psychiatric diagnoses and fear of childbirth (52, 54). A large epidemiological study using three National Health Registers in Finland over a period of eight years (n=511,422) reported that fear of childbirth was a significant predictor of postpartum depression [adjusted OR 2.71, 95%CI 1.98 to 3.71] (55). Low self-efficacy in the ability to give birth has been associated with fear of childbirth (42, 56). Pain-catastrophising and generally anxious personalities in which women cannot tolerate uncertainty have been associated with fear of childbirth (51, 57-59). The intolerance of uncertainty is a characteristic in which women tend to have a pessimistic view of possible outcomes of a situation (58).

Sexual abuse (adult or childhood), intimate partner violence and unintended pregnancy are associated with fear of childbirth (48, 60-66). Occult memories of sexual abuse may be triggered during labour and birth. Thus fear of childbirth may present in women after birth which was not previously present (66). In a study of 426 women in Denmark, 9.2% (n=244), women experienced sexual violence in their lifetime and experience of sexual violence was associated with increased risk of fear of childbirth after delivery, compared to those who had never experienced violence [OR 1.5, 95%CI, 1.02-2.27] (66).

Moreover, fear of childbirth is associated with low social support (48, 51). In a Swedish study (n=606) of which 22% were born in a foreign country reported that primiparous foreign-born mothers were significantly more likely to have high fear of childbirth [OR 3.8, 95%CI 1.8-8.0]. Therefore it is possible that various ethnic groups may have culturally sensitive requirements (67). In terms of socio-demographic risk factors, reports have varied. This may be related to cultural or societal norms such as the availability of contraception, reproductive rights, and obstetric care models. In Finland, fear of childbirth was more prevalent among women of high maternal age

and high or unspecified economic status (68), whereas in a Danish study, it was more prevalent in women with low maternal age (25).

There is little information about fear of childbirth in low and middle-income countries. A small study of nulliparous women (n=160) in Iran using the CAQ found that fear of childbirth was not a predictor of postpartum depression, but presence of state and trait anxiety was (69). No previous published Irish study investigated risk factors for fear of childbirth. Thus, the secondary aims of the prevalence study in this thesis were to investigate risk factors of fear of childbirth.

The reasons for fear of childbirth are complex. Common fears include fear of labour pain, fear of the unknown and fear for the infants' health (70). Giving birth is a private and intimate experience. Therefore, women fear being cared for by an unknown person or fear loss of control by being unable to take an active role in decision-making about their birth (71). As mentioned, fear of childbirth has strong associations with previous sexual abuse (62) and also with intimate partner violence and unintended pregnancy (61, 66). WHO estimated in 2006 that lifetime prevalence of physical or sexual partner violence varied from 15 to 71% (17). More recently in 2013, a meta-analysis estimated 30% of women aged 15 and over worldwide experienced physical and or sexual intimate partner violence (18). Therefore, this is a common issue which women may or may not disclose during pregnancy.

Traditionally research on fear of childbirth suggests women fear vaginal birth and request Caesarean Section (CS) as a way of coping. However, it has become apparent that conversely, some women fear medical intervention, lack of control or being involved in decisions about their birth, and may fear having a CS. Thus, as mentioned, the issue is, not psychopathological or situated within women, but rather external,

within health care systems and medical routines inherent in current practice. Additionally, issues with staffing and increased pressure on maternity systems which lead to stressed staff and subsequent negative experiences of women. Moreover, internationally, in certain contexts, it has come to light that health care professionals may be the perpetrators of institutional abuse-physical, verbal or sexual, termed 'obstetric violence'(72). As a result, some women may be fearful of abuse by health care professionals or neglect during labour.

At any point in the perinatal period, fear of childbirth may be triggered, resolved, or be aggravated, resulting in tocophobia, or Post Traumatic Stress Disorder (PTSD), which are inter-related issues, and may overlap (30). Rachmann (1977) described three pathways of fear (73); fear conditioning (learned association); vicarious exposure; and indirect transmission via information. An example of learned association could be a negative experience of being in hospital, or a negative birth experience. Vicarious exposure to a stimulus can have a positive or negative influence on fear. For example, witnessing a birth without adequate explanation could trigger fear. However a controlled exposure to birth, or witnessing birth with support may reduce fear in some cases. Some interventions use controlled exposure to the stimulus as a treatment. Finally, transmission via information (such as horror stories about birth) has been topical. Sharing dramatic stories via social media has been suggested as a trigger of fear of childbirth (74).

Characteristically, when faced with a perceived threat to survival, there is a neural and physiological response to the fear stimuli, commonly known as the 'Fight or Flight response' (first described in 1929) (39). In the brain, the amygdala stimulates the autonomic nervous system and triggers the release of hormones, such as epinephrine (adrenaline) and cortisol (39) (Figure 1-1). The neural changes result in a physical

response since energy is diverted to parts of the body that would allow the women to mobilise to avoid danger (39). This physical response thus incorporates tachycardia and shallow breathing, cognitive changes (hyper-arousal or alertness) and behavioural (usually a wish to escape) (39). Furthermore, chronic activation of the 'Fight or Flight' response, may lead to immunosuppression, chronic fatigue, depression and recurrent physical ailments such as headaches or stomach aches (39), but it is unknown at what level of fear this response occurs (75).

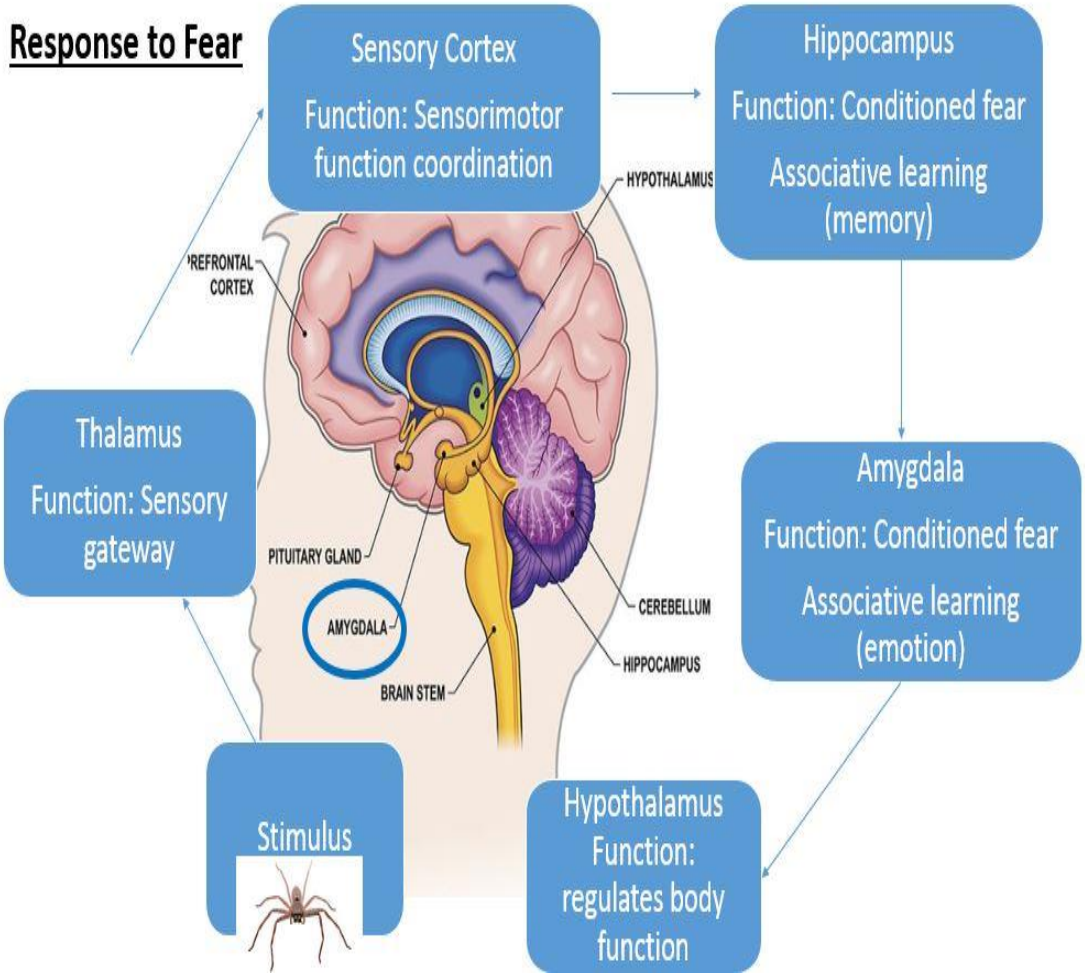


**Figure 1-1. The neurological response to fear**

In the case of tocophobia, the situation feared most is unavoidable (since pregnant women must give birth), and some women will seek a CS (70, 76) as a means of coping since they find it preferable to vaginal birth. Although for some women, the source of fear is indescribable and is not necessarily related to fear of a vaginal birth, but other complex factors, such as maternal self-efficacy in the ability to birth (42), as well as external reasons such as lack of trust in maternity systems, being left alone in labour or lack of control or participation in decision-making during labour (70, 76, 77).

Fear of childbirth can occur after birth trauma, in severe cases resulting in tocophobia. When this occurs, women may avoid subsequent pregnancy, have large gaps between pregnancies or request a sterilisation (78). Approximately 30% of women report some aspect of their birth as traumatic (79) and not all women with birth trauma develop Post-Traumatic Stress Disorder (PTSD). Birth trauma can lead to PTSD, Obsessive Compulsive Disorder (OCD), depression and anxiety. Approximately 3-6% of women may have PTSD and experience symptoms of trauma such as panic attacks, intrusive thoughts, anxiety and anger or irritability (80). For these women, attending the hospital where they previously gave birth may lead to flashbacks, and ultimately, they may request a CS as a way of having control over the situation feared. Some women will go on to have a positive vaginal birth experience with sensitive birth planning. However, if there is a deviation from the plan, and the woman has another negative birth experience, women with pre-natal fear of childbirth are particularly vulnerable to post-traumatic stress and postnatal depression (55).

Fear of childbirth is particularly relevant for midwifery care since there is cumulative evidence to suggest that midwives play a critical role in ensuring a positive birth experience for women (81-83). A qualitative study in the UK described the profound impact a traumatic birth may have on a mother and the subsequent redemptive experience of a positive birth experience following a traumatic birth with the support of a trusted caregiver (84). The subsequent birth was described by women as ‘joyful’ and ‘unexpectedly life-changing’(Pg. 108) (84). Thus, women need an individual mutual discussion to consider their birth preferences and to plan for mode of birth.

### 1.1.7 Fear of childbirth and Caesarean Section

Globally, increasing CS rates in developed countries have risen from 5% in the 1970s to greater than 50% in parts of the world in the 1990s, which is concerning (85). In line with these global increases highlighted by the WHO survey in 2005 (85), rates in Ireland have increased in the last ten years with approximately one-third of pregnant women having a Caesarean birth. This may be attributed to the increasing institutionalisation of birth in an attempt to make childbirth safer for mother and baby as CS was seen as a universal solution to all obstetric complications (86). Conversely, the 2005 WHO global study on maternal and perinatal health discovered that while CS is more and more perceived to be safe, increased rates of CS are associated with greater severe maternal morbidity and mortality, and higher fetal and neonatal morbidity even after adjustment for demographic characteristics, risk factors and pregnancy complications, type and complexity of institution (85). CS was not found to improve perinatal outcomes; in fact, an increase in fetal death was noted, especially with elective CS (85).

Previous research found that strong fear of childbirth is associated with a preference for CS (68, 87) and women with a history of previous CS are more likely to have strong fear of childbirth (87, 88). As discussed, fear of childbirth is a recognised reason for CS in the UK according to NICE CG 192 (29). Some women with fear of childbirth see CS as a solution to cope and will avoid discussing the birth process or attending birth preparation classes (82, 89). However, some studies suggest that vaginal birth may be acceptable to some women, with adequate support during childbirth, and in the case of PTSD, subsequent birth has the power to heal or to re-traumatise women (84, 90-93). In addition, due to the lack of clarity in defining tocophobia, in some cases, what may be considered ‘normal’ fear of childbirth has been conflated with

tocophobia since the concept is not well-understood (44). Overall, the emotional well-being of the woman should be the priority, rather than the mode of birth.

### 1.1.8 Fear of childbirth and pregnancy outcomes

To date, there is a lack of research in relation to fear of childbirth and pregnancy outcomes. Only two studies reporting pregnancy outcomes for women with fear of childbirth were located in a search of the literature (68, 94). There were no adverse pregnancy outcomes reported for this cohort of pregnant women. While one study was a large epidemiological study (68) based on information from the Finnish Medical Birth Register, FOC was defined using an ICD-10 code used for women who attended a clinic for counselling for FOC, which limits to women who accessed treatment. The other study (94) reported on the duration of labour and found that women with FOC had on average a one hour longer labour duration.

The literature on anxiety in pregnancy has inconsistent evidence in relation to pregnancy outcomes. One meta-analysis (95) found an increased risk of preterm birth and low birthweight in mothers with anxiety in pregnancy. Low birthweight may represent a pathological limiting of fetal growth and a failure of the fetus to reach its growth potential (96). This is of concern since it is well-established that in utero growth restriction (IUGR) is associated with stillbirth (96, 97) and childhood morbidity (96, 98). Moreover, IUGR has long-term consequences such as chronic hypertension, cardiovascular disease and type two diabetes in adulthood (99). IUGR is the term used in relation to the fetus, whereas the term “Small for gestational age” (SGA) is used for the new-born baby (96). A birthweight less than the 10$^{th}$ centile for gestational age would be considered SGA (96). Thus, birthweight is a measure of the function of growth (96). However, the findings of another large meta-analysis (100)

found no evidence of an association with adverse perinatal outcomes. Therefore, significant gaps in the literature exist in this area and there is a need for further research. Thus, this doctoral thesis included a prospective cohort study to investigate the pregnancy outcomes of women in the prevalence study.

## 1.2 Overall aims and objectives

The overall aim of this thesis is to undertake the first Irish exploration of tocophobia (severe fear of childbirth).

The objectives of the thesis are outlined in Figure 1-2.

Methodology and methods used are described in Figure 1-3.

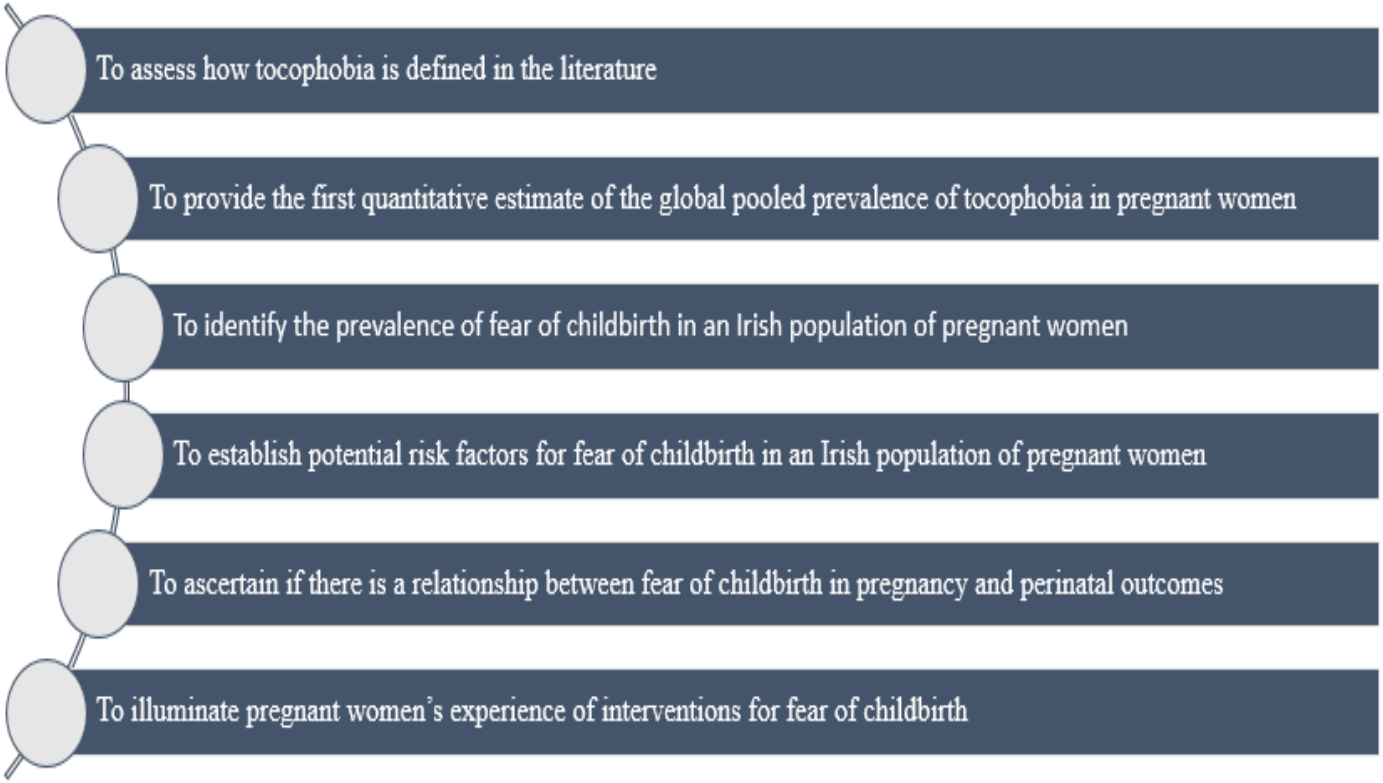


**Figure 1-2. Objectives of an exploration of tocophobia in an Irish maternity setting**

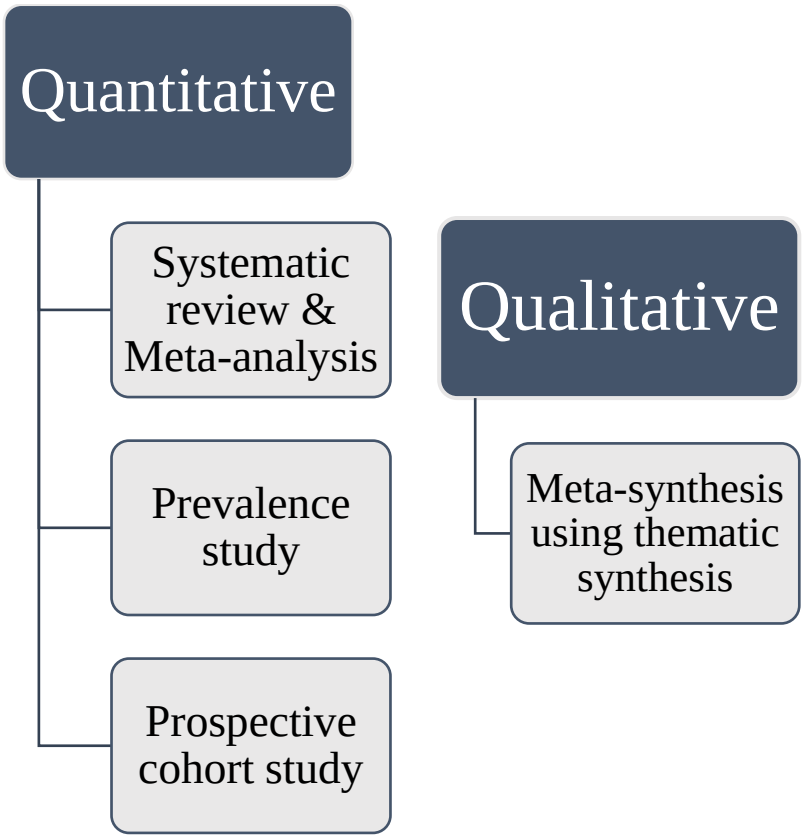


**Figure 1-3. Methodology and Methods**

## 1.3 Study Design and methods

An observational study using a cross-sectional design was deemed appropriate to investigate the prevalence of fear of childbirth. Performing an observational study allowed the researcher to investigate differences in phenomena in natural settings and attempts to gain associations, rather than "cause and effect" conclusions. In observational studies, confounding variables are acknowledged as potential challenges. A structured survey design was used, aiming to systemically collect data from a particular population in order to describe the prevalence, distribution and explore the relationship between variables. A broad range of data was collected from as large a sample as was available to minimise the margin of error. A case study may have also been an option to examine this research question. However, this would have been difficult due firstly, to the sensitive nature of the subject of interest, and at present, women with fear of childbirth are not routinely identified in Irish maternity services. There is also usually no specialised pathway of care or interventions available to women. A cross-sectional survey design was thought to be more appropriate in order to gain a detailed description of trends.

While quantitative research is appropriate to describe data about a phenomenon about which little is known, it must be acknowledged that quantitative data may lack depth of understanding of more complex experiences; therefore this doctoral research employed a mixed methods approach, first of all using quantitative research, followed by qualitative research, in order to gain a more in-depth understanding of the research question. It is common to use qualitative research to better understand and explore more complex aspects of human phenomena in midwifery research. Therefore, it was

considered appropriate to also incorporate a qualitative study as part of this doctoral thesis. The qualitative method utilised was a meta-synthesis.

A meta-synthesis is an amalgamation of existing qualitative research studies on a topic, which aims to go beyond the data to draw new conclusions about a phenomenon and develop new themes.

## 1.4 Study Sample

In order to investigate the prevalence of tocophobia in Ireland, a national sample would have been optimal. However, we were limited due to lack of resources for the study. Therefore, a convenience sample was used for the cross-sectional study. The limitations of the generalisability of a convenience sample are acknowledged. However, the study took place in Cork University Maternity Hospital, which is a large tertiary referral centre in the South of Ireland, with over 8,000 births and 90,000 outpatient appointments every year.

## 1.5 Meta-Synthesis

Meta-synthesis is a relatively new method of synthesising and interpreting qualitative research findings from disparate investigations which may add contextual depth and breadth to existing knowledge on a subject (101). The value of synthesising qualitative research is increasingly recognised in facilitating evidence-informed practice (102). Findings of a meta-synthesis may be more practical in terms of influencing policy development and clinical practice guidelines than traditional qualitative research by making the results more accessible (101, 102). Most individual qualitative research tends to produce findings which are not broadly generalisable, thus are highly unlikely to trigger any change in systems (101). This is particularly important when it comes

to developing and evaluating interventions comprehensively, allowing a more context-sensitive evaluation of the intervention (101).

Researchers that perform meta-synthesis may be referred to as meta-synthesists. Meta-synthesists aim to generate valid, generalizable research findings (101) by using a rigorous and explicit technique to bring the findings from primary qualitative research studies together. The ability to transfer findings from one context to another is fundamental to validity (101). Finfgeld (101) proposed that validity is enhanced by triangulation of studies using a group of researchers to perform an investigation of the phenomenon of interest as each individual brings their unique perspective to the meta-synthesis. This may be thought of as "second-tier" triangulation (101) and involves the same strategies as first tier triangulation. Previously, there were concerns that the aggregation of studies that used various epistemological perspectives may misrepresent the original research findings. However, these concerns are not warranted (101). In fact, there is evidence that merging findings from various epistemological approaches may enhance truth value (101).

Reflexivity is encouraged in the process of meta-synthesis. Meta-synthesists must be aware of their own personal outlooks which may bias their interpretation of the data and also consider alternative interpretations when performing the data analysis (101).

### 1.5.1 Sampling in Meta-Synthesis

To increase generalisability, it is paramount to obtain a contextually diverse sample. This may be achieved by casting a large, wide sampling net (101). It is not helpful to sample more of the same from a single group in terms of transferability to other diverse groups (101). Given the pace of change in nursing and midwifery practice, it is suggested that when evaluating qualitative research studies, findings may be out-

dated. Therefore, studies that are more than ten to fifteen years old should be checked for relevancy in contemporary practice (101). When deciding on the sample inclusion and investigating the available literature, a preliminary review is recommended to establish if a meta-synthesis about the topic is possible. The sample is ideally homogeneous enough to confirm findings but heterogeneous enough to ensure abstraction with meaning (101, 102). Meta-synthesists focus on finding points of similarity rather than difference or irregularities, in order to shape theoretical frameworks and towards generalisability (101, 102). Findings must have explicit meaning in order to be useful for clinicians and policy-makers (101).

## 1.6 Thesis Outline

This doctoral thesis includes a literature review and 4 research papers which investigated tocophobia from an overall global perspective and reported on fear of childbirth in an Irish population of pregnant women. These studies are presented in Chapters Two, Three, Four, Five and Six (See Figure 1-4).

Chapter Two: Literature Review (Paper 1 consisting of an educational review)

Chapter Three: Systematic Review and Meta-Analysis (Paper 2 )

An update of the systematic reviews and meta-analysis using results from this thesis and newly published studies.

Chapter Four: A cross-sectional prevalence study undertaken in Cork (Paper 3).

Chapter Five: A short report on perinatal outcomes for women with FOC (Paper 4).

Chapter Six: A meta-synthesis of women's experiences of interventions for fear of childbirth (Paper 5).

Chapter Seven: Discussion and Conclusion.

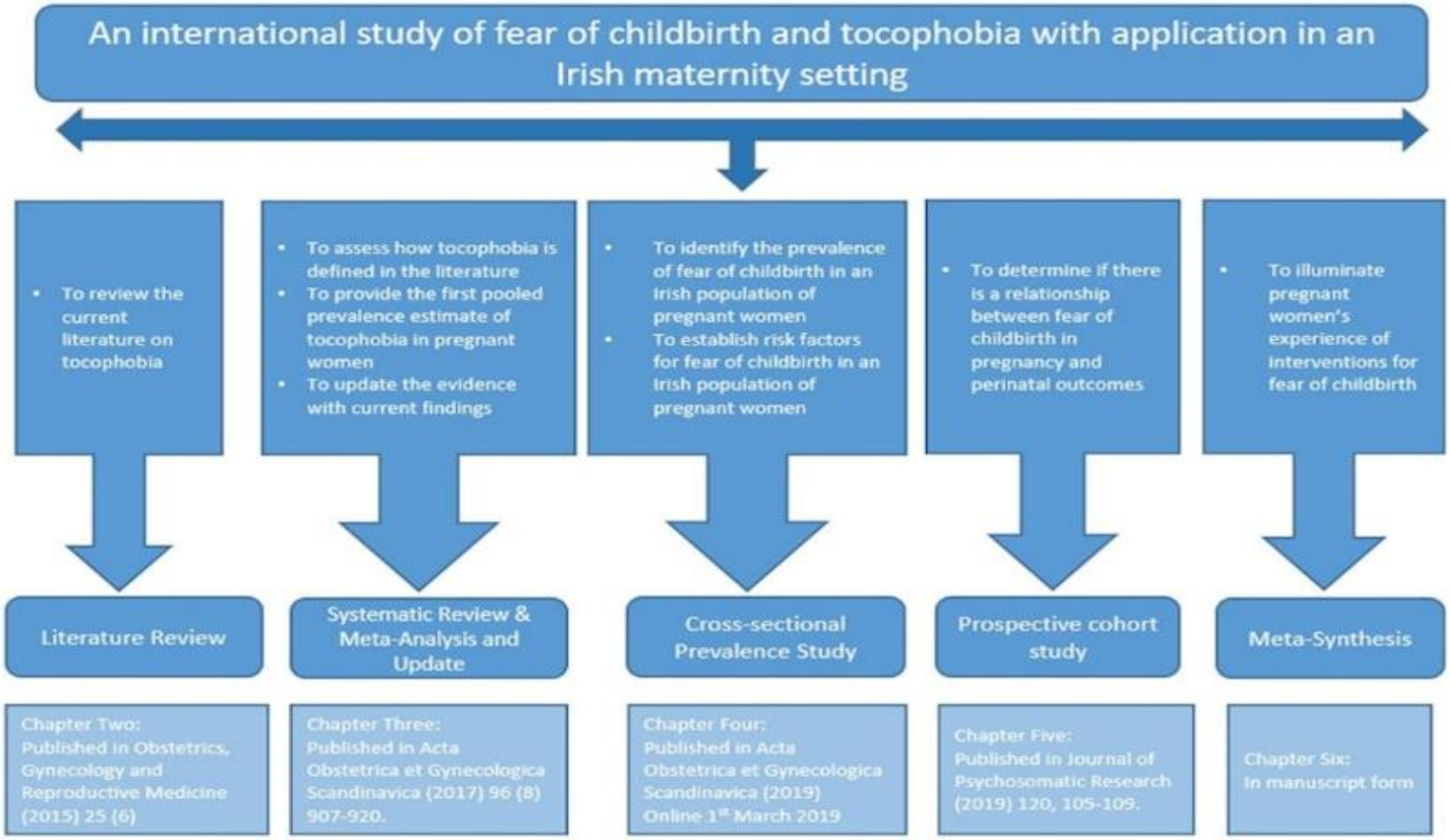


**Figure 1-4. Overall thesis outline with aims, chapters and corresponding publication**

## 1.7 Author Contributions

The PhD candidate was the lead author in the five original research papers presented in this thesis which involved developing the research questions, conducting the literature search, collecting and analysing data, and preparing a draft manuscript for publication.

# CHAPTER TWO.

# LITERATURE REVIEW

# 2.0 TOCOPHOBIA, THE NEW HYSTERIA? [PAPER 1]

Maeve O'Connell

Patricia Leahy-Warren

Ali S Khashan

Louise C Kenny

Invited Peer-Reviewed Published Literature Review:

in OBSTETRICS, GYNAECOLOGY AND REPRODUCTIVE MEDICINE in 2015

## 2.1 Literature Review Methods

The literature review is presented in this chapter, which is comprised of an invited peer-reviewed published paper which is an educational literature review aimed at health care professionals. The paper is presented in the final pre-publication manuscript format. [DOI:10/1016/j.ogrm.2015.03.002].

## 2.2 Abstract

Tocophobia is a severe fear of pregnancy and childbirth. There is increasing evidence that tocophobia has serious adverse effects on both mother and baby, which can be long term. In this review, the concept of tocophobia is discussed in the context of current maternity practice. Maternity caregivers need to be aware of presentation, symptoms and predisposing characteristics of women with tocophobia so that plans can be put in place to help them. Management of tocophobia is individualised and depends on the cause. Early psychological support is vital. Women need to be involved in developing an appropriate birth plan. For some women, it may be necessary to carry out an elective CS. Other considerations may be required depending on the cause of the phobia. If tocophobia is not addressed, it may become worse in subsequent pregnancies or women may avoid further pregnancies. The overall aim is to ensure a safe birth outcome for mother and baby.

**Keywords:** Delivery, Obstetric, Phobic disorders, Fear, Caesarean Section

## 2.3 Introduction

Tocophobia is a severe fear of pregnancy or childbirth (103). Most first time mothers describe fear for the child's health, fear of pain in labour and fear of the unknown; these are completely natural reactions (89). However, tocophobia refers to a severe anxiety disorder characterised by an extreme, irrational fear of childbirth, which provokes a physiological response. When affected individuals are faced with their fear, panic, shortness of breath, tachycardia, trembling and a strong desire to get away may be experienced. Women with tocophobia often usually request CS as a perceived solution (86, 104).

Tocophobia has been documented as far back as the 18th Century. Dr. Osiander in Germany wrote about women who were suicidal due to this severe fear in 1797 (105). This was echoed by the more commonly cited writings of Dr Louise Victor Marcé in 1858 (105) who wrote that pregnant women with tocophobia:

"*…are privately convinced that they are going to die from this ordeal that awaits them. The idea becomes fixed in their heads and triggers a melancholy which takes over all their thoughts*".

150 years ago maternal and infant mortality rates were high and these fears may have been rational. However, maternity care is now safer than ever before and therefore fear of childbirth is now deemed to be irrational. Nevertheless, for a minority of women it is an extremely debilitating condition. In this review, we discuss the aetiology, the effect on pregnancy outcomes, symptoms and management of tocophobia.

## 2.4 Definition and Prevalence

There is no general consensus as to the precise definition of tocophobia and therefore prevalence estimates vary widely. Since 1997, tocophobia was included under ICD-10 Code O99.80 Other specified diseases in pregnancy. Presently, it is included under 2015 ICD-10-CM Diagnosis Code F40.9 Phobic anxiety disorder, unspecified.

Tocophobia may be primary or secondary (78, 106). Primary tocophobia affects nulliparous women. These women have a deep fear of childbirth, which may conflict with a strong desire to be a mother (105). Primary tocophobia often originates in childhood or adolescence following a negative experience such as sexual abuse or hearing of negative birth experiences from family members. The actress Dame Helen Mirren has identified as being tocophobic, blaming a graphic video she watched as a schoolgirl for her phobia leading to her decision never to have children (107). Secondary tocophobia affects multiparous women and is often the result of a previous traumatic experience such as stillbirth, fetal abnormality or birth trauma (78).

Scandinavian countries have pioneered in the field of Tocophobia research.

There are specific multi-disciplinary clinics in most Scandinavian countries for Tocophobia and women under this care pathway have been allocated ICD codes. This has resulted in the generation of significant data, some of which has recently been published. A 2014 Finnish study found the prevalence of tocophobia to be lower than previous studies (2.5-4.5% compared to previous estimates of 6-10%) (68). This study (68) highlighted the significant morbidity associated with Tocophobia such as postnatal depression, higher neonatal ICU admissions, reduced birth weight and reduced infant bonding and attachment. This study (68) also showed that prevalence increased significantly over this period of time (from 1.5% in 1997 to 7.8% in

multiparous women in 2010 and from 1.1% in 1997 to 3.6% in 2010 in primiparous women). This is possibly due to increased public and clinical awareness of tocophobia, which, over the course of the study, led to increased referral and self-referral for treatment. The BIDENS study of 7200 women in 6 European countries found significant differences in prevalence between countries ranging from 1.9 to 14.2% (108). Women in Belgium had significantly less fear than women in Sweden and Estonia (108). This increased prevalence of tocophobia may be explained by a higher immigrant population and a higher number of primigravid women in this study in Sweden. There is increasing evidence that foreign-born mothers are more likely to have tocophobia (109).

## 2.5 Aetiology of Tocophobia:

### 2.5.1 Secondary to Personality Characteristics

Background personality characteristics predispose women to tocophobia. Women who fear childbirth have been shown to have higher levels of generalised anxiety and depression (110). This may be linked to a perceived lack of social supports and low self-esteem. Low self-esteem is associated with low self-efficacy. Accordingly, women who have low self-efficacy are more likely to have tocophobia (42). Tocophobia has been strongly linked to both antenatal and postnatal depression and anxiety, thus it also increases a pregnant woman's risk for suicide (25).

Tocophobia is also more common in women with obsessive/compulsive personalities who often exhibit obsessive behaviour regarding cleanliness and contamination and seek the 'ideal' birth and motherhood experience (105, 110).

### 2.5.2 Physical Causes

Tocophobia may result from previous sexual abuse (62, 111). Women fear giving birth as procedures such as vaginal examinations may trigger flashbacks. A previous traumatic birth experience or complicated birth may result in tocophobia (104, 112).

### 2.5.3 Social causes

There is significant evidence that social factors contribute to the aetiology of tocophobia. Women are influenced by the experience and opinions of other female friends and family members when they are pregnant (104). Common myths about labour and birth may cause fear in women. They may fear lack of access to pain relief or being left alone in labour (70). Birth stories from family and friends may affect self-efficacy and confidence in a pregnant woman's ability to give birth (104). See also accompanying table where characteristics of women with tocophobia are described.

### 2.5.4 Cultural Causes

There is much speculation about the negative influence of the media (113). The majority of women and their partners use the Internet as a knowledge source during pregnancy. The quality of information sources may be poor and even incorrect. Reality TV has become popular. Programmes depicting childbirth often do so in a slightly dramatised way and adolescent exposure to these shows without context has been speculated to provoke a morbid fear of birth (113).

In support of this, a Canadian Study of university students showed that those who relied on the media alone as their source of knowledge had the highest levels of fear of childbirth and were twice as likely to prefer a CS as those who cited a variety of sources (114).

It is not just women who fear birth and are affected by societal portrayal of birth. In a recent Swedish study of 1047 expectant fathers 13% reported tocophobia (115). Men may influence their partner's self- esteem and confidence in their ability to give birth (115). Men with tocophobia may also drive the decision to request an elective Caesarean section, their partners have less attendance at antenatal classes, and they have more parenting stress at one year after birth.

## 2.6 Characteristics of women with tocophobia:

- Young Maternal age
- Advanced Maternal Age (>40 years old)
- High Socioeconomic Status
- Low level of education
- Unemployment
- Smoking
- Anxiety before or during pregnancy
- Depression before or during pregnancy
- Single marital status
- High Risk Pregnancy factors such as: IVF Pregnancy, Gestational Diabetes or congenital anomalies
- A Previous C-Section
- More common in nulliparous women
- In Nulliparous women, tocophobia is associated with smoking
- Witnessing birth at a young age with no explanation

## 2.7 Presentation:

Women may have panic attacks, insomnia and nightmares (50) . They may express disgust at pregnant women and related stories or pictures. They may leave antenatal appointments abruptly or walk out of an antenatal class.

Women with tocophobia may have repeated GP attendances or day admissions or on the contrary, book late and may be poor attenders. These women often present to clinicians late in pregnancy with a request for an elective Caesarean section as they approach their due date.

## 2.8 Consequences of Tocophobia:

### 2.8.1 Risks to the Mother

- Insomnia/ sleeplessness
- Antenatal depression
- Requests for Caesarean section
- Longer labours (Related to increased use of epidural analgesia)
- Increased risk of postnatal depression
- Increased instrumental births
- Post-traumatic stress disorder
- Reduced infant bonding and attachment
- No further pregnancies or large gap between pregnancies
- Subsequent sterilisation

### 2.8.2 Risks to the Baby

- Reduced Infant bonding and attachment
- Increased NICU admissions (8% higher frequency)

- Reduced Infant birth weight
- Long-term emotional effects on infant

## 2.9 Management of Tocophobia:

There is no robust evidence base to demonstrate who is best placed to deal with tocophobia. Consequently, all maternity caregivers need to be mindful of the presentation and aware of management strategies. Recognition and treatment is important. If Tocophobia is not addressed, it may go on to become more intense in subsequent pregnancies and affect women's relationships with their partners and child. However, there is no internationally agreed measure for assessment of tocophobia and no definitive treatment.

The well-established 'Aurora' clinics in Sweden were not preceded by a randomised controlled trial, however there has been general satisfaction with the service and a significant reduction in caesarean section requests with psychosomatic counselling (86% of women who originally preferred to request an elective caesarean section decided to aim for vaginal birth following counselling). A recent randomised control trial of a psycho-educative technique was shown to be effective in reducing fear of birth in Australia (116).

Management of tocophobia depends on its aetiology and severity. For women with mild primary tocophobia, simply listening to their fears and dispelling common myths about labour and birth and offering reassurance of adequate support in labour may be of great benefit in reducing their fear. An opportunity to reflect and de-brief following a traumatic birth experience may be cathartic for women with secondary tocophobia. An explanation as to why things happened may be sufficient to alleviate anxiety.

It is important to be aware that tocophobia may present as a symptom of prenatal depression. The Confidential Enquiries of Maternal Deaths in the United Kingdom have recognised suicide as a leading cause of death in pregnancy and during the first postnatal year and postnatal depression affects 13% of women according to a recent meta-analysis. The Royal College of Obstetricians and Gynaecologists (RCOG) and National Institute of Clinical Excellence (NICE) Guidelines do not specifically refer to tocophobia. It is included under the umbrella of perinatal mental health. The RCOG acknowledge that assessment and appropriate referral of pregnant women presenting with antenatal depression is crucial as there is a risk of suicide. Practitioners should therefore be aware that tocophobia might be a symptom of prenatal depression. Good communication is essential and a multi-disciplinary approach may be necessary. The NICE Guidance incorporates tocophobia under the Caesarean Section on Maternal Request Guidance. There is a focus on encouraging women to have a vaginal birth where possible. It is advised that Caesarean section may be necessary in some cases.

There is increasing evidence that psycho-educative programmes for women with tocophobia may be successful in reducing fear. These counselling programmes focus on reinforcing the woman's confidence in her ability to give birth, allowing her time to ask questions and discuss her prior experiences of birth. Other treatments in use include self-hypnosis in labour and mindfulness therapies. Ongoing support and an individual assessment are beneficial in the treatment of tocophobia. A planned Caesarean section may be necessary for some women.

For others, there may be specific requests that may be identified to help them to deal with their fears such as a female birth attendant or an early epidural. Some women will agree to a trial of labour if they have the 'get out clause' option, an informed choice to not have an instrumental delivery if circumstances allow the option of Caesarean

section instead. This involves a detailed individualised birth plan being developed in partnership with the Obstetrician, Midwives and the woman and her partner. The overall aim of management should be to have an optimal birth experience for the woman and assist her to a happy transition to motherhood whether it is for her first or fifth baby.

## 2.10 Conclusion

Having a better knowledge of the aetiology, symptoms and risks of tocophobia is important for maternity practitioners so that we may offer sensitive, optimal care to these women. Although there is no definitive treatment, it is clear we need to develop a trusting relationship with these women and offer them early psychological support to foster healthy outcomes for mothers and babies. Further research is needed to develop a definitive treatment for tocophobia.

## 2.11 Literature review conclusions

While it is evident that fear of childbirth is an issue which is pertinent to perinatal mental health and well-being, has serious consequences both short and long term on mothers, new-borns and their partner relationships, very little is known about FOC. The majority of research has been carried out in Scandinavia to date and outside of Scandinavia there is a lack of research on this subject area. Therefore, there is a need to explore FOC in an Irish context. Moreover, it appears that the recognition of FOC in the pre-natal period may be a valuable marker of women's vulnerability to postnatal health issues such as post-traumatic stress disorder (PTSD) and postpartum depression (PPD). In addition, there is a paucity of qualitative research to illustrate how women experience fear of childbirth and interventions or support offered in pregnancy.

# CHAPTER THREE.

# WORLDWIDE PREVALENCE OF TOCOPHOBIA IN PREGNANT WOMEN: A SYSTEMATIC REVIEW AND META-ANALYSIS

# 3.0 WORLDWIDE PREVALENCE OF TOCOPHOBIA IN PREGNANT WOMEN: SYSTEMATIC REVIEW AND META-ANALYSIS [PAPER 2]

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## 3.1 Systematic Review Methods

The systematic review and meta-analysis is presented in this chapter, which is comprised of a peer-reviewed published paper. The paper is presented in the final pre-publication manuscript format. [DOI: 10.1111/aogs.13138].

## 3.2 Abstract


**Introduction**

To determine the global prevalence of tocophobia in pregnancy.

**Material & Methods**

Relevant articles were identified through searching six relevant databases: MEDLINE, Cinahl, Pubmed, PsycINFO, Maternity & Infant Care and Scopus between 1946 and April 2016. We used search terms for tocophobia prevalence in pregnant women which we agreed with a medical librarian. 468 articles were screened by title and 29 relevant articles were retrieved for full text evaluation. A further five relevant articles were included following hand searching bibliographies. There were no language restrictions. Two review authors independently assessed data for inclusion, extracted data and assessed quality using a standardised appraisal tool.

**Results**

Thirty-three studies were included in the systematic review from 18 countries of which data from 29 studies were used in the meta-analysis of 853,988 pregnant women. Definitions varied widely. In addition, prevalence rates of between 3.7% and 43% were reported. A meta-analysis was performed to determine the overall pooled prevalence of tocophobia. Subgroup and sensitivity analyses were then conducted.The overall pooled prevalence of tocophobia, using a random-effects model, was 14% (95% CI 0.12-0.16). Significant heterogeneity was observed ($I^2=99.25\%$, $p<0.0001$) which was not explained in subgroup analyses including tocophobia definition used, screening trimester and parity.

**Conclusion**

Heterogeneity in reports of tocophobia means prevalence is difficult to accurately assess. Considerable heterogeneity was noted (99.25%) therefore our results should be interpreted with caution. The concept of tocophobia is complex and evolving.

**Keywords** Tocophobia, pregnancy, systematic review, epidemiology, fear of childbirth, W-DEQ

**Key Message**

This meta-analysis estimated a global pooled-prevalence of 14% however, this should be interpreted with caution due to significant heterogeneity. This is the first systematic review in the field, therefore findings are useful for developing recommendations

## 3.3 Introduction

Pregnancy is a time of immense change and can be a challenging, emotional period (18, 112, 117). This formative time can affect mental health as evidenced in the recent Lancet Perinatal Mental Health series (18, 20). There has been a shift in research focus from postnatal depression and puerperal psychosis to recognising that women suffer from a broad range of mental disorders including anxiety disorders, panic and phobias (112). It seems that anxiety disorders are as common as depression and there is increasing evidence of morbidity related to anxiety disorders (20, 112). Yet, they are only recently becoming prominent and are not yet embedded into clinical practice (112).

The concept of 'Fear of Childbirth' (FOC) first appeared in the literature in the 1980s (16, 118-120) and is currently widely accepted as a psychological domain in its own right (38, 121). In 2000, Hofberg & Brockington coined the psychiatric term 'tocophobia' and defined it as "an unreasoning dread of childbirth" in a document which classified primary and secondary tocophobia (78). Primary tocophobia affecting nulliparous women may originate in childhood and secondary tocophobia affecting parous women usually develops following a previous birth experience (78, 106). Some women will choose to sacrifice their much longed for infant by choosing to terminate the pregnancy rather than facing childbirth (103, 122). Tocophobia has become a term commonly used to describe severe fear of childbirth in clinical practice, however there is no one agreed definition. While there are no standard criteria for defining tocophobia, the Wijma Delivery Expectancy Questionnaire Part A (W-DEQ A) is the most commonly used tool for assessment and diagnosis (123, 124). It consists of 33 questions on a Likert scale with a minimum score of 0 and maximum of 165 possible;

a score greater than or equal to 85 indicates tocophobia (40). Other tools include the Fear of Birth Scale (FOBS) and Childbirth Attitudes Questionnaire (67, 123, 125).

Increasing clinical interest in tocophobia may be attributed to the fact that it has been documented as a reason for planned Caesarean births (116, 126, 127). A Swedish epidemiological retrospective cohort study found that FOC was the predominant reason for elective Caesarean with no medical indication in 2005 (127).This is particularly concerning in the case of nulliparous women with no medical indication for Caesarean since Caesarean section rates are rapidly increasing over the last few decades having effects on long and short term maternal and neonatal health, social and economic consequences (86, 127-131). However, the National Institute for Health and Clinical Excellence has recognised that Caesarean may be appropriate for women with tocophobia after discussion and offer of appropriate support (132). While Caesarean may be appropriate for some women, particularly those at risk of re-traumatisation (122), it is important that psychological support is offered since the reasons for tocophobia can be complex (eg. Previous sexual abuse or trauma) and FOC often coincides with depressive and compulsive personalities predisposing these women to postnatal depression and Post Traumatic Stress Disorder (PTSD) (62, 103, 112, 133).

It must be acknowledged that tocophobia can arise as a result of women's perinatal experience which may result in PTSD (112). Thus, it is potentially a modifiable factor since midwifery care could help (20, 112). There are considerable gaps in knowledge since this is a relatively new field.

It is generally accepted that 6-10% of pregnant women suffer with FOC that affects everyday life (94, 126, 134, 135). However, as discussed, a lack of consistency in defining tocophobia has led to variation in prevalence reports (136, 137). Prevalence rates of tocophobia in pregnant women have varied widely from 3.7-42.9% (68, 138). Estimating a global pooled prevalence of tocophobia is important with the aim of assessing the global public health burden, planning care pathways and in order to calculate optimum sample size for future research studies. Furthermore, estimating a global pooled prevalence of tocophobia will add to the growing body of knowledge in this evolving area of research.

The prevalence of tocophobia has been reported in various cross-sectional studies using various tools as outlined and more recently by analysis of the International Classification of Diseases 10$^{th}$ Revision codes, assigned to women who attended tocophobia clinics in countries where care pathways are well established (68). While, various studies have reported the prevalence of tocophobia in pregnant women over the last few decades, there has been no systematic review to date (48, 68, 139). There is a need for a systematic review of the published literature that will incorporate a detailed, comprehensive search strategy, provide clear inclusion and exclusion criteria, assess study quality using a suitable quality assessment tool and where feasible to provide the first quantitative estimate of the prevalence of tocophobia in pregnant women worldwide through a meta-analysis.

The main objective of this systematic review was to perform a comprehensive search of the published literature to date and to 1) assess how tocophobia is defined in the literature and 2) to provide the first quantitative pooled estimate of the prevalence of

tocophobia in pregnant women by synthesizing the data from eligible studies in a meta-analysis. The primary outcome of interest was an estimate of the global pooled prevalence of tocophobia in pregnant women as defined using any scale assessing tocophobia (W-DEQ A, FOBS, self-reported, International Classification of Diseases codes, etc.).

## 3.4 Material and methods

The review adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (140) guidelines, has been registered on the International prospective register of systematic reviews database for systematic reviews (PROSPERO ID: CRD42015017443) and is available in full on the National Institute for Health Research website (141)and in this thesis, Appendix 1 . Data were extracted from published manuscripts therefore ethical approval was not necessary.

*Sources*

Six electronic databases (PubMed, CINAHL, PsycINFO, Maternity & Infant Care, Scopus and MEDLINE) were searched for all published literature up until April 11th 2016 using a detailed search strategy and without date or language restrictions (Appendix 2). Medical subject headings or keyword terms for tocophobia were combined according to the principles of Boolean logic (AND, OR, NOT) and included:

"*tocophobia", "to?ophobia", "parturiphobia", "maiesuophobia", "kakorrhaphiophoboia", "maleusiophobia", "lockiophobia", "enfantophobia", "fear of childbirth", "fear of labour", "fear of labor", "fear of birth", "childbirth related fear", "childbirth related anxiety", "fear in pregnancy"*.

Terms for pregnancy included *"pregnancy", "antenatal", "ante natal", "ante-natal", "prenatal", "pre natal", "pre-natal" and "childbirth".*

### 3.4.1 Study Selection

Published observational studies including pregnant women of any age and origin and reporting the prevalence of tocophobia (or sufficient data in order for us to compute this estimate) were eligible for inclusion. Where the review identified multiple papers from the same study cohort or population, only the main paper reporting the largest number of participants was included in the meta-analysis.

Two researchers (MOC and SMON) independently reviewed study titles and abstracts as appropriate using the review protocol inclusion and exclusion criteria. When potential studies were identified, full-text studies were obtained for further evaluation. Disagreements were resolved by discussion and where there was discrepancy, a third reviewer (PLW) ensured consensus was reached. The reference lists of studies eligible for inclusion were hand searched for further potentially eligible studies. The following data were then abstracted from the study using a standardised data abstraction form by MOC: Author, year, study location (country), study design, scale used, sample size, and prevalence and crosschecked by SMON. If it was considered that a study had collected data on the prevalence of tocophobia but had not reported it, the authors were contacted for this information.

### 3.4.2 Quality assessment

Quality assessment of each included study was independently evaluated by reviewers (MOC and SMON) based on a standardised assessment tool consisting of eight questions to assess bias (142) (Appendix 3). This quality assessment tool looked at the following criteria: target population, sampling ascertainment methods, response rate, information on non-responders, if the sample was representative, data collection methods, was a validated tool used to assess tocophobia and whether the estimates of prevalence with 95% CIs were reported. The reviewers compared scores and reached a consensus before calculating the final appraisal score. Each study received a score of between 0 and 8 points, based on meeting the prescribed criteria. High quality studies were defined as those receiving a score of 5 or more out of 8 in the quality assessment.

### 3.4.3 Statistical analysis

Search results were compiled in Endnote Reference Manager (Endnote, Version X7). Characteristics of the included studies (study design, sample, definition used and measurement of tocophobia) were summarised and presented in Table 3-1. For the meta-analysis, an overall pooled prevalence estimate was calculated using the sample size and the proportion of women with tocophobia and the fixed-effect model or random-effects model as appropriate. Using the *metaprop* command, we generated pooled proportions and an overall pooled estimate with inverse variance weights derived from a random-effects model (143). Statistical analysis was performed using STATA software (Stata, Version 13.1).

### 3.4.4 Subgroup and sensitivity analyses

We planned the following *a priori* sensitivity analyses: including studies which used a W-DEQ A ≥85 for tocophobia, by parity (including studies with nulliparous women only, and subsequently including studies with multiparous women only), by screening trimester (including studies which screened women in the first trimester only, studies which screened women in the second trimester only, and studies which screened women in the third trimester only). We planned the following *a priori* subgroup analyses: by study quality (high versus low), by region (Scandinavia versus Rest of Europe versus Australia versus America versus Asia), and by time period (1980s versus 1990s versus 2000-2009 versus 2010-2016). These *a priori* defined sensitivity and subgroup analyses were conducted to try and explain the wide variation in prevalence within countries and between countries.

### 3.4.5 Heterogeneity assessment

Any kind of variability in the way outcomes are reported can be called heterogeneity (144). Heterogeneity between studies included was assessed by examining the study characteristics including the study setting, study design and definition used for tocophobia. The $I^2$ statistic was used in the meta-analysis to determine statistical heterogeneity in accordance with the Cochrane Handbook for Systematic Reviews threshold recommendations (144). This formal assessment of heterogeneity assumes that $I^2$ between 0 and 40% heterogeneity might not be important, 30-60% denotes moderate heterogeneity, 50-90% denotes substantial heterogeneity and 75-100% denotes considerably significant heterogeneity. Where heterogeneity was greater than 50% the random-effects model was used (145).

## 3.5 Results

Results of the systematic search are presented in Figure 3-4, which yields 33 studies for inclusion in the systematic review (146). Twenty-four high quality studies and five low quality studies were included in the meta-analysis. Where there was more than one publication on a cohort of patients (i.e. the same population), data on the prevalence of tocophobia were taken from those that described the total population rather than a subset.

### 3.5.1 Study characteristics

Study characteristics are presented in Table 3-1. One study was published in 1981 (16), one study in the late 1990s (147), fourteen studies were published between 2000 and 2009 (42, 50, 62, 76, 110, 134-136, 139, 148-152) and seventeen studies were between 2010 and April 2016 (23, 33, 47, 48, 54, 67, 68, 76, 94, 153-155). Study settings included the following: USA (42), Canada (50) , Australia (33, 47, 156), Sweden (16, 33, 67, 76, 110, 134, 147, 148, 150, 152, 154, 157), Norway (23, 54, 62, 94), Finland (68, 136), Switzerland (139), Denmark (134, 135), Italy (126), Turkey (158), Iran (138), China (159), Japan (160), South India (161) and the Netherlands (155). One study was conducted across six countries- Belgium, Iceland, Denmark, Estonia, Norway and Sweden (48). Study population sizes ranged from 105 to 788,317 (68, 155). One study was limited to multiparous women (158). Seven studies included nulliparous women only and 25 were not restricted by parity.

### 3.5.2 Definition of tocophobia in the included studies

Tocophobia was defined using a variety of measures and cut-offs. Most [21/33 studies (23, 48, 50, 54, 56, 62, 94, 110, 116, 126, 134, 147-152, 155, 158, 160, 162)] used the W-DEQ Part A to assess tocophobia [of which three of these studies (23, 54, 94) used the same cohort], meaning that 19 different cohorts in this review used the W-DEQ Part A as a tool to assess tocophobia. Whereas the majority of included studies in the systematic review used W-DEQ Part A, only a minority of the total study population (21,619/ 853,988) were assessed with this tool. Other methods used to define tocophobia included the FOBS [three studies (33, 67, 162)], CAQ [3 studies (42, 125, 159)] and International Statistical Classification of Diseases and Health Related problems 10$^{th}$ Revision [1 study (68)] (Table 3-1). A Finnish study comprised the largest study population (n=788,317) which reported the prevalence of tocophobia based on an International Classification of Diseases and Health Related Problems-10$^{th}$ Revision Code allocated to all women who attended tocophobia clinics during the period of the study (68). In addition, tocophobia was measured using phone interviews with pre-defined standardised questions, face to face interviews using standardised questions or self-reported questionnaires completed in the clinic or returned via post (16, 76, 135, 138, 161). Sampling was done in different languages, and in the case of standardised instruments (W-DEQ A, FOBS, CAQ) the questionnaire was translated into the most commonly spoken languages of the study area (forward translation); the various language versions of the questionnaire were translated by both lay and professional translators (expert back translation); draft versions of the translated questionnaire were assessed for accuracy and validated by professionals who were fluent in one or more of the languages (pre-testing) (23, 108, 161, 163). One study

(160) was the first to use the W-DEQ A in the Japanese language and so needs to be validated in further studies.

Of the 21 studies that used the W-DEQ Part A, two used ≥100 as a cut-off for tocophobia (62, 162), one used ≥95 (62), one used ≥85.8 (152), 12 used ≥85 (23, 47, 48, 54, 94, 110, 134, 150, 151, 154, 158, 164), one used ≥84 (147), one used ≥71 (149) and two used ≥66 (50, 148). Studies that used the FOBS estimated a much higher prevalence estimate (double the other prevalence estimates) than the other studies included in the review. Regarding screening trimester, four studies questioned women in all trimesters (16, 48, 154), twelve studies recruited women in the second trimester (12-27 weeks) (16, 33, 48, 56, 62, 67, 68, 76, 116, 135, 138, 139) and 17 studies recruited women in the third trimester (28-41 weeks) (16, 42, 48, 50, 94, 110, 126, 134, 135, 147-149, 151, 152, 158, 161, 164). Of these studies, one recruited in both the second and third trimesters (135). Data on the prevalence of tocophobia were available for two population-based (68, 135) and 31 hospital-based cohorts of pregnant women.

### 3.5.3 Quality assessment

Study quality was assessed independently by two reviewers (MOC, SMON). While there was variation in the quality of the studies, overall quality was considered high [26/33 studies with a score of 5 or more out of 8] (Table 3-1). Seven studies were considered low quality (a score of ≤4 out of 8) due to the following: the target population was not clearly defined, the response rate was not reported, information on non-responders was not provided or the sample selection was unclear or not reported or did not use validated tools for tocophobia.

### 3.5.4 Prevalence of tocophobia - meta-analysis

Of the 33 studies included in the systematic review, data from 28 studies were included in the meta-analysis. One study (33) included two cohorts from Australia and Sweden which we split into two studies for the purpose of the meta-analysis, (Haines 2011a, and Haines 2011b), resulting in 29 studies in total. A fixed-effects model yielded a 4% (95% CI; 0.04-0.04) prevalence of tocophobia in pregnant women. Due to significant heterogeneity *($I^2$=99.5%, p<0.0001)*, a random-effects model was used and a pooled prevalence of 14% (95% CI; 0.12-0.16) for tocophobia, with considerable heterogeneity *($I^2$ = 99.25%)* (Figure 3-2) was obtained.

### 3.5.5 Sensitivity Analysis

*W-DEQ A ≥85*

The twelve studies which used a W-DEQ A score of ≥85 as the definition of tocophobia detected a pooled prevalence of 12% (95% CI; 0.09-0.14) and significant heterogeneity *($I^2$ = 95.41%, p<0.0001)* using the random-effects model (Figure 3-3).

*Parity*

Studies including nulliparous women (Figure 3-4), yielded a pooled prevalence of 16% (95%CI; 0.14-0.19) with significant heterogeneity *($I^2$=99.42%, p<0.0001).* Studies including multiparous women (Figure 3-5), resulted in a pooled prevalence of 12% (95% CI; 0.10-0.14) and significant heterogeneity *($I^2$=97.81%, p<0.0001).*

*Screening Trimester*

In one study women were screened in the first trimester of pregnancy and was not included in a sensitivity analysis (108). Studies which screened women in the second trimester (Figure 3-6), yielded a pooled prevalence of 14% (95% CI; 0.12-0.16) and significant heterogeneity remained *($I^2$=98.1%, p<0.0001).*Studies which screened in the third trimester yielded (Figure 3-7), a pooled prevalence of 12% (95% CI; 0.10-0.14), with significant heterogeneity *($I^2$=97.78%, p<0.0001).*

### 3.5.6 Sub-group analysis

*Study Quality*

The prevalence of tocophobia in the high quality studies was 13% (95% CI; 0.11-0.15) *($I^2$ = 99.3%, p<0.0001)* compared to 19% (95% CI; 0.08-0.30) *($I^2$ = 97.96%, p<0.0001)* in the low quality studies (Figure 3-8).

*By Region*

The prevalence of tocophobia found in Scandinavia was 12% (95% CI; 0.09-0.15) *($I^2$ = 99.51%, p<0.0001)* (Figure 3-9). In the Rest of Europe the prevalence was 8% (95% CI; 0.04-0.13) *($I^2$ = 99.51%, p<0.0001),* in Australian studies the prevalence was 23% (95%CI; 0.07-0.39) *($I^2$ = 98.63%, p<0.0001),* in American studies the prevalence was 11% (95% CI; 0.03-0.20) *($I^2$ = 92.97%, p<0.0001)* and in Asian studies the prevalence was 25% (95% CI; 0.11-0.40) *($I^2$ = 97.69%, p<0.0001).*

*By Time Period*

One study looked at the prevalence of tocophobia in the 1980s, which was 6% (95% CI; 0.03- 0.12) (Figure 3-10). Prevalence of tocophobia was reported by one study in the 1990s at 10% (95% CI; 0.09-0.11). Fourteen studies between 2000 and 2009 examined the prevalence of tocophobia which was 12% (95% CI; 0.10-0.15) *($I^2$=98.18%, p<0.0001),* and 13 studies conducted between 2010 and 2016 resulted

in a pooled prevalence of 17% (95% CI; 0.13-0.21) *($I^2$=98.98%, p<0.0001)*. Overall heterogeneity was highly significant *($I^2$= 99.26%, p<0.0001)*.

### 3.5.7 Studies not eligible for inclusion in the meta-analysis

Three studies (125, 159, 160) did not include data that could be included in the meta-analysis and two studies (23, 54) included the same population as a third study (94). A brief summary of the studies not included in the meta-analysis are presented in Table 3-2.

## 3.6 Discussion

To our knowledge, this is the first systematic review and meta-analysis of the prevalence of tocophobia in pregnant women. Overall, the pooled prevalence of tocophobia was 14%. Subgroup analyses according to region showed a significant difference in the prevalence of tocophobia. For example in Scandinavia the prevalence was 12% compared to 8% in the rest of Europe and 23% in Australia. Furthermore when we looked at the prevalence of tocophobia by time period, it was lower in the earlier years (1980s, 1990s) but increased in the more recent years (2000 onwards). However, our findings need to be interpreted with caution since significant heterogeneity was found *($I^2$=99.25%, p<0.0001)*. Extensive pre-specified subgroup and sensitivity analyses did not explain the significant heterogeneity in the meta-analysis. Differences in the way studies were conducted and information collected and recorded as well as variations in the social and cultural characteristics of women included in these studies may explain the heterogeneity (145).

There has been conflicting evidence as to the prevalence of tocophobia in nulliparous and multiparous women (108, 165). We carried out a subgroup analysis which identified that tocophobia was more prevalent in nulliparous women (who have never experienced childbirth before), this is similar to the findings of nine previous studies (33, 48, 50, 67, 94, 116, 126, 148, 149).

Although tocophobia has become a term commonly used to describe severe FOC, a clear, consistent operational definition is lacking (68, 166). This was reflected in the literature where several tools were used to assess FOC and tocophobia (Table 3-1). The W-DEQ A questionnaire was employed in nineteen studies, and although there is a recommended cut-off point for the definition of tocophobia (≥85), some studies used different cut-off points (126, 147, 148, 167). Terms used included 'high childbirth related fear', 'intense fear', 'high childbirth fear', 'severe childbirth fear' or 'severe FOC' (16, 67, 138, 139, 155, 158, 159). It is important to recognise that it may be normal for pregnant women to have worries (139, 149, 153) (recurrent but unspecific thoughts) since birth is unpredictable, however fears can be strong, specific and continuous (34). It has been suggested that when a woman expresses FOC during pregnancy and requests support, this could be in itself a definition (166).

Tocophobia is difficult to quantify. Currently, the W-DEQ A is used as the 'gold standard' for assessment and 'on the spot' diagnosis (123, 168). As mentioned, we found a variation in the cut-off point used for the W-DEQ A. A criticism of this tool has been that it may exclude some women who could benefit from support, therefore some studies used a slightly lower cut-off (66 or 71 rather than 85) (148, 149), resulting in more referrals for intervention. Moreover, an in-depth psychometric

analysis of the W-DEQ A advised that calculating a total score and using a cut-off to define tocophobia may not be appropriate as this is based on the premise that the W-DEQ A, is a uni-dimensional instrument (38, 149, 169-171). The use of subscales has been advocated to determine specific reasons behind the woman's fear and identify risk factors which might make a woman more vulnerable such as lack of social support (169). In addition to the issues outlined above, the W-DEQ A is lengthy and impractical for clinical use therefore researchers are striving to establish more practical tools (123, 137).

The FOBS (a two question Visual Analogue Scale) is deemed a feasible tool to prompt referral in clinical practice (34, 137) and has recently been validated in samples of Swedish and Australian populations (sensitivity (89%) and specificity (79%)) (137, 172). It is argued there is likely to be high compliance as it is easily understood (137). Screening for FOC is suggested in order to offer appropriate referral as there is evidence that women may benefit if offered timely antenatal support (112, 116, 137, 173, 174). However, similarly to the introduction of other screening assessments to the antenatal booking appointment, it may be envisaged that time constraints in the clinic and lack of clear referral pathways may be barriers to the effectiveness of this tool (175-177).

There is considerable evidence to endorse improved perinatal psychological support (18, 20, 112, 122, 165). Reasons for tocophobia may be complex (10, 110, 112) and include lack of trust in or worries about unfriendly staff (149), being left alone in labour, appearing silly and lack of involvement in decision-making (42, 76, 117) as well as trauma and previous sexual abuse. In addition, FOC often coincides with

depressive and compulsive personalities predisposing women to postnatal depression and Post Traumatic Stress Disorder (62, 112, 122, 133). Therefore various strategies have been proposed to help women cope i.e. psycho-education, birth preparation, improving self-confidence (34, 116). Furthermore, continuity of care, developing meaningful, trusting relationships, involving women fully in decision-making and working in partnership to provide woman-centered care can improve outcomes (174, 178-180). Future strategies should draw on these values and aim to use a holistic and personalised approach to address tocophobia.

This comprehensive systematic review was based on a detailed search carried out on six relevant databases with no language or date restrictions and is based on a protocol which is registered on the International prospective register of systematic reviews database (141). This protocol was available on the National Institute for Health Research website and subsequently, the systematic review followed standardised reporting guidelines (141, 181). The strength in our review lies in the large number of studies which allowed extensive sensitivity and subgroup analysis to be conducted.

The main limitation in this study was the very high statistical heterogeneity evident from the $I^2$ estimates in the meta-analyses. It was not possible to carry out a subgroup analysis on maternal age, social supports and existing mental health due to lack of such data in the included studies. These factors are reported to be associated with tocophobia (68, 76, 135, 165). When we conducted a subgroup analysis including only studies that used the W-DEQ A to define tocophobia, significant heterogeneity remained suggesting that this issue is more complex than simply being explained by variation in the definition used. The authors acknowledge that the prevalence of tocophobia depends on several factors including various personality characteristics,

previous birth experiences and cultural determinants including local obstetric norms, personal and religious beliefs (10, 153, 166). Furthermore many of the studies included in the systematic review were of a cross sectional design which only capture FOC at one point in time during pregnancy (See Table 3-1).

It is possible that questionnaires may not be applicable in different countries and in other cultural contexts (even in the same language) since psychometric aspects of the tool may be lost (123) thus tools should be specifically validated for use in each country (123, 160). This is a limitation of our study as we included studies that used various questionnaires administered in different languages (160). Of note, a high literacy level is required to complete the W-DEQ A (123). However, some studies used the three step approach to minimise any potential foreign language misinterpretation (23, 108, 161, 163). We acknowledge that the variety of different measurements for tocophobia both validated and non-validated used by the studies included in this systematic review may introduce possible bias including responder bias, language barrier bias, and reporter bias.

Despite these limitations, the information from this review provides important findings for use in future research and clinical practice. We identified that there are variations in the definition of tocophobia and that the prevalence of tocophobia appears to be increasing over time. Future researchers could strive to develop appropriate interventions aimed at identifying pregnant women at risk of tocophobia, such as decision aids which are increasingly being used in healthcare settings (182). Clinicians and the healthcare service need to be aware of and encourage women to express FOC since identifying women with tocophobia early in pregnancy may

provide an opportunity for an intervention to support maternal mental health (112, 137, 172). This is important as there is growing evidence linking tocophobia with increased maternal cortisol levels as well as the exacerbation of other mental health issues, which may lead to serious and long-term consequences (165).

## 3.7 Conclusion

This systematic review and meta-analysis of the prevalence of tocophobia in pregnant women found a prevalence of 14%. However, these findings should be interpreted with caution due to significant heterogeneity which was not explained by extensive subgroup and sensitivity analysis. We ascertained that a clear operational definition for tocophobia is lacking in the literature. More research is required to gain a better understanding of FOC and how women with tocophobia may be given optimum support in clinical practice to achieve positive birth experiences. Despite limitations, these findings add to our limited understanding of tocophobia.

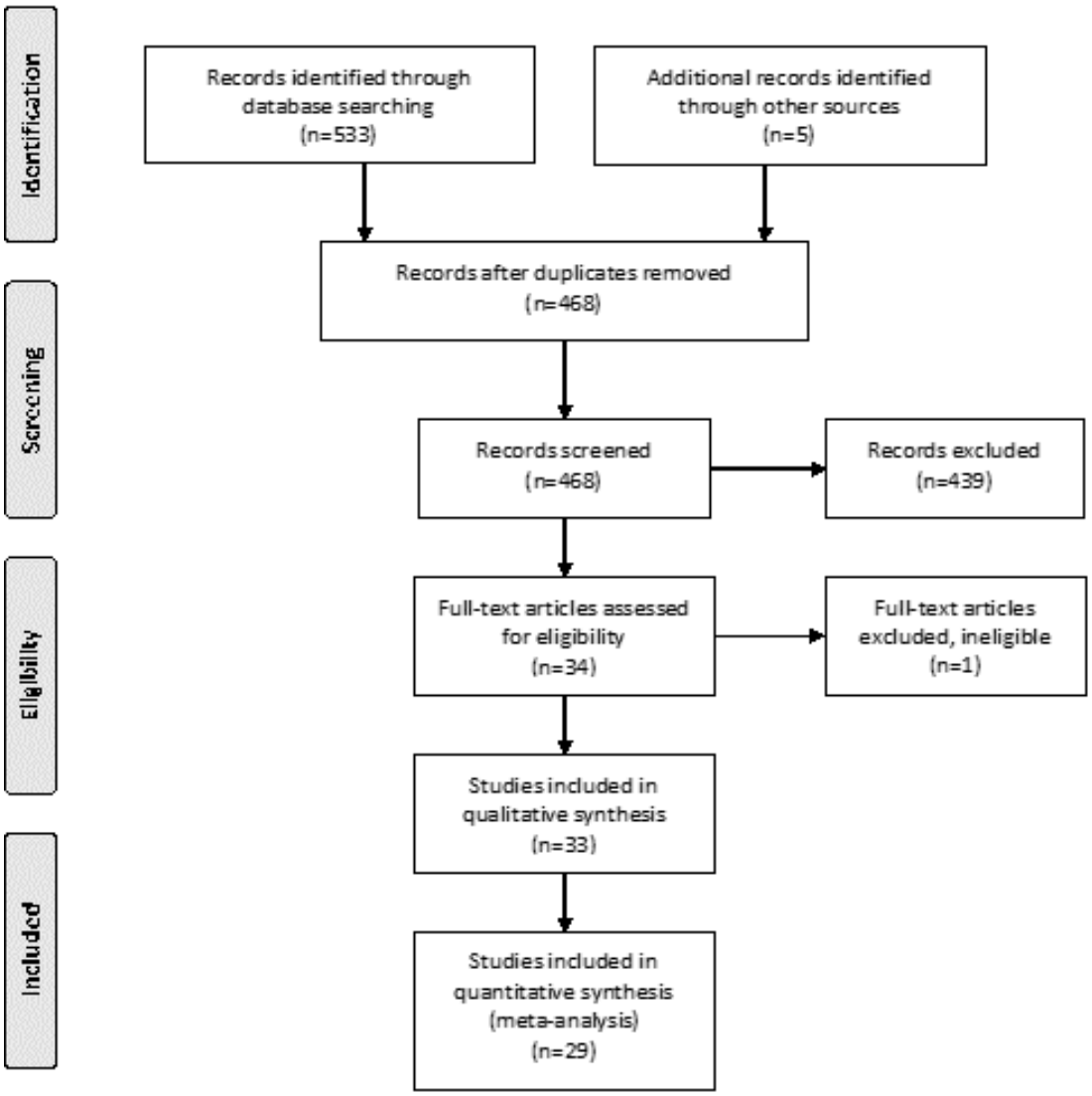


**Figure 3-1. Flow chart of systematic search**

**Table 3-1. Characteristics and quality assessment of studies included in the systematic review**

| *Study (Year)* | *Country* | *Study Design (Sample size)* | *Scale* | *Trimester Screened* | *Parity* | *Tocophobia Prevalence* | *Quality ( out of 8)* |
|---|---|---|---|---|---|---|---|
| **Adams et al* (2012)** | Norway | Prospective cohort (2206) | W-DEQ A ≥85 | 3rd | All | 7.5% | 5 |
| **Aksoy et al (2015)** | Turkey | Cross sectional (817) | W-DEQ A ≥85 | 3rd | Multi-parous | 15.7% | 5 |
| **Areskog et al (1981)** | Sweden | Qualitative (139) | Interview | 2nd | All | 6.5% | 5 |
| **Christiaens et al (2011)** | Belgium/ The Netherlands | Prospective cross cultural comparison study (799) | CAQ | 3rd | All | Not reported | 4 |
| **Fenwick et al (2009)** | Australia | Prospective cohort (401) | W-DEQ A≥71 | 3rd | All | 26.2% | 7 |
| **Gao et al (2015)** | China | Cross sectional (353) | Chinese CAQ | 3rd | All | No tocophobia reported, moderate fear only | 5 |
| **Geissbuehler et al (2002)** | Switzerland | Prospective cohort (8528) | 50 Qs | 2nd | All | 5.3% | 6 |
| **Haines et al (2011)** | Australia/ Sweden | Prospective cross cultural (123/ 386- 509 combined) | FOBS VAS tool (cut-off 5) | 2nd | All | 31.1% Australia 29.5% Sweden | 5 |
| **Hall et al (2009)** | Canada | Cross sectional (650) | W-DEQ A ≥66 | 3rd | All | 24.9% | 7 |
| **Heimstad et al (2006)** | Norway | Prospective cohort (1452) | W-DEQ A ≥95 | 2nd | All | 7.3% | 4 |
| **Jaju et al (2015)** | South India | Cross sectional (368) | Interview based on ICD-10 Code | 3rd | Nulli-parous | 17.7% | 4 |
| **Kjaergaard et al (2008)** | Sweden/ Denmark | Prospective cohort (110/ 55-165 combined) Two separate studies carried out over 2 time periods 1996/ 2004-2005 | W-DEQ A ≥85 | 3rd | Nulli-parous | 10.9% | 5 |
| **Laursen et al (2008)** | Denmark | Population cohort (Danish Birth Register) (30,380) | Phone interviews | 2nd & 3rd | Nulli-parous | 11.74% | 5 |

**Table Legend: * Data from same population, CAQ** Childbirth Attitudes Questionnaire, **W-DEQ A** Wijma Delivery Experience Questionnaire Part A, **Qs** Questions, **CI** Confidence Intervals, **FOBS** Fear of Birth Scale, **VAS** Visual Analogue Scale, **ICD-10** International Classification of Diseases, **J-WDEQ A** Japanese Wijma Delivery Experience Questionnaire Part A, **Trimester screened** refers to the gestation at which women were screened for tocophobia **1st Trimester:** weeks 1-12, **2nd Trimester:** weeks13-20, **3rd Trimester:** 21-, **All** refers to both nulliparous and multiparous women

| *Study (Year)* | *Country* | *Study Design (sample size)* | *Scale* | *Trimester Screened* | *Parity* | *Tocophobia Prevalence* | *Quality ( out of 8)* |
|---|---|---|---|---|---|---|---|
| **Lowe (2000)** | USA | Cross sectional (280) | CAQ | 3rd | Nulli-parous | 19.29% | 4 |
| **Lukasse et al (2014)** | BIDENS (Belgium Iceland, Denmark, Estonia Norway Sweden) | Cross sectional (6870) | W-DEQ A ≥85 | All | All | 11.2% | 6 |
| **Matinnia et al (2015)** | Iran | Cross sectional (342) | Fear related to Pregnancy & Childbirth Questionnaire | 2nd | Nulli-parous | 42.9% | 3 |
| **Nieminen et al (2009)** | Sweden | Cross sectional (1,635) | W-DEQ A ≥85 | All | All | 15.5% | 6 |
| **Nordeng et al* (2012)** | Norway | Birth cohort study (1,984) | W-DEQ A ≥85 | 3rd | All | 7.8% | 8 |
| **Pazzagli et al (2015)** | Italy | Prospective correlational design (158) | W-DEQ A in Italian | 3rd | All | 9.5% | 7 |
| **Raisanen et al (2014)** | Finland | Retrospective cohort (788,317) | ICD Code O99.80 | All | All | 3.7% | 8 |
| **Rouhe et al (2009)** | Finland | Prospective cohort(1276) | W-DEQ A ≥100 | All | All | 7.5% | 7 |
| **Ryding et al (1998)** | Sweden | Prospective cohort (1981) | W-DEQ A ≥84 | 3rd | All | 10.0% | 7 |
| **Salomonssen et al (2013)** | Sweden | Cross sectional (1000) | W-DEQ A ≥85 | 2nd | Nulli-parous | 20.8% | 6 |
| **Sluijs et al (2012)** | The Netherlands | Prospective cohort (105) | W-DEQ A ≥85 | 3rd | All | 12.4% | 6 |
| **Spice et al (2009)** | Canada | Cross sectional (110) | W-DEQ A ≥85 | 3rd | All | 9.1% | 4 |

**Table Legend: * Data from same population, CAQ** Childbirth Attitudes Questionnaire, **W-DEQ A** Wijma Delivery Experience Questionnaire Part A, **Qs** Questions, **CI** Confidence Intervals, **FOBS** Fear of Birth Scale, **VAS** Visual Analogue Scale, **ICD-10** International Classification of Diseases, **J-WDEQ A** Japanese Wijma Delivery Experience Questionnaire Part A, **Trimester screened** refers to the gestation at which women were screened for tocophobia **1st Trimester:** weeks 1-12, **2nd Trimester:** weeks13-20, **3rd Trimester:** 21-, **All** refers to both nulliparous and multiparous women

| *Study (Year)* | *Country* | *Study Design (sample size)* | *Scale* | *Trimester Screened* | *Parity* | *Tocophobia Prevalence* | *Quality ( out of 8)* |
|---|---|---|---|---|---|---|---|
| **Storksen et al* (2012)** | Norway | Cross sectional (1642) | W-DEQ A ≥85 | 3rd | All | 8% | 6 |
| **Takegata et al (2014)** | Japan | Cross sectional (240) | J-WDEQ A | 3rd | All | J-WDEQ A cut-off not confirmed - no prevalence estimate | 2 |
| **Ternstrom et al (2015)** | Sweden | Cross sectional (606) | FOBS>60 | 2nd | All | 22.10% | 7 |
| **Toohill et al (2014)** | Australia | Cross sectional (1,410) | W-DEQ A ≥85 | 2nd | All | 4.9% | 7 |
| **Waldenstrom et al (2006)** | Sweden | Prospective cohort study (2662) | Two questions –attending Aurora Clinic? Or feeling very negative about birth? | 2nd | All | 10.9% | 6 |
| **Wiklund et al (2007)** | Sweden | Prospective cohort (496) | W-DEQ A ≥85.8 | 3rd | Nulli-parous | 18.5% | 5 |
| **Zar et al (2001)** | Sweden | Cross sectional (196) | W-DEQ A ≥66 | 3rd | All | 25.9% | 5 |
| **Zar et al (2002)** | Sweden | Cross sectional (506) | W-DEQ A ≥85 | 3rd | All | 11.1% | 8 |

**Table Legend: * Data from same population, CAQ** Childbirth Attitudes Questionnaire, **W-DEQ A** Wijma Delivery Experience Questionnaire Part A, **Qs** Questions, **CI** Confidence Intervals, **FOBS** Fear of Birth Scale, **VAS** Visual Analogue Scale, **ICD-10** International Classification of Diseases, **J-WDEQ A** Japanese Wijma Delivery Experience Questionnaire Part A, **Trimester screened** refers to the gestation at which women were screened for tocophobia **1st Trimester:** weeks 1-12, **2nd Trimester:** weeks13-20, **3rd Trimester:** 21-, **All** refers to both nulliparous and multiparous women

**Table 3-2. Studies not included in the meta-analysis**

| | |
|---|---|
| **Gao et al, 2015** | **Moderate levels of fear reported. No tocophobia reported.** |
| **Takegata et al, 2014** | JW-DEQ A Mean Score= 50.0 (n=240). Sense of coherence is a direct cause of fear of childbirth. High sense of coherence works as a resiliency factor to cope with birth and reduce fear of birth. |
| ***Nordeng et al, 2012** | 7.8% of the study population had tocophobia (W-DEQ A≥85) (n=1,984).<br>Tocophobia was significantly associated with use of psychotropic drugs, but not the use of analgesics or medications in general. |
| ***Storksen et al, 2011** | 8% of the study population had tocophobia (W-DEQ A≥85) (n=1,642).<br>While presence of anxiety or depression increased prevalence of tocophobia, the majority of women with tocophobia had neither anxiety nor depression. |

Table Legend: JW-DEQ A Japanese Version Wijma Delivery Experience Questionnaire, Part A, W-DEQ A Wijma Delivery Experience Questionnaire Part A, ***Nordeng et al** and **Storksen et al** include the same study population as Adams et al (2012) included in the meta-analysis.

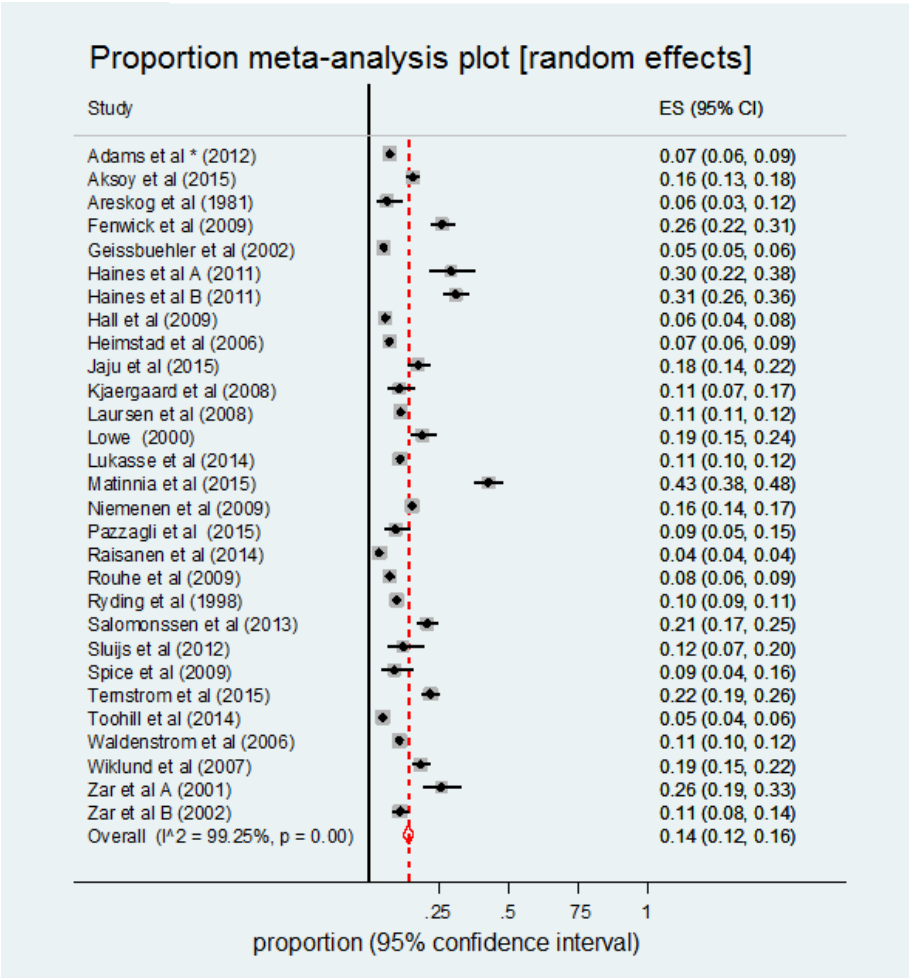


**Figure 3-2. Forest plot of the pooled prevalence of tocophobia for all studies included in the meta-analysis.**

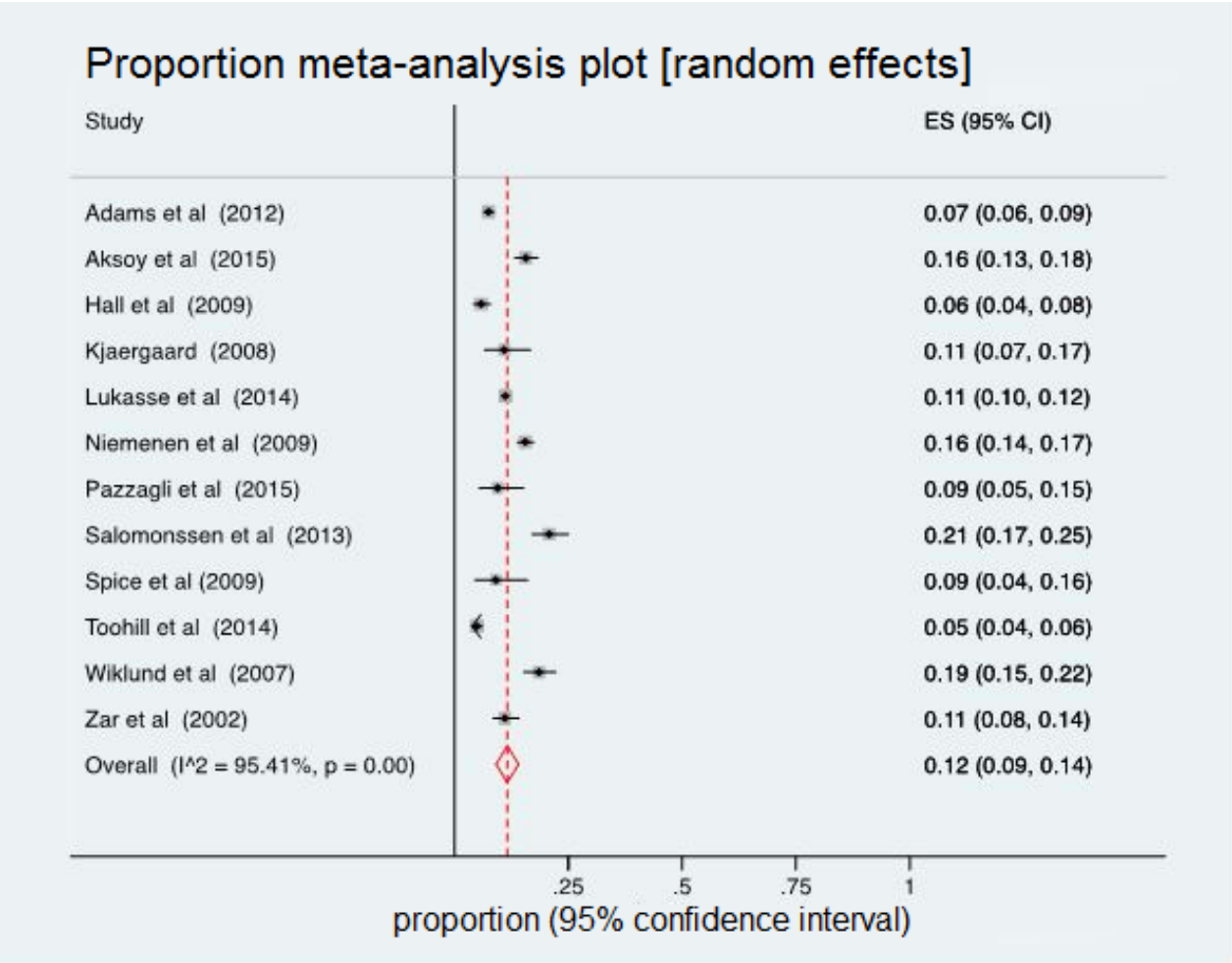


**Figure 3-3. Sensitivity analysis: Forest plot of the pooled prevalence of tocophobia including studies which used W-DEQ A ≥85 as the definition for tocophobia.**

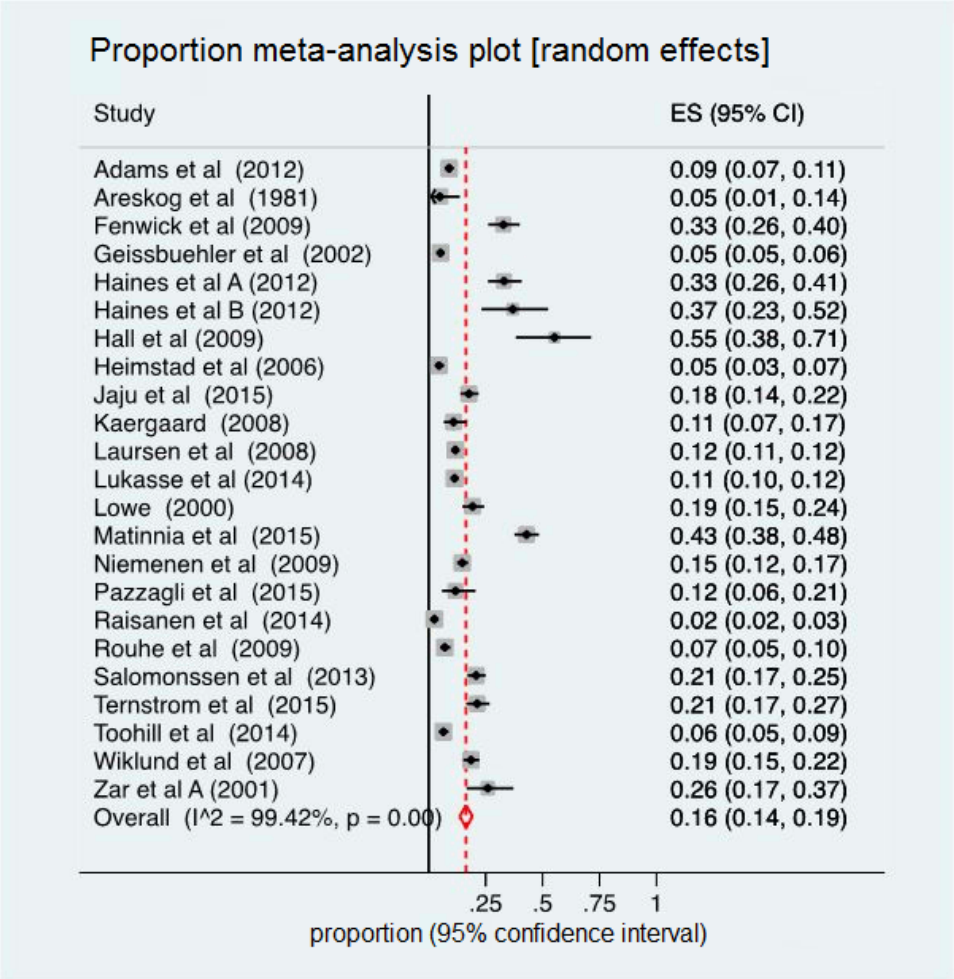


**Figure 3-4. Sensitivity analysis: Forest plot of the prevalence of tocophobia for studies that included nulliparous women only.**

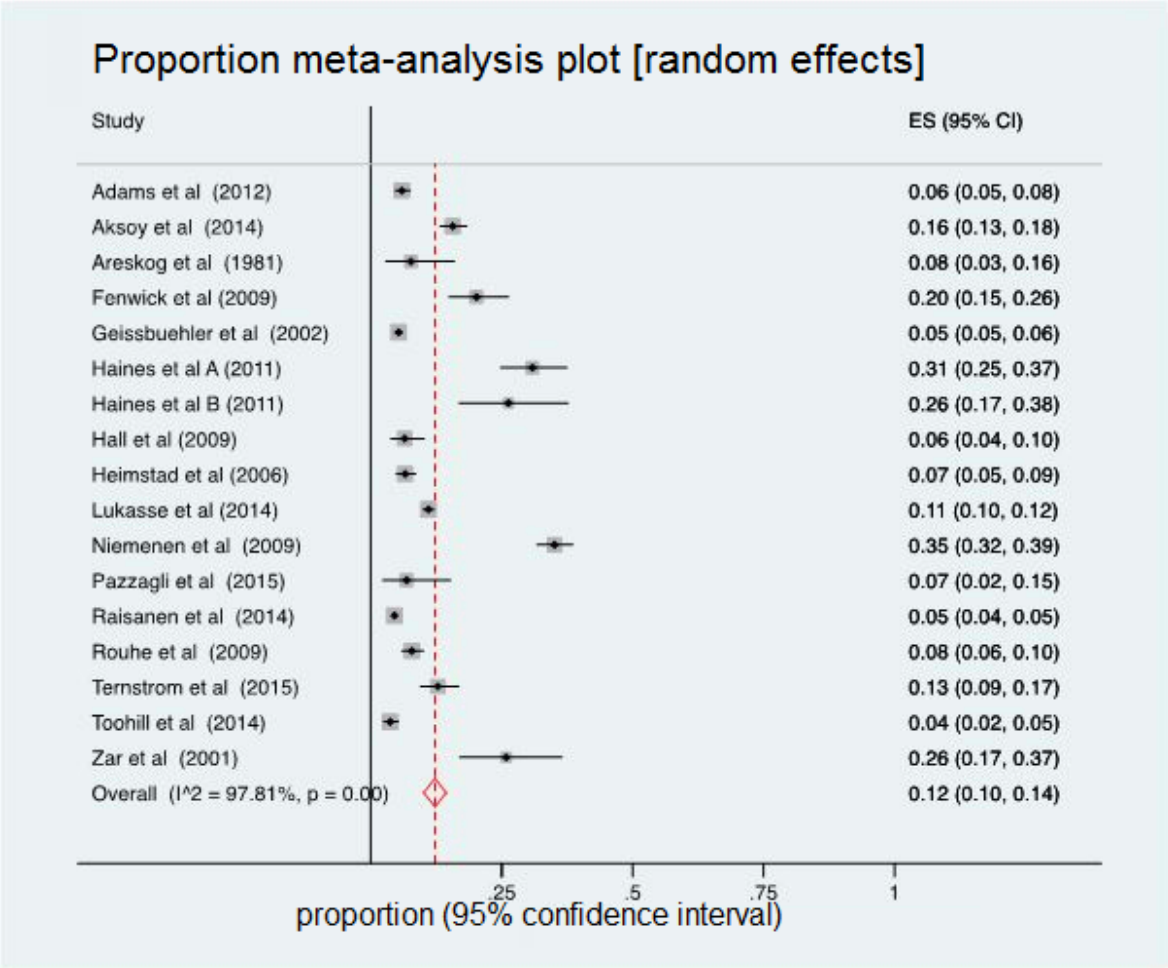


**Figure 3-5. Sensitivity analysis: Forest plot of the pooled prevalence of tocophobia for studies which included multiparous women only**

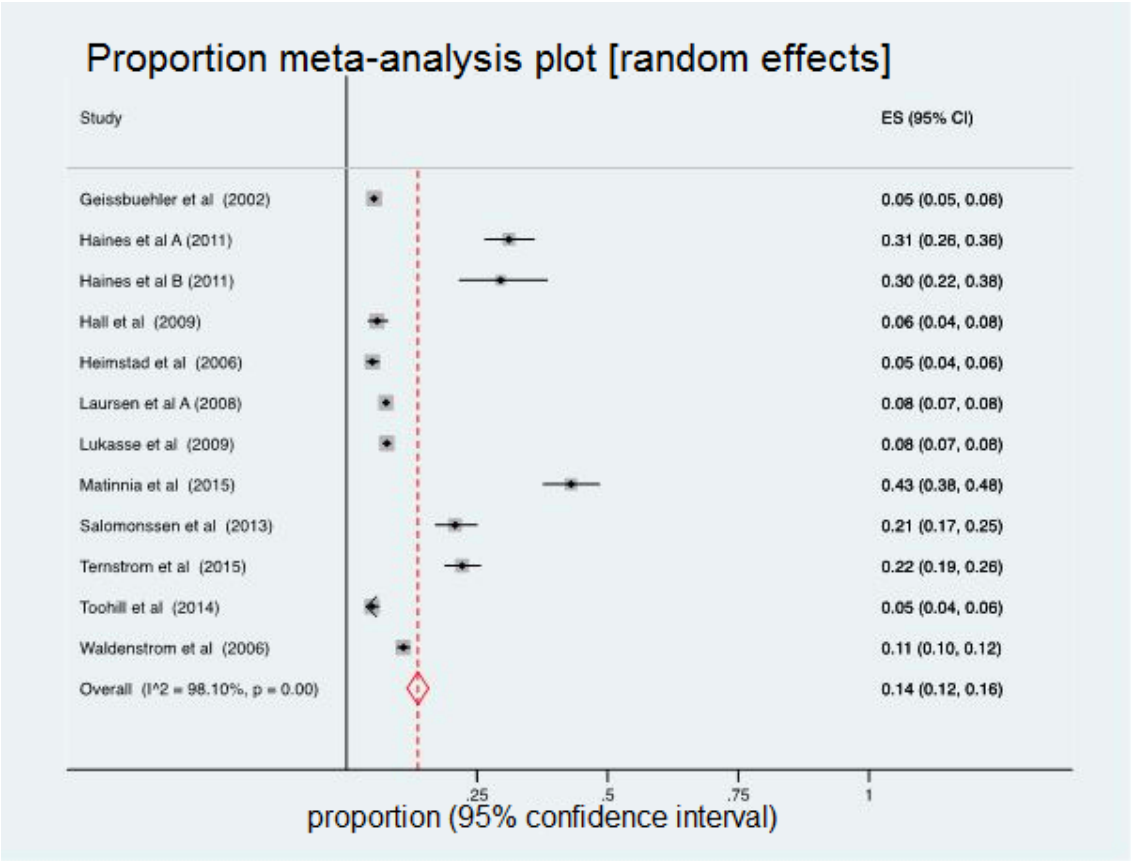


**Figure 3-6. Sensitivity analysis: Forest plot of the pooled prevalence of tocophobia using studies that screened women in the second trimester (13–27 weeks of gestation) only.**

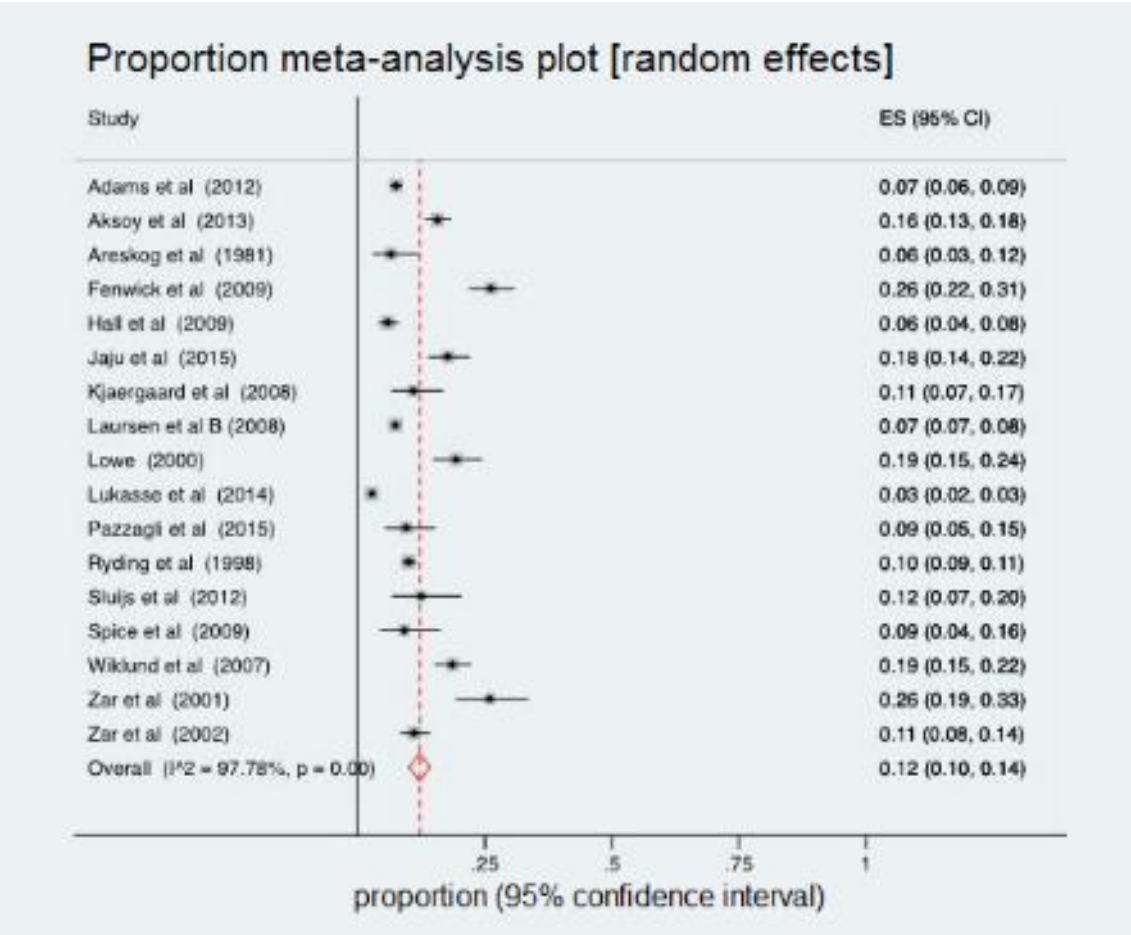


**Figure 3-7. Sensitivity analysis: Forest plot of the pooled prevalence of tocophobia using studies that screened women in the third trimester (27–42 weeks of gestation) only.**

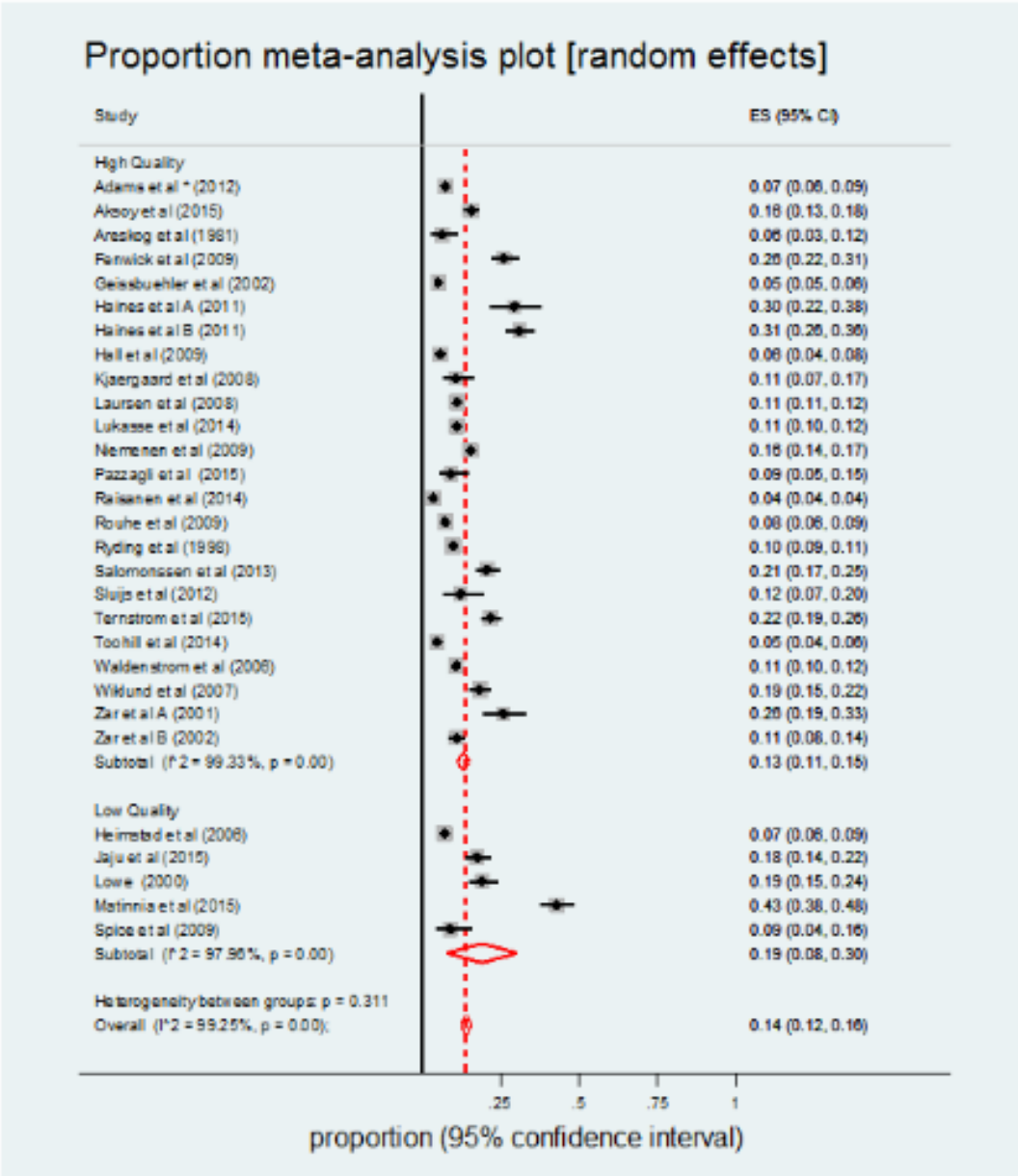


**Figure 3-8. Subgroup analysis: Forest plot of the pooled prevalence of tocophobia in high- and low-quality studies as determined by the quality assessment score. High-quality studies were studies that scored 5 or more out of a maximum of 8.**

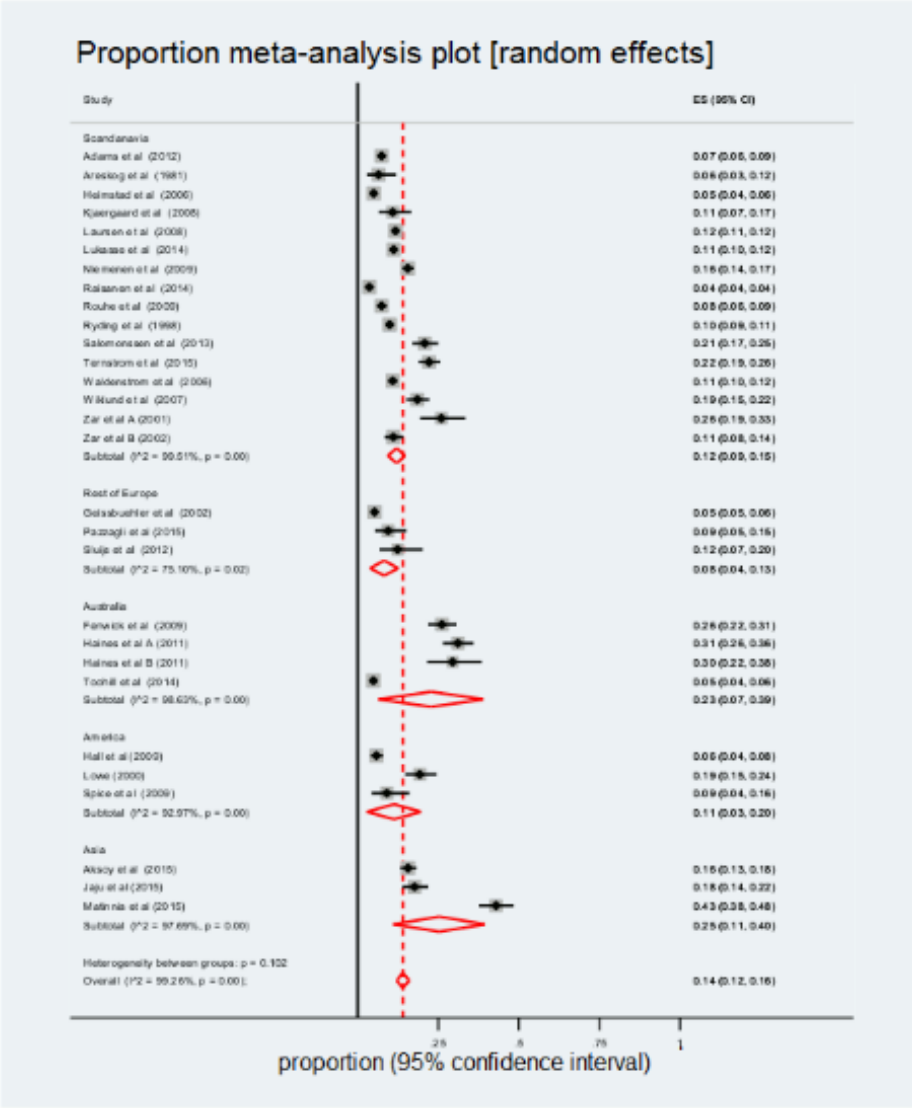


**Figure 3-9. Subgroup analysis: Forest plot of the pooled prevalence of tocophobia by study region.**

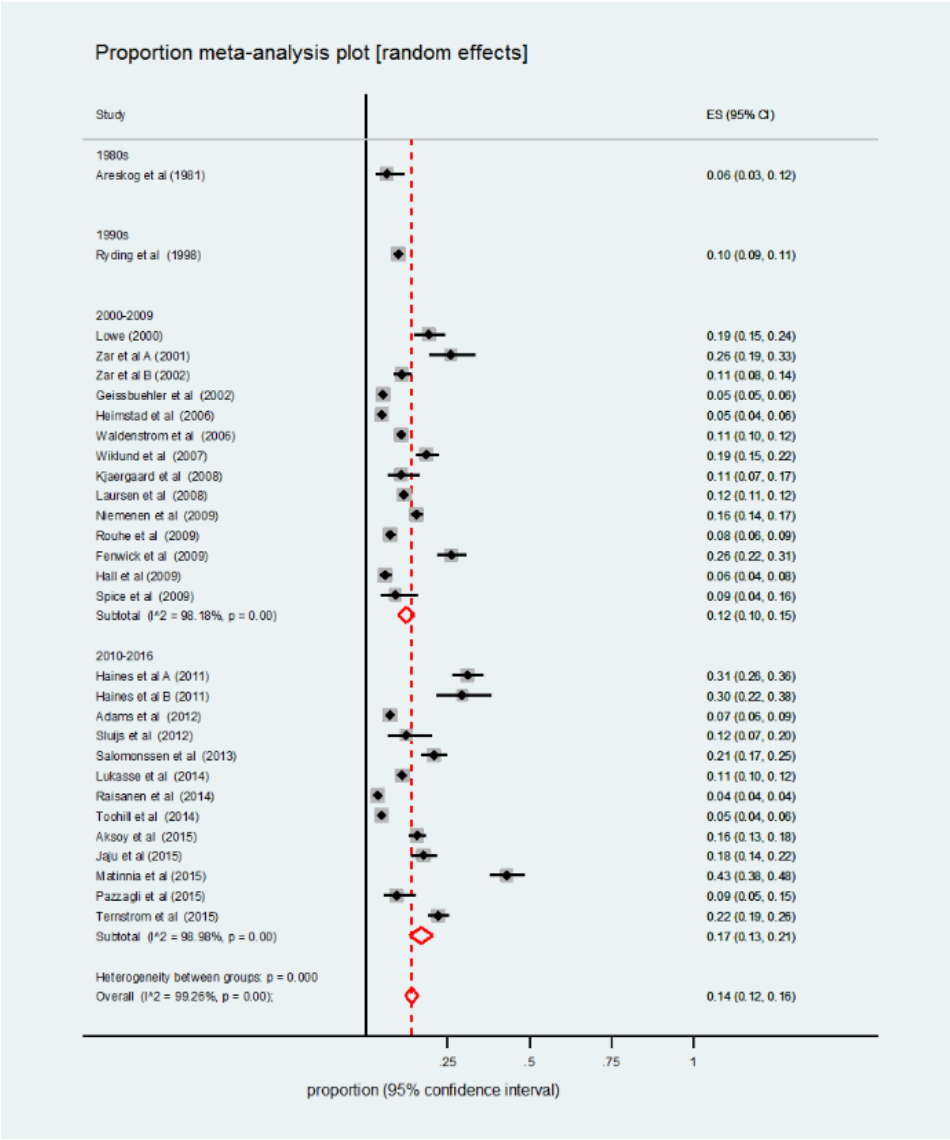


**Figure 3-10. Subgroup analysis: Forest plot of the pooled prevalence of tocophobia according to the time period in which the studies were conducted**

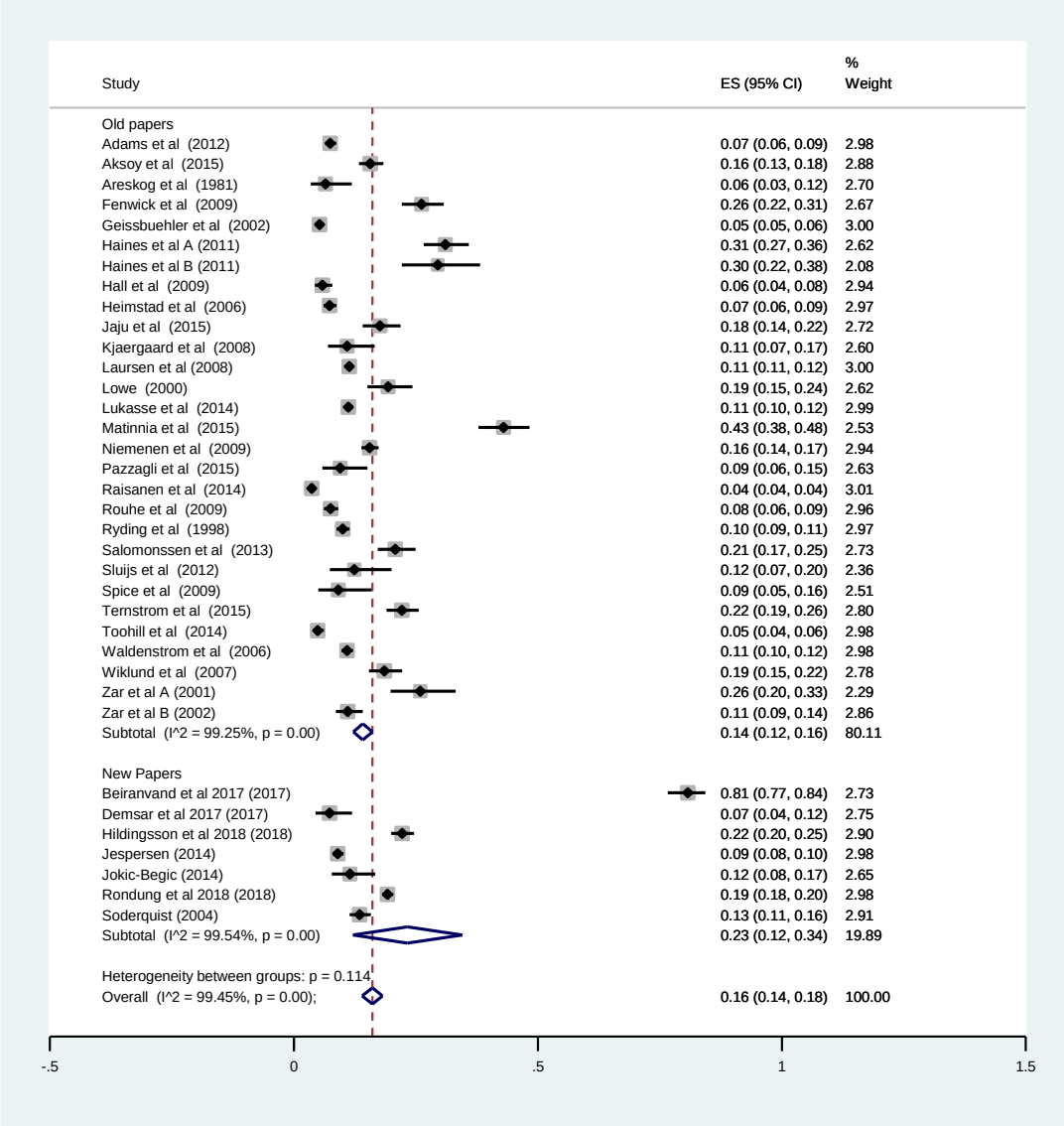


**Figure 3.11. Forest plot of the pooled prevalence estimate of tocophobia using a random effects model including data from 35 studies comprised of 863, 739 women**

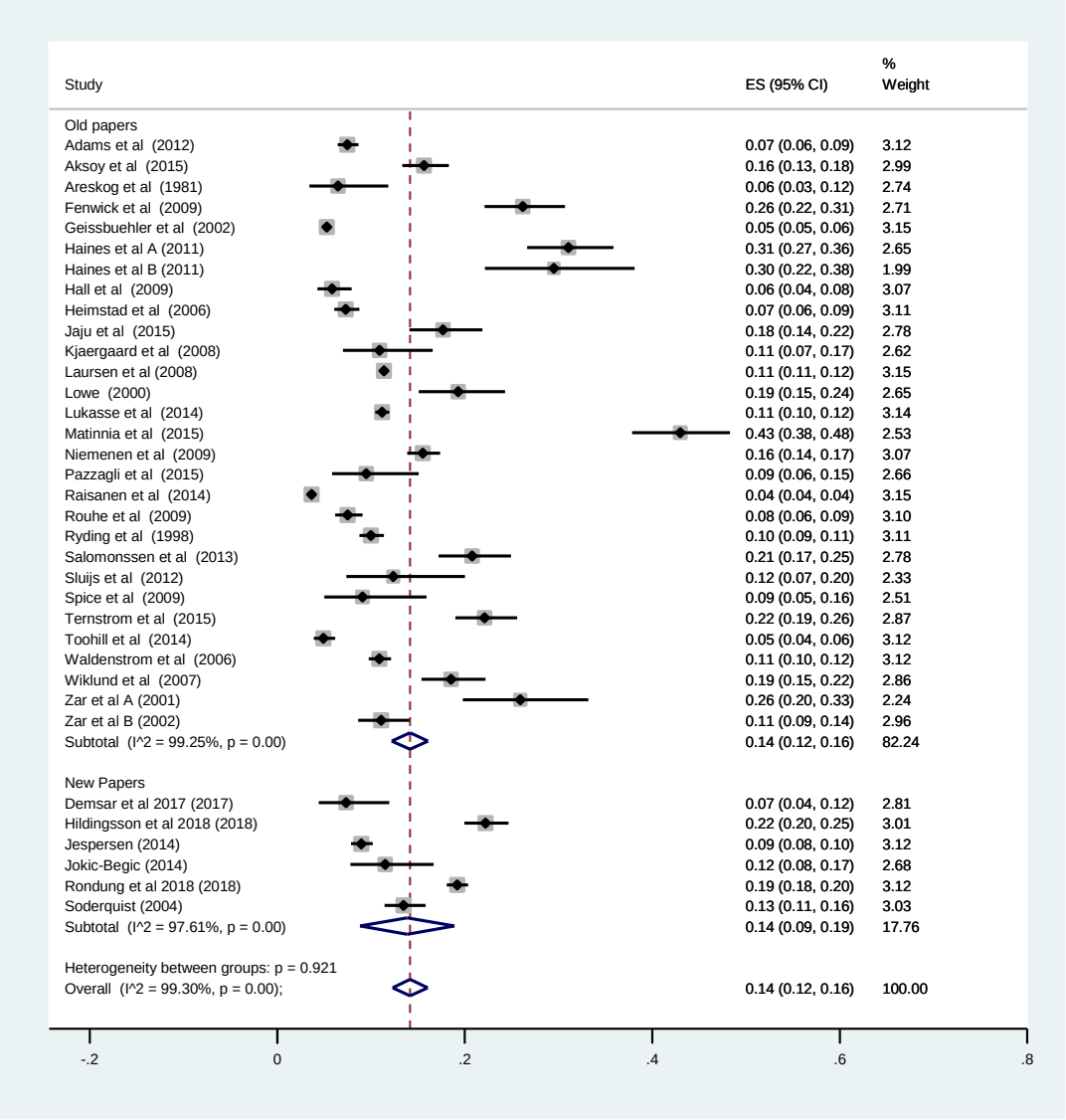


**Figure 3.12. Forest plot of the pooled prevalence estimate of tocophobia using a random effects model including data from 34 studies comprising 863,379 women**

# UPDATED SYSTEMATIC REVIEW AND META-ANALYSIS

## 3.8 Updated review methods

An updated systematic search of the literature published in the period from April 2016 until 22nd October 2018 was performed using the methods described in Chapter Three. This search resulted in 69 new titles which were screened. Of these, 7 were eligible for inclusion in worldwide prevalence of tocophobia in pregnant women. Through the updated search, a systematic review of definitions, measurement and prevalence of FOC (183) was located, and 7 further titles were located with sufficient data to be included in the updated meta-analysis (184-187). Six of the studies were conducted in Europe, three in Sweden (184, 188, 189), one in Denmark (185), one in Croatia (186), and one in Slovakia (190). One study was conducted in Iran (187). An additional 9,751 women were included in the analysis, meaning there were 863,739 women in the final meta-analysis.

## 3.9 Updated meta-analysis results

The updated meta-analysis including data from the original studies and all seven additional studies provided an overall pooled-prevalence estimate of 16% (95%CI 14-18%). Heterogeneity remained high (*($I^2$=99.45%, p<0.001)* (Figure 3-13). One study (187) used a lower cut-off on the CAQ than was previously recommended by Lowe *et al*. (42) . Therefore, we performed an analysis excluding this study (187). This analysis yielded a pooled-prevalence estimate of 14% (95%CI 12-16%) and heterogeneity remained high *($I^2$=99.30%, p<0.001)* (Figure 3-14).

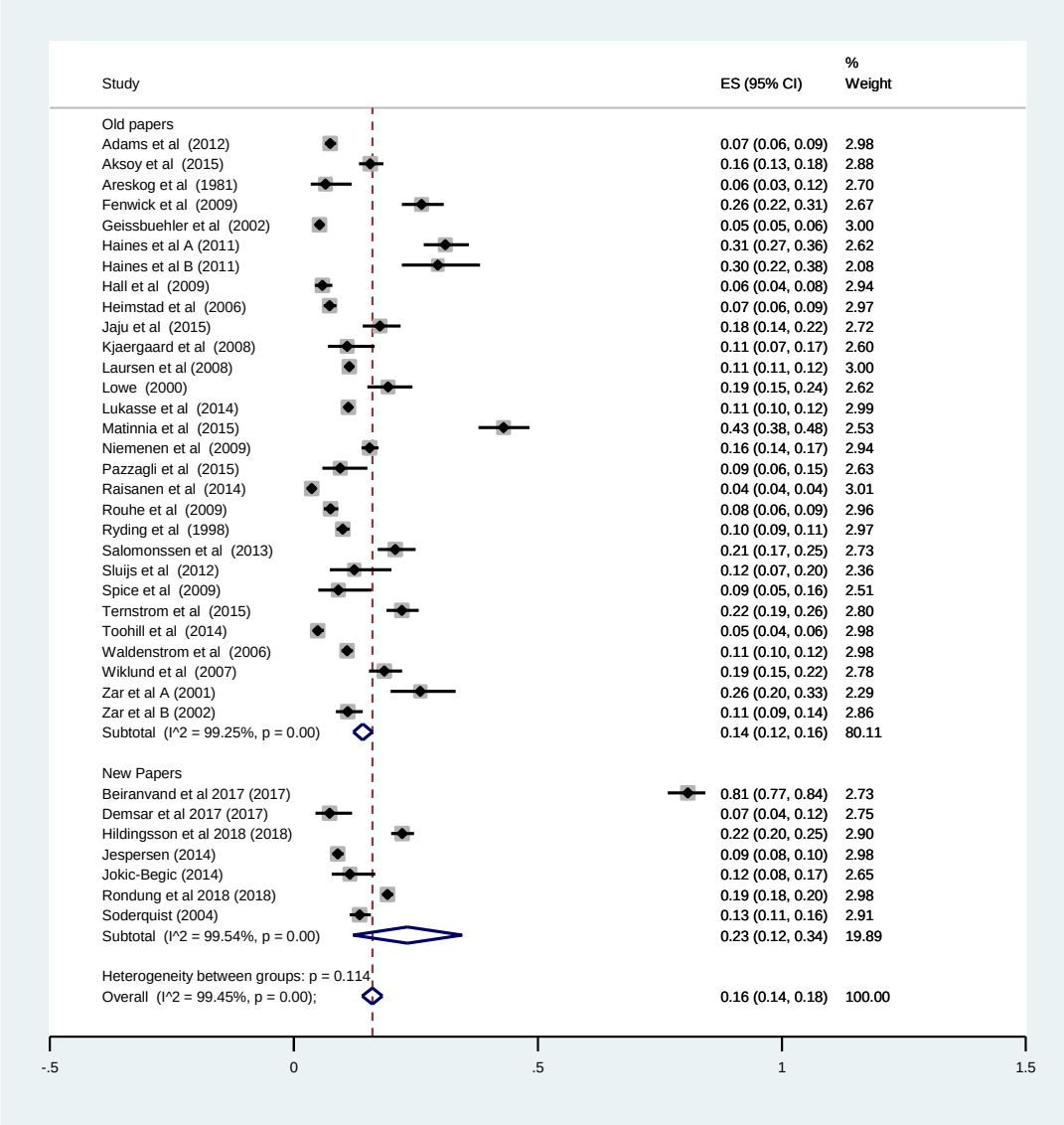


**Figure 3-13 Forest plot of the pooled prevalence estimate of tocophobia using a random effects model including data from 35 studies comprised of 863, 739 women**

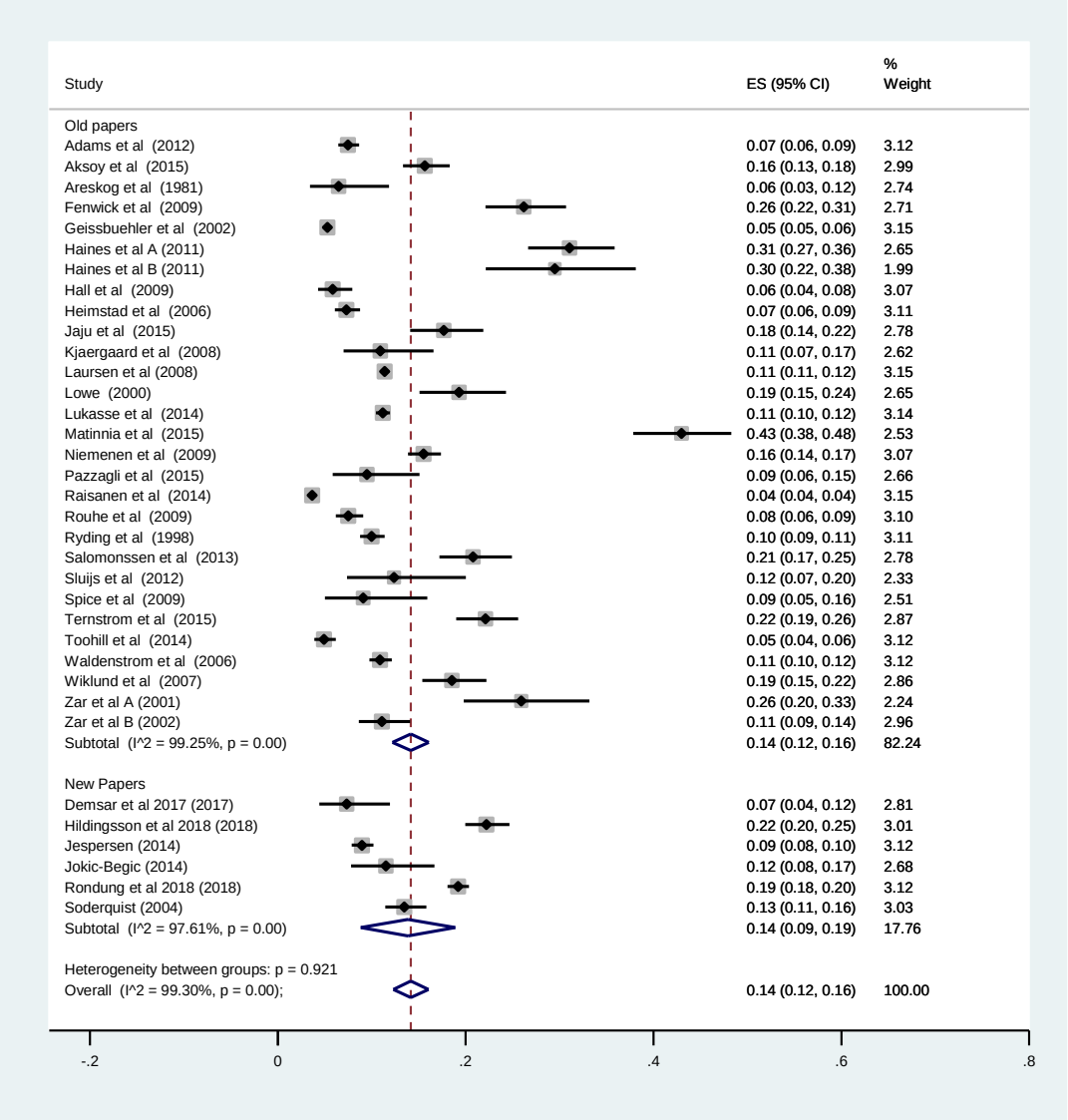


**Figure 3-14 Forest plot of the pooled prevalence estimate of tocophobia using a random effects model including data from 34 studies comprising 863,379 women**

# CHAPTER FOUR:
# THE EXPRESS STUDY PART 1

(Exploring women's perceptions and feelings surrounding childbirth)

(Paper 3: Prevalence Paper)

# 4.0 THE PREVALENCE AND RISK FACTORS OF FEAR OF CHILDBIRTH AMONG PREGNANT WOMEN: A CROSS SECTIONAL STUDY IN IRELAND (PAPER 3)

Maeve Anne O'Connell,

Patricia Leahy-Warren,

Louise C Kenny,

Sinéad M O'Neill,

Ali S Khashan

## 4.1 Prevalence study

The cross-sectional study is presented in this chapter. The paper is presented in the final publication manuscript format, which was published in Acta Obstetricia et Gynecologica Scandinavica in March 2019.

## 4.2 Abstract

**Introduction:** There is growing evidence of the considerable impact of fear of childbirth on women's health and well-being, but prevalence reports of high and severe fear of childbirth and reported risk factors have been inconsistent in various studies. Therefore, this study aimed to determine the prevalence of high and severe fear of childbirth and to identify risk factors of childbirth fear.

**Material and methods:** A cross-sectional study was conducted among a convenience sample of 882 pregnant women attending antenatal care in Cork, Ireland. Fear of childbirth was assessed using the Wijma Delivery Expectancy Questionnaire version A (W-DEQ A) using a cut-off ≥66 to define high fear and ≥85 to define severe fear. Associated risk factors were investigated using univariate and multivariate multinomial logistic regression analyses. Four W-DEQ A subscales were calculated using a cut-off ≥2.5 to determine the nature of childbirth fear.

**Results:** Overall prevalence of severe fear of childbirth was 5.3% (95%CI 4.0-7.0%), and high fear of childbirth was 36.7% (95%CI 33.6-39.9%). The prevalence of severe fear of childbirth in nulliparous women was 7.4% (95%CI 4.9-10.9%) and 4.3% (95%CI 2.9-6.3%) in multiparous women. However, the difference was not statistically significant ($p=.07$). The prevalence of high fear of childbirth was 43% (95%CI 37.5-48.6%) in nulliparous women, compared to 33.6% (95%CI 29.8-37.5%) in multiparous women, and this difference was statistically significant ($p<.005$). High fear of childbirth was associated with single marital status when compared with married or cohabiting women ($p=.008$). In a multivariate analysis, high fear of childbirth was significantly associated with low perceived informational support (adjusted relative risk ratio 2.62 (95%CI 1.34 to 5.13) and possible depression (assessed by the Edinburgh Postnatal Depression Scale) (adjusted relative risk ratio

12.87 (95%CI 6.07 to 27.25). In the W-DEQ A subscales: 35.6% of women scored ≥2.5 in Negative Emotions, 29.4% scored ≥2.5 in Lack of Positive Emotions, 9.9% scored ≥2.5 in Social Isolation, and 7.8% scored ≥2.5 in Moment of Birth.

**Conclusions:** Fear of childbirth is relatively common, with varying severity, and was more common in first-time mothers. Using W-DEQ A subscales provided additional information about the nature of the fear, in addition to severity of fear of childbirth.

**Key Message:**

Pregnant women commonly experience high and severe fear of childbirth. Single women were more likely to report high, but not severe childbirth fear. Findings from this study highlight the value of strong social support and quality information during pregnancy.

## 4.3 Introduction

Fear of childbirth (FOC) exists on a continuum from normal worries and fears, to severe fear, (tocophobia) (38, 40, 77). While tocophobia is not clearly defined, the adverse impact of FOC on women's health and well-being in the perinatal period is well-established (38, 191, 192). Previous studies have reported that sleep disturbances, nightmares, palpitations, stomach pains, panic attacks, flashbacks (after trauma), and a request for Caesarean are associated with FOC (106, 108, 191, 193). Furthermore, the impact on emotional well-being may be long-term and powerful, affecting partner relationships (194) and breastfeeding (195).

Prevalence estimates from single country (47) and multi-country (108) studies differ (3.7-43%)(77), due firstly, to poor consensus on definition, and secondly to various methods of measuring FOC (68, 77, 169). A meta-analysis estimated the global pooled-prevalence at 14% (77), noting increased prevalence in recent years, which may be attributable to increased awareness and reporting (77). Notably, no Irish study on the prevalence of FOC was retrieved in the systematic literature search (77). The meta-analysis found inconsistent evidence in relation to parity and FOC, with the majority of studies reporting higher prevalence in first-time mothers (77), but, with some studies reporting higher prevalence in parous women (68, 77, 150). Previous research suggests an association between low perceived social support and FOC (106, 108).

The Wijma Delivery Expectancy Questionnaire version A (W-DEQ A) (40) is the most commonly used tool to measure FOC severity (77) and is validated in many countries and languages (77). The prevalence of severe FOC (defined as W-DEQ A ≥85), is reported between 5-21% (77) and high FOC (W-DEQ A ≥66), between 24-

26% (47, 77, 196). Researchers (108, 169) suggest that the W-DEQ A consists of four subscales (169), which may facilitate health care professionals assessment of the nature of FOC, in addition to assessing severity, thereby facilitating a more personal approach to support offered for women (169). There is limited evidence in relation to these subscales at present, thus assessing the subscales in various cultural settings was recommended (169).

Due to this knowledge gap, the primary objective of this study was to establish the prevalence of high and severe FOC in a sample of pregnant women in Ireland. Secondary objectives were to identify potential risk factors of high FOC and elucidate the nature of FOC by applying W-DEQ A Subscales in this study.

## 4.4 Materials and Methods

### 4.4.1 Study design and population

We conducted a cross-sectional study between April 2015 and June 2016 in Cork, Ireland. A convenience sample of pregnant women attending routine antenatal appointments was recruited from public and private clinics. Recruitment took place over time periods when the researchers were available to recruit, rather than a consecutive period of time, since the study was carried out as part of part-time doctoral studies by the research midwife. The midwife trained the undergraduate students to recruit women to the study and either the midwife or research students invited pregnant women to participate. All the participants were planning to give birth at Cork University Maternity Hospital. Participation in this study was short, requiring the completion of just one questionnaire. The follow-up to the study for pregnancy outcomes was done using access to medical charts and the outcome data will be presented in a separate publication.

In Ireland, universal maternity benefits are available to all women, which means that free care is available during pregnancy and up to six weeks post-partum for those ordinarily resident (197). The predominant model of care is obstetric-led, with combined care involving the woman's GP being provided under the HSE Maternity & Infant Care Scheme (197). Women who choose shared care are seen by several different midwives and hospital doctors during their pregnancy, normal births would be facilitated by midwives and operative births by an obstetrician. DOMINO (Domiciliary Care In and Out of Hospital) is an option available in certain counties for women considered 'low risk' and within a certain local radius of the hospital, allowing continuity of midwifery care and early discharge home. Private antenatal care led by one obstetric consultant is available for a fee. Private maternity care is available at all 19 maternity units in Ireland and there is also one fully private unit.

The study population included; women >18 years, able to complete the questionnaire in English, and between 12 and 24 weeks' gestation at the time of recruitment. Previous studies suggest that FOC is not a stable construct and FOC levels may increase in the third trimester (47).

### 4.4.2 Variables

We developed a questionnaire package based on the literature to meet the aims of the study (Appendix 4). Demographic information collected included: age (by category), marital status, country of birth, education, smoking, weight and height, and employment status. Women were asked to rate their general health from 1 to 5, (poor to very good). Obstetric questions included: gestational age, number of previous

children, and number of previous miscarriages or stillbirths, any maternal or fetal complications in current or previous pregnancies, and their preference for normal birth or Caesarean. Psychological factors examined included: a history of anxiety, depression or postnatal depression using closed questions and the Edinburgh Postnatal Depression Score (EPDS).

FOC was measured by the English W-DEQ A (40), a self-assessment rating scale comprising 33 questions on a Likert scale. Negative questions are reverse-scored and a total calculated, with scores 0 to 165 possible. To determine severity of FOC, women scoring ≥85 were classified as having severe FOC (40, 47), ≥66, high FOC (196), 38-65, moderate FOC and ≤ 37, low fear. Data on women who answered a minimum of 27 questions were included, as advocated in a European cohort study (108). To investigate the nature of FOC, four W-DEQ A subscales (developed by researchers (169) who refined the original W-DEQ A (169)) were also applied: 1)'Negative Emotions'- containing questions relating to self-efficacy, negative appraisal and lack of positive anticipation (comprising 5 items: 2, 6, 8, 12, 19), 2)'Lack of Positive Emotions'- containing questions: happy, relaxed, confident, and safe (comprising 5 items: 5, 9, 17, 18, 23), 3)'Social Isolation'-containing questions relating to perceived social support (comprising 4 items: 3, 7, 11, 15), and 4)'Moment of Birth' - containing questions relating to how the woman imagines she will feel during birth (comprising 3 items: 28, 29, 30)(169). Using a cut-off ≥2.5 (the midpoint) was recommended for comparison purposes (169).

The EPDS is a widely used and well-validated self-report screening tool for recognising women at risk of perinatal depression (198, 199). Negative questions are reverse-scored and a total score calculated, with scores 0 to 30 possible. A systematic review of studies validating the use of EPDS in antenatal and postpartum women recommended using a cut-off of 9 or 10 for very likely risk of depression (199). Therefore, a cut-off ≥10 was used in this study (199).

The Perinatal Infant Care Social Support Scale (PICSS) (200) was used to measure maternal social support by investigating functional social support using four domains- informational, instrumental, emotional, and appraisal support (201), and structural social support or people available in a person's social networks (formal and informal) (200, 201). An individual score was calculated for each domain. For informational and instrumental support domains, low support was defined as a score ≤20 (200). For emotional and appraisal support domains, low support was defined as a score <12. Structural social support was measured by asking what individuals from the participant's social network (i.e. formal such as health professionals and informal such as family/friends) would be available to provide the four types of functional supports. Formal or informal structural support was considered available if any type of support was available from at least one source (200).

The questionnaire was piloted for ease of use with the first 100 women, and the font size increased on the PICSS (200), as it was deemed unclear in the initial format (Appendix 5).

### 4.4.3 Statistical Analyses

IBM SPSS Version 22.0 statistical software programme (Chicago, USA) was used for all statistical analyses. When determining sample size, the literature was examined, and a sample of 1,000 women deemed adequate on the basis of findings of previously published prevalence studies (47). Descriptive statistics were calculated for all variables and presented as n (%) or mean with standard deviation as appropriate. Following this, for each standardised measure (EPDS and W-DEQ A), scores were calculated.

FOC prevalence was estimated using the whole study population and subsequently in subgroups according to *a priori* chosen variables; parity, marital status, and history of pregnancy loss (history of miscarriage or stillbirth). Student's t-tests were used for continuous variables and Chi-squared tests for categorical variables as appropriate. $P<.05$ was considered statistically significant. One way analysis of variance was performed to compare group mean scores. Correlations of depression and fear of childbirth were examined using continuous scales by Spearman's rank correlation. The W-DEQ A was treated as a categorical variable (0-37; 38-65; 66-165) for this analysis because the study was not adequately powered for the risk factor analysis of the W-DEQ A ≥85 category. When there were ≤6 missing items, each item was replaced by the series mean for each participant (108) and total score calculated (n=44). Participants with >7 W-DEQ A items were excluded. Internal consistency in each scale used was determined using Cronbach's co-efficient alpha (202) (.70 was the minimum acceptable measure of instrument reliability). In our study, scale reliability was high; Cronbach's α values for W-DEQ A, PICSS (functional), PICSS

(structural), and EPDS were 0.89, 0.97, 0.81, and 0.99 respectively. Cronbach's α for each of the four W-DEQ A subscales was acceptable (0.78, 0.71, 0.76, and 0.80 respectively). Individual variables from the original W-DEQ A were combined as recommended (169), to calculate the four subscales. Missing data were handled in the same way as for the original W-DEQ A. The median and interquartile range were reported for each of the four W-DEQ A subscales and each individual subscale reported using a cut-off ≥2.5.

Relative risk ratio (RRR) and 95% confidence intervals (CI) were calculated to examine the association between each selected variable and risk of high FOC, firstly using univariate multinomial logistic regression analysis, followed by multivariate multinomial logistic regression. Variables with a *p-value* less than <0.15 in the univariate models were included in the multivariate models (maternal age, marital status, employment, smoking, BMI, living with partner, EPDS history of anxiety with treatment, history of depression, history of postnatal depression, low formal and informal social supports).

In addition, linear regression was performed to determine a correlation between FOC and the continuous variables (EPDS and PICSS).

### 4.4.4 Ethical Approval

This study obtained full ethical approval from the Cork Research Ethics Committee for the Teaching and Learning Hospitals ECM 4 (06/01/15) and ECM 3 (03/03/15) (Appendix 6). The study was explained using the information leaflet (explaining the voluntary nature of the study), eligibility clarified and written consent (separate from the questionnaire) obtained. Participants returned completed questionnaires to a sealed box.

## 4.5 Results

A total of 1,180 women were invited to participate, 1,056 women consented and were given questionnaires. Of these, 1,001 pregnant women self-completed and returned questionnaires (Figure 4-1). Data on demographics for 69 women who refused to participate are not available, reasons for declining are outlined in Figure 4-1. Fifty-five women were ineligible. A further 21 (2%), returned ineligible questionnaires (Figure 4-1). While there was a high overall response rate (n=980 (85%)), outcome data were available for 882 (75%) of these women. Participants had a median gestational age of 20 weeks and interquartile range 15-21. Distribution of the W-DEQ A scores among 882 women are presented in Figure 4-2.

### 4.5.1 Demographic and maternal characteristics

Demographic characteristics (n=882) are summarised in Table 4-1. The majority of women were aged 31-35 years (44%, n=388) and married (62.2%, n=549). Most women were Irish (78%, n=688), employed (64.5%, n=569) and had a university education (39.9%, n=352). Sixty-eight women (7.7%) were self-reported smokers. Of the total sample, 298 (33.8%) were nulliparous, and 581 (65.9%) women were multiparous, and 3 women did not report parity. Three women who reported the current pregnancy as their first stated they had at least one child at home, this may be a partner's child or adopted child (Table 4-1). At least one pregnancy loss was reported by 174 (19.7%) women (Table 4-1).

### 4.5.2 Prevalence of Fear of Childbirth

Of the 882 study participants, 47 women scored W-DEQ A≥85, resulting in a prevalence of 5.3% (95%CI 4.0-7.0%), with severe FOC, and 324 women scored W-DEQ A≥66, resulting in a prevalence of 36.7% (95%CI 33.6-39.9%) with high FOC. The prevalence of severe FOC was 7.4% (95%CI 4.9-10.9%) (n=22) in nulliparous women, and 4.3% (95%CI 2.9-6.3%) (n=25) in multiparous women (Table 4-2), but there was no statistically significant difference when compared ($p=.07$). The prevalence of high FOC (W-DEQ A≥66) was 43% (95%CI 37.5-48.6%) (n=128) in nulliparous women, and 33.6% (95%CI 29.8-37.5%) (n=195) in multiparous women (Table 4-2); when compared, the difference was statistically significant ($p<.005$). The prevalence of severe FOC among women who reported at least one pregnancy loss was 4.3%, and 5.2% among women who reported no pregnancy loss, this difference was not statistically significant ($p=.34$) and was not significant for high fear ($p=.38$). The distribution of the W-DEQ A score was normal (Figure 4-2). The mean W-DEQ Score was 57.34 (SD 18.47). In the group of women with severe FOC (W-DEQA≥ 85) the mean score was 91.26 (SD 7.76). In women with W-DEQA 66-84, the mean was 73.31 (SD5.13). The minimum W-DEQ A score reported was 1 and maximum 128. A comparison of mean W-DEQ A scores across groups is presented in Table 4-3. Significant differences in mean W-DEQ A score were seen in the following groups: marital status (p=.001), number of children (p=0.000), and women with a self-reported history of depression (p=.001).

The number and percentage of women across FOC groups is presented in Table 4-4.

### 4.5.3 Risk Factors of Fear of Childbirth

Among the 882 women in our study, there was a moderate correlation with fear of childbirth (W-DEQ A) and the EPDS Score (Spearman's correlation 0.38). The analysis of demographic factors revealed that high FOC was significantly more common among women who identified themselves as single (*p=.008*), when compared with married or cohabiting women, but there was no difference at the severe level of fear (*p=.13*). Adjusted results from the multivariate analysis are presented in Table 4-5. In terms of psychological factors, a history of depression or current depressive symptoms per the EPDS were identified as statistically significant factors associated with high FOC in the multivariate analysis (EPDS>6 (aRRR 2.8 (95%CI 1.7-4.7) and EPDS>10 (aRRR 12.9 (95%CI 6.1-27.3)) (Table 4-5). The importance of social factors on high FOC was demonstrated in the results of the multivariate analysis; those with low informational support (PICSS ≤20) were more likely to report high FOC (aRRR 2.6 (95%CI 1.3-5.1) (Table 4-5). The results of the linear regression (Table 4-6) suggested that the relationship between FOC and social support was statistically significant (p=0.000), while the relationship with depression, was not (p=0.12).

### 4.5.4 W-DEQ A Subscales

Table 4-7 presents results obtained from our analysis of the four W-DEQ A subscales. In the first subscale, Negative Emotions, 35.6% (95%CI 32.5-38.8) women scored ≥2.5. In the second subscale, Lack of Positive Emotions, 29.4% (95%CI 26.5-32.5) women scored ≥2.5. In the third subscale, Social Isolation, 9.9% (95%CI 8.1-12.0) women scored ≥2.5. Finally, in the fourth subscale, Moment of Birth, 7.8% (95%CI 6.2-9.8) of women scored ≥2.5.

## 4.6 Discussion

To the best of our knowledge, this is the first Irish prevalence estimate of FOC. International prevalence studies use various measurement and sampling methods, but our results are similar and therefore of value (77). Other studies using W-DEQ A ≥85 also reported a prevalence of 5%, in Australia (47) and in Europe- including Belgium, Iceland, Denmark, Estonia and Norway (108). The latter study (108) found a prevalence of 4.5% in Belgium and a higher prevalence (9-16%) in the other countries. A large epidemiological cohort study from Finland (17), where FOC is well recognised in maternity care, used ICD-10 codes to define FOC and reported the lowest prevalence of 3.7%. Limited data in relation to FOC in low-middle income countries suggests prevalence may be higher there. A study in India determined a prevalence of 17.7% using a binary question regarding FOC(161). The prevalence of high FOC (W-DEQ A ≥66) in the present study was high compared with other studies since previous research assessing high FOC using W-DEQ A ≥66 in Sweden, Canada and Australia found a prevalence of between 24-26% (77).

In this study, high FOC was associated with first-time mothers ($p<.005$). These findings are in line with similar findings in at least nine studies (77), but one study (150) found FOC more common in multiparous women, and two studies showed no association between FOC and parity (203, 204). In this study, we found no significant difference in prevalence in women with and without previous pregnancy loss, which was associated with FOC in a large epidemiological study (17).

Our finding that women who identified as single were more likely to have high FOC is aligned with findings from previous research (17). Consistent with previous studies (52, 68), we found a statistically significant association between high FOC and depression. A large register-based study of pregnant women referred for consultation with FOC (n=2405) in Finland (52) reported that women with FOC were twice as likely to experience mental health morbidity. They recommended; assessing the psychological status of all pregnant women, inter-disciplinary support for mental health, and postnatal follow-up assessment as appropriate (52).

This is the first study, to our knowledge, using the PICSS to investigate FOC and social supports. While previous studies found an association with high FOC and a poor social network (106, 108) or low self-efficacy (42), we did not locate any studies which specifically investigated low perceived informational support. Thus, our finding that low perceived informational support increased the risk of high FOC by almost three-fold is important (aRRR 2.6 (95%CI 1.34-5.13), and this factor may be potentially modifiable. Informational support can be defined as the exchange of knowledge, advice or feedback on actions (205). Therefore, if this factor were identified, midwives should aim to provide women with adequate, consistent information about birth in a way which does not trigger anxiety, ensuring sufficient time and emotional support are available in line with the World Health Organisation guidance (206). Moreover, Sheen et al suggested that women with FOC have an increased need for informational support since they are more likely to expect a negative outcome from an ambiguous situation due to a characteristic 'intolerance of uncertainty' (58). Findings from a qualitative study in Australia (70) suggests that women with FOC tend to avoid thinking or talking about birth and learning what to

expect in labour (70), and reported that quality of information from professionals influenced FOC (70). Traditionally, new mothers rely on health care professionals, books, family and friends (70) for information, whereas digital technologies are creating new forms of social support and information sources. The influence of digital technologies may be worth investigating since social media is commonly accessed and information quality may be dubious (205). The role of a strong social network, becomes increasingly significant in the perinatal period for women with childbirth fear.

An important finding in the present study, was 35.6% of all women and 53.4% of nulliparous women scored ≥2.5 in the W-DEQ A subscale 'Negative Emotions'. Women with low self-efficacy find it difficult to manage labour and may be more likely to have a CS (42), thus discussing their fears may facilitate positive birth preparation, information giving, and coping strategies (47, 173). Investigating women's concerns is clinically important, but more work is required to verify the utility of the W-DEQ A subscales (169).

A major strength is the high response rate (85%), the relatively large sample size for this research topic. The questionnaires used in this study were a validated and commonly used measure for fear of childbirth (W-DEQ A) using the original cut-offs (40, 77). We were also able to apply the proposed W-DEQ A subscales.

When considering generalizability and external validity of the study, the convenience sample which was recruited from a single site, and not selected randomly must be

taken into account. This may limit the degree to which results are generalizable to the Irish pregnant population. However, this was one of the largest maternity hospitals in Europe with approximately 8,000 births annually and our sample would appear to be comparable with national averages (207) (Table 4-8), apart from the figure for smoking, which was lower than the most recent National figure of smoking during pregnancy (208). Among the study participants 39.9% compared with 33.5% at the national level. The small difference in higher education rate could be due to the large University based in Cork or because the only available figure is for all females rather than mothers. We cannot rule out, however, that this difference is due to other reasons. With these limitations in mind, findings from this study may still be considered useful.

An important limitation in this study is that multiparous women were not asked about previous birth mode, since women who report a previous negative birth or FOC in one pregnancy are more likely to report FOC in a subsequent pregnancy (108). Another weakness in the study is that it was primarily designed to estimate the prevalence of FOC, but not powered for the risk factor analysis, which may have led to several associations with moderate to large RRR but not statistically significant, which could be due to small numbers within categories. The women completed questionnaires only in the second trimester, therefore this is acknowledged as a study limitation. There were missing BMI data for 124 (14.0%) women. Body mass index was self-reported with 72 (8.1%) women having missing weight and the rest having missing height and weight. Forty one (4.6%) women did not complete the EPDS questionnaire. The mean W-DEQ score for women who completed the EPDS was 57.08, while the mean W-DEQ score of women who did not complete the EPDS was 62.66. The data were incomplete for the whole EPDS questionnaire in those 41 participants, rather than

missing certain questions. In conclusion, this study found a similar prevalence of severe FOC, but a higher prevalence of high FOC when compared with reported international prevalence. High FOC was associated with depression, being a first time mother, and low perceived informational support, therefore assessing social supports, antenatal education provision and high quality information are essential in pregnancy. The use of a binary question to investigate previous mental health is a limitation of the study. Furthermore, the knowledge gain of the study is limited due to the relatively few risk factors which were examined. Nevertheless, this study adds to our limited understanding of FOC by using subscales to explore the nature of, as well as the severity of FOC. More investigation of other possible risk factors is recommended for future research.

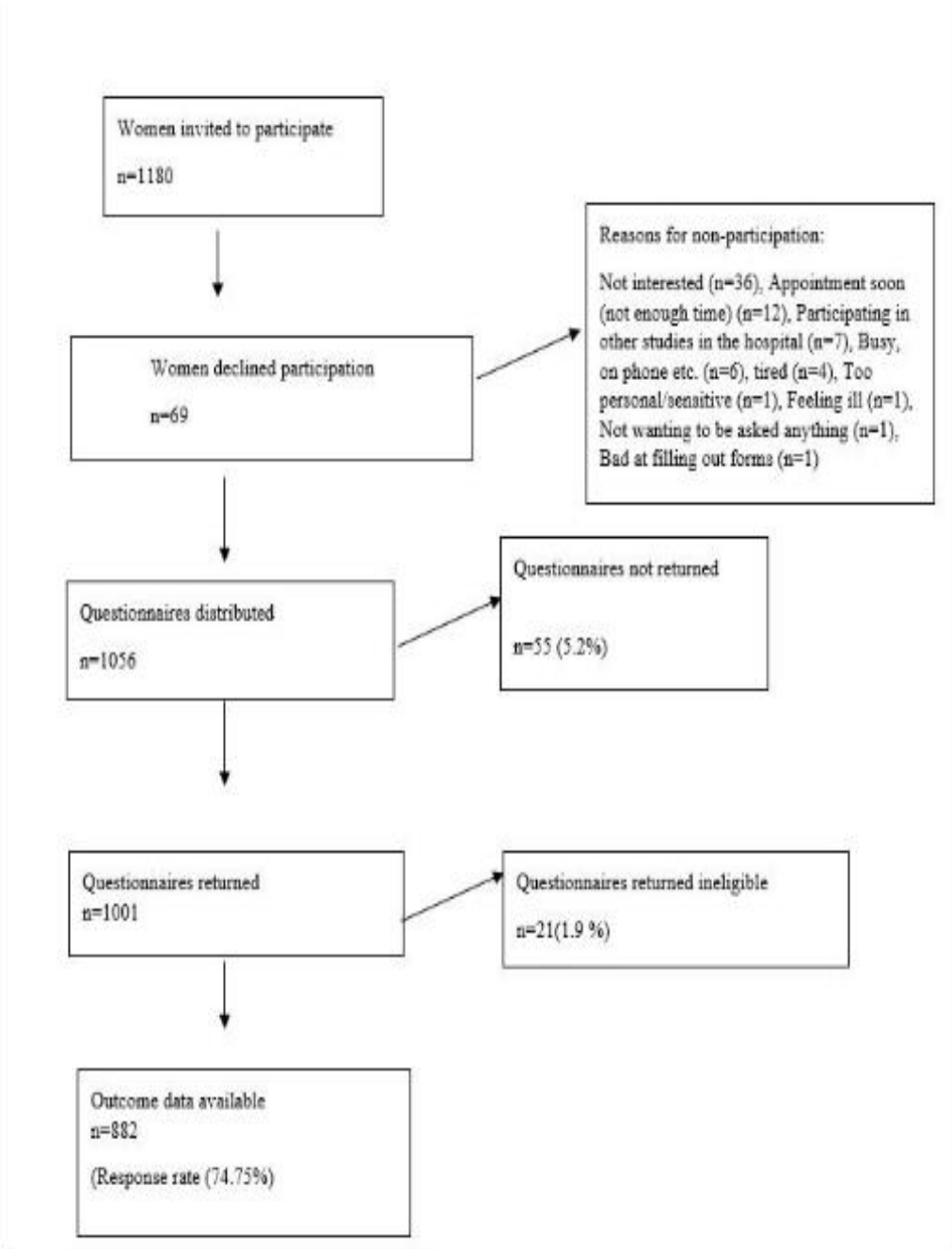


**Figure 4-1. Flow chart of study recruitment**

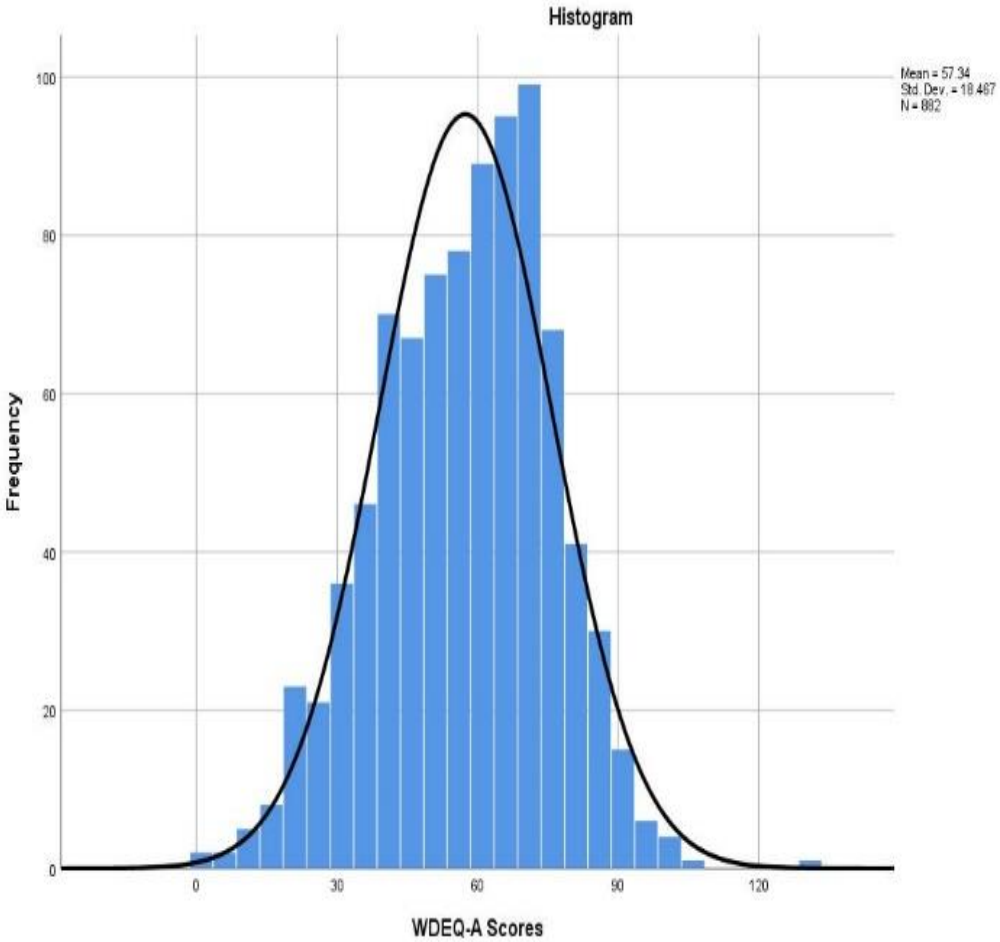


**Figure 4-2. Distribution of the Wijma Delivery Expectancy Questionnaire (W-DEQ A) Scores among 882 women**

## Table 4-1. Demographic and maternal characteristics of participants

| | | *Parity ** | |
|---|---|---|---|
| | ***Total Sample N (%)*** | ***Nulliparous N (%)*** | ***Multiparous N (%)*** |
| **Gestational Age** | **882 (100.0)** | **298 (100.0)** | **581 (100.0)** |
| Mean (SD, range) | 18.39 (3.40, 12) | 18.42 (3.32, 12) | 18.37 (3.43, 12) |
| Missing | 9 (1.0) | 2 (0.7) | 6 (1.0) |
| **Age** | | | |
| 18-25 | 97 (11.0) | 57 (19.1) | 40 (6.9) |
| 26-30 | 192 (21.8) | 90 (30.2) | 101 (17.4) |
| 31-35 | 388 (44.0) | 114 (38.3) | 273 (47.0) |
| ≥36 | 196 (22.2) | 35 (11.7) | 161 (29.7) |
| Missing | 9 (1.0) | 2 (0.7) | 6 (1.0) |
| **Marital Status** | | | |
| Married or Co-Habiting | 793 (89.9) | 253 (84.9) | 539 (92.8) |
| Other (Single, Divorced, Separated) | 80 (9.1) | 42 (14.1) | 37 (6.4) |
| Missing | 9 (1.0) | 3 (1.0) | 5 (0.9) |
| **Country of Birth** | | | |
| Rep. of Ireland | 688 (78.0) | 240 (80.5) | 446 (76.8) |
| UK & Northern Ireland | 62 (7.0) | 21 (7.0) | 41 (7.1) |
| Other | 127 (14.4) | 37 (12.4) | 90 (15.5) |
| Missing | 5 (0.6) | 0 (0.0) | 4 (0.7) |
| **Duration of residence** | | | |
| ≤10 years | 107 (12.1) | 33 (11.1) | 74 (12.7) |
| ≥11 years | 82 (9.3) | 25 (8.4) | 57 (9.8) |
| Always resident in Ireland | 693 (78.6) | 240 (80.5) | 450 (77.5) |
| **Education/ Qualifications** | | | |
| Secondary School | 160 (8.1) | 55 (18.5) | 105 (18.1) |
| Some College | 202 (22.9) | 61 (20.4) | 130 (24.1) |
| Bachelor's degree or Higher | 511 (57.9) | 180 (60.4) | 330 (56.8) |
| Missing | 9 (1.0) | 2 (0.7) | 6 (1.0) |
| **Employment** | | | |
| Employed | 732 (83.0) | 260 (87.3) | 470 (80.9) |
| Unemployed | 40 (4.5) | 16 (5.3) | 23 (4.0) |
| Student | 20 (2.3) | 15 (5.0) | 5 (0.9) |
| Homemaker | 86 (9.8) | 5 (1.7) | 81 (13.9) |
| Missing | 4 (0.5) | 2 (0.7) | 2 (0.3) |
| **Body Mass Index (BMI)** | | | |
| Underweight or Normal weight ≤24.9 | 442 (50.1) | 142 (47.6) | 300 (51.7) |
| Overweight 25.0-29.9 | 245 (27.8) | 93 (31.2) | 152 (26.2) |
| Obese ≤30.0 | 71 (8.1) | 18 (6.1) | 56 (9.1) |
| Missing | 124 (14.0) | 45 (15.1) | 76 (13.1) |
| **Smoking Status** | | | |
| Smoker | 68 (7.7) | 23 (7.7) | 45 (7.7) |
| Non-smoker | 805 (91.3) | 271 (90.9) | 534 (91.9) |
| Missing | 9 (1.0) | 4 (1.3) | 2 (0.3) |
| **Obstetric Factors:** | | | |
| **Previous Pregnancy Loss** | | | |
| 0 | 626 (71.0) | 291 (97.7) | 335 (57.7) |
| 1 | 174 (19.7) | 4 (1.3) | 170 (29.3) |
| ≥2 | 70 (7.9) | 0 (0.0) | 70 (12.0) |
| Missing | 12 (1.4) | 3 (1.0) | 6 (1.0) |
| **No. of Children** | | | |
| 0 children | 360 (40.8) | 293 (98.3) | 67 (11.5) |
| 1 child | 304 (34.5) | 1 (0.3) | 303 (52.2) |
| 2 or more children | 204 (23.1) | 2 (0.7) | 202 (34.7) |
| Missing | 14 (1.6) | 2 (0.7) | 9 (1.5) |
| **Psychological History (self-report)** | | | |
| History of Anxiety | 205 (23.2) | 64 (21.5) | 139 (23.9) |
| No history of Anxiety | 673 (76.3) | 232 (77.9) | 441 (75.9) |
| Missing | 4 (0.5) | 2 (0.7) | 1 (0.2) |
| History of Depression | 111 (12.5) | 30 (10.1) | 80 (13.8) |
| No history of Depression | 767 (87.0) | 267 (89.6) | 499 (85.9) |
| Missing | 4 (0.5) | 1 (0.3) | 2 (0.3) |

Table Legend *Missing data on parity for 3 women.

## Table 4-2. Prevalence of fear of childbirth by severity and by parity

| Parity* | Total sample | Nulliparous | Multiparous |
|---|---|---|---|
| W-DEQ A Score | N (%)<br>882 (100%) | N (%)<br>298 (100%) | N (%)<br>581 (100%) |
| W-DEQ A: 0-65<br>Moderate Fear | 558 (63.3%) | 170 (57.0%) | 386 (66.4%) |
| W-DEQ A: 66-84<br>High Fear | 277 (31.4%) | 106 (35.6%) | 170 (29.3%) |
| W-DEQ A: 85-165<br>Severe Fear | 47 (5.3%) | 22 (7.4%) | 25 (4.3%) |

Table Legend *Parity missing for 3 women; W-DEQ A Wijma Delivery Experience Questionnaire Part A, CI Confidence Intervals.

## Table 4-3. A comparison of mean W-DEQ A Scores across groups

| | | | | *Parity ** | | | |
|---|---|---|---|---|---|---|---|
| | ***Total Sample N (%)*** | | | ***Nulliparous N (%)*** | | ***Multiparous N (%)*** | |
| | **882 (100.0)** | **Mean W-DEQ A score** | **p-value** | **298 (100.0)** | **Mean W-DEQ A score** | **581 (100.0)** | **Mean W-DEQ A score** |
| **Age** | | | | | | | |
| 18-25 | 97 (11.0) | 60.56 | | 57 (19.1) | 62.12 | 40 (6.9) | 58.33 |
| 26-30 | 192 (21.8) | 58.05 | | 90 (30.2) | 62.22 | 101 (17.4) | 54.37 |
| 31-35 | 388 (44.0) | 56.13 | | 114 (38.3) | 59.73 | 273 (47.0) | 54.62 |
| ≥36 | 196 (22.2) | 56.94 | 0.18 | 35 (11.7) | 65.14 | 161 (29.7) | 55.16 |
| **Marital Status** | | | | | | | |
| Married or Co-Habiting | 793 (89.9) | 55.73 | | 253 (84.9) | 61.15 | 539 (92.8) | 54.50 |
| Other (Single, Divorced, Separated) | 80 (9.1) | 63.63 | 0.001* | 42 (14.1) | 65.38 | 37 (6.4) | 61.86 |
| **Country of Birth** | | | | | | | |
| Rep. of Ireland | 688 (78.0) | 57.14 | | 240 (80.5) | 60.87 | 446 (76.8) | 55.13 |
| UK & Northern Ireland | 62 (7.0) | 56.66 | | 21 (7.0) | 63.76 | 41 (7.1) | 53.02 |
| Other | 127 (14.4) | 58.28 | 0.79 | 37 (12.4) | 64.14 | 90 (15.5) | 55.87 |
| **Duration of residence** | | | | | | | |
| ≤10 years | 107 (12.1) | 56.58 | | 33 (11.1) | 60.36 | 74 (12.7) | 54.89 |
| ≥11 years | 82 (9.3) | 57.80 | | 25 (8.4) | 66.88 | 57 (9.8) | 53.82 |
| Always resident in Ireland | 693 (78.6) | 57.40 | 0.69 | 240 (80.5) | 61.07 | 450 (77.5) | 55.40 |
| **Education/ Qualifications** | | | | | | | |
| Secondary School | 160 (8.1) | 57.56 | | 55 (18.5) | 62.04 | 105 (18.1) | 55.22 |
| Some College | 202 (22.9) | 58.84 | | 61 (20.4) | 63.80 | 130 (24.1) | 56.87 |
| Bachelor's degree or Higher | 511 (57.9) | 56.80 | 0.63 | 180 (60.4) | 61.16 | 330 (56.8) | 54.61 |
| **Employment** | | | | | | | |
| Employed | 732 (83.0) | 57.02 | | 260 (87.3) | 57.07 | 470 (80.9) | 55.15 |
| Unemployed | 40 (4.5) | 63.58 | | 16 (5.3) | 63.58 | 23 (4.0) | 58.78 |
| Student | 20 (2.3) | 60.60 | | 15 (5.0) | 60.60 | 5 (0.9) | 63.00 |
| Homemaker | 86 (9.8) | 57.15 | 0.14 | 5 (1.7) | 57.15 | 81 (13.9) | 56.67 |
| **Body Mass Index (BMI)** | | | | | | | |
| Underweight or Normal weight ≤24.9 | 442 (50.1) | 56.17 | | 142 (47.6) | 59.95 | 300 (51.7) | 54.38 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Overweight 25.0-29.9 | 245 (27.8) | 58.42 | | 93 (31.2) | 62.15 | 152 (26.2) | 56.14 |
| Obese ≤30.0 | 71 (8.1) | 56.58 | 0.31 | 18 (6.1) | 60.61 | 56 (9.1) | 55.21 |
| **Smoking Status** | | | | | | | |
| Smoker | 68 (7.7) | 59.66 | | 23 (7.7) | 63.09 | 45 (7.7) | 57.91 |
| Non-smoker | 805 (91.3) | 57.02 | 0.26 | 271 (90.9) | 61.30 | 534 (91.9) | 54.85 |
| **Obstetric Factors:** | | | | | | | |
| **Previous Pregnancy Loss** | | | | | | | |
| 0 | 626 (71.0) | 57.65 | | 291 (97.7) | 61.56 | 335 (57.7) | 54.26 |
| 1 | 174 (19.7) | 56.97 | | 4 (1.3) | 42.25 | 170 (29.3) | 57.32 |
| ≥2 | 70 (7.9) | 54.46 | 0.38 | 0 (0.0) | - | 70 (12.0) | 54.46 |
| **No. of Children** | | | | | | | |
| 0 children | 360 (40.8) | 61.24 | | 293 (98.3) | 61.17 | 67 (11.5) | 61.54 |
| 1 child | 304 (34.5) | 54.97 | | 1 (0.3) | 39.00 | 303 (52.2) | 55.02 |
| ≥2 children | 204 (23.1) | 53.44 | 0.000* | 2 (0.7) | 84.00 | 202 (34.7) | 53.13 |
| **Psychological History (self-report)** | | | | | | | |
| History of Anxiety | 205 (23.2) | 59.41 | | 64 (21.5) | 66.61 | 139 (23.9) | 55.97 |
| No history of Anxiety | 673 (76.3) | 56.68 | 0.06 | 232 (77.9) | 60.08 | 441 (75.9) | 54.89 |
| History of Depression | 111 (12.5) | 62.68 | | 30 (10.1) | 70.63 | 80 (13.8) | 59.51 |
| No history of Depression | 767 (87.0) | 56.52 | 0.001* | 267 (89.6) | 60.31 | 499 (85.9) | 54.48 |

**Table**

**Legend:** *p<0.05, W-DEQ A= Wijma Delivery Experience Questionnaire Part A

## Table 4-4. Number and percentage of women across FOC groups

**Table Legend:** BMI=Body Mass Index, W-DEQ A=Wijma Delivery Expereicne Questionnaire Part

| **Risk factor** | N | WDEQ-A: 0-37 *Low fear* *N (%)* | WDEQ-A: 37-66 *Moderate fear* N (%) | WDEQ-A: 66-166 *High to severe fear* N (%) |
|---|---|---|---|---|
| **Maternal age** | | | | |
| <25 years | 97 | 11 (11.3) | 47 (48.5) | 39 (40.2) |
| 26-30 years | 192 | 29 (15.1) | 89 (46.4) | 74 (38.5) |
| 31-35 years | 388 | 51 (13.1) | 205 (52.8) | 132 (34) |
| 36+ years | 196 | 36 (18.4) | 88 (44.9) | 72 (36.7) |
| **Marital Status** | | | | |
| Married | 549 | 90 (16.4) | 277 (50.5) | 182 (33.1) |
| Co-habiting | 244 | 32 (13.1) | 117 (48.0) | 95 (38.9) |
| Other (Single/ Divorced/ Separated) | 80 | 6 (7.5) | 34 (42.5) | 40 (50.0) |
| **Ethnicity** | | | | |
| White | 850 | 125 (14.7) | 417 (49.1) | 308 (36.2) |
| Other | 24 | 3 (12.5) | 11 (45.8) | 10 (41.7) |
| **Country of Birth** | | | | |
| Rep. of Ireland | 688 | 97 (14.1) | 341 (49.5) | 250 (36.3) |
| UK & Northern Ireland | 62 | 9 (14.5) | 35 (56.4) | 18 (29.0) |
| Other | 127 | 22 (17.3) | 52 (40.9) | 53 (41.7) |
| **Years in Ireland** | | | | |
| if resident <5years | 47 | 11 (23.4) | 16 (34.0) | 20 (42.6) |
| if resident 6-10years | 60 | 6 (10.0) | 34 (56.7) | 20 (33.3) |
| if resident 11+years | 82 | 15 (18.3) | 36 (43.9) | 31 (37.8) |
| **Qualifications** | | | | |
| Secondary School | 160 | 26 (16.3) | 67 (41.9) | 67 (41.9) |
| College | 162 | 21 (12.9) | 74 (45.7) | 67 (41.3) |
| University/ Degree | 352 | 51 (14.5) | 186 (52.8) | 115 (32.7) |
| Postgraduate qualification | 159 | 24 (15.1) | 80 (50.3) | 55 (34.6) |
| Other | 40 | 6 (15.0) | 21 (52.5) | 13 (32.5) |
| **Employment** | | | | |
| Full time | 569 | 81 (14.2) | 287 (50.4) | 201 (35.3) |
| Part time | 163 | 27 (16.6) | 78 (47.9) | 58 (35.6) |
| Home maker | 86 | 10 (11.6) | 45 (52.3) | 31 (36.0) |
| Other | 60 | 8 (13.3) | 19 (31.7) | 33 (55.0) |
| **Self-reported Smoker** | | | | |
| Yes | 68 | 6 (8.8) | 34 (50.0) | 28 (41.1) |
| No | 805 | 122 (15.1) | 391 (48.6) | 292 (36.3) |
| **Self-reported BMI** | | | | |
| Underweight | 8 | 0 (0.0) | 4 (50.0) | 4 (50.0) |
| Normal weight | 434 | 69 (15.9) | 221 (50.9) | 144 (33.2) |
| Overweight | 245 | 34 (13.9) | 110 (44.9) | 101 (41.2) |
| Obese/ Morbidly obese | 71 | 11 (15.5) | 37 (52.1) | 23 (32.4) |
| **History of pregnancy loss** | | | | |
| Yes | 244 | 42 (17.2) | 116 (47.5) | 86 (35.2) |
| No | 626 | 85 (13.6) | 307 (49.0) | 234 (37.3) |

A

**Table 4-5. Multivariate multinomial logistic regression analysis of psycho-social factors associated with fear of childbirth**

| Risk factor | N | W-DEQ A 0-37: *Low Fear* | W-DEQ A 38-65: *Moderate Fear* | | W-DEQ A 66-165: *High to Severe Fear* | |
|---|---|---|---|---|---|---|
| | 882 | *Reference Group* | *aRRR (95%CI)* | *p-value* | *aRRR (95% CI)* | *p-value* |
| History of Anxiety | | | | | | |
| **No** | 673 | *Ref* | | | | |
| **Yes** | 205 | *Ref* | 0.98 (0.57, 1.69) | 0.95 | 0.81 (0.46, 1.44) | 0.48 |
| **Missing** | 4 | *Ref* | | | | |
| History of Depression | | | | | | |
| **No** | 767 | *Ref* | | | | |
| **Yes** | 111 | *Ref* | 1.18 (0.54, 2.56) | 0.68 | 2.10 (0.96, 4.57) | 0.06 |
| **Missing** | 4 | *Ref* | | | | |
| EPDS | | | | | | |
| **0-5 (unlikely depression)** | 294 | *Ref* | | | | |
| **6-9 (possible depression)** | 337 | *Ref* | 1.99 (1.26, 3.14) | 0.003 | 2.81 (1.68, 4.70) | 0.000 |
| **≥10 (likely depression)** | 210 | *Ref* | 3.26 (1.57, 6.78) | 0.002 | 12.87 (6.07, 27.25) | 0.000 |
| **Missing** | 41 | *Ref* | | | | |
| Social Support | | | | | | |
| Low Informational Support (PICSS≤20) | | | | | | |
| **High Support** | 612 | *Ref* | | | | |
| **Low Support** | 270 | *Ref* | 2.34 (1.22, 4.47) | 0.01 | 2.62 (1.34, 5.13) | 0.005 |
| Low Instrumental Support (PICSS≤20) | | | | | | |
| **High Support** | 412 | *Ref* | | | | |
| **Low Support** | 470 | *Ref* | 1.06 (0.68, 1.66) | 0.79 | 1.50 (0.93, 2.41) | 0.096 |
| Low Emotional Support (PICSS≤12) | | | | | | |
| **High Support** | 711 | *Ref* | | | | |
| **Low Support** | 55 | *Ref* | - | - | - | - |
| **Missing** | 116 | *Ref* | 0.88 (0.26, 3.02) | 0.84 | 1.47 (0.41, 5.26) | 0.56 |
| Low Functional appraisal support (PICSS≤12) | | | | | | |
| **High Support** | 697 | *Ref* | | | | |
| **Low Support** | 69 | *Ref* | 1.41 (0.45, 4.45) | 0.55 | 1.61 (0.51, 5.13) | 0.41 |
| **Missing** | 116 | *Ref* | | | | |
| Formal social supports (any type of support available from each source PICSS) | | | | | | |
| **Yes** | 674 | *Ref* | | | | |
| **No** | 183 | *Ref* | 1.16 (0.67, 2.01) | 0.60 | 1.29 (0.73, 2.29) | 0.38 |
| **Missing** | 25 | *Ref* | | | | |
| Informal social supports (any type of support available from each source PICSS | | | | | | |
| **Yes** | 851 | *Ref* | | | | |
| **No** | 31 | *Ref* | 0.51 (0.17, 1.53) | 0.23 | 0.86 (0.29, 2.55) | 0.79 |

Table Legend Ref=reference group, W-DEQ A= Wijma Delivery Experience Questionnaire Part A, EPDS= Edinburgh Postnatal Depression Score, PICSS=Perinatal Infant Care Social Support Scale, *p-value* significance .05, aRRR=Adjusted Relative Risk Ratio, 95% CI=95% Confidence Intervals, - =no results possible *Only variables that were significant in the univariate analysis p≤.15 were included in the multivariate analysis (i.e. Age, Marital Status, Employment, Smoking, BMI, Living with, Risk of Depression (EPDS>10), Self-reported History of Anxiety with treatment, Self-reported History of Depression, History of Postnatal Depression, and PICSS Informational, Instrumental, Emotional, Functional Appraisal and Formal Supports).

**Table 4-6. Correlation of fear of childbirth with depression and overall social support using linear regression**

| Variable<br>N | EPDS score<br>Co-efficient | PICSS Overall Score<br>Co-efficient |
|---|---|---|
| Overall sample (continuous)<br>W-DEQ A 0-165<br>N=882 | 0.001 (0.12) | 0.145 (0.000)* |

*p<0.05

**Table 4-7. W DEQ A Subscales**

| *Subscale* | *Negative Emotions* | | | *Lack of Positive Emotions* | | | *Social Isolation* | | | *Moment of Birth* | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Sample** | Total n (%) n=882(100%) | Nulliparous n=298(100%) | Multiparous n=581(100%) | Total n (%) n=882(100%) | Nulliparous n=298(100%) | Multiparous n=581(100%) | Total n (%) n=882(100%) | Nulliparous n=298(100%) | Multiparous n=581(100%) | Total n (%) n=882(100%) | Nulliparous n=298(100%) | Multiparous n=581(100%) |
| **Median** | 9.20 | 10.60 | 8.40 | 9.20 | 9.20 | 8.80 | 3.00 | 4.00 | 3.00 | 2.33 | 2.33 | 2.33 |
| **IQR** | 5 | 4 | 4 | 5 | 4 | 5 | 4 | 5 | 5 | 3 | 3 | 3 |
| **Score ≤2.49** | 568 (64.4) | 139 (46.6) | 428 (73.7) | 623 (70.6) | 206 (69.1) | 415 (71.4) | 795 (90.1) | 265 (88.9) | 527 (90.7) | 813 (92.2) | 270 (90.6) | 540 (92.9) |
| **Score ≥2.50** | 314 (35.6) | 159 (53.4) | 153 (26.3) | 259 (29.4) | 92 (30.9) | 166 (28.6) | 87 (9.9) | 33 (11.1) | 54 (9.3) | 69 (7.8) | 28 (9.4) | 41 (7.1) |

Table Legend W DEQ A≥85= Severe fear of childbirth, SD=Standard Deviation, IQR= Interquartile Range.

**Table 4-8. A comparison of National statistics with study results**

| *Variable* | *National Average Statistic 2016* | *Study findings* | *p-value* | *Cork University Maternity Hospital Statistics 2016* |
|---|---|---|---|---|
| **Age at maternity** | 32.2 years* | 31-35 years (44%) | - | Not available |
| **Married at maternity** | 62.2%* | 62.2% | 0.04 | Not available |
| **Mothers from Ireland, United Kingdom, Europe** | 88%* | 85% | 0.03 | Not available |
| **Nulliparous mothers** | 38% | 33.8% | 0.04 | 38% |
| **Multiparous mothers** | 62% | 65.9% | 0.04 | 62% |
| **Employment at maternity** | 73.5%* | 64.5% | 0.09 | Not available |
| **Completed third level education**** | 33.5% | 39.9% | 0.05 | Not available |
| **Self-reported smoker in pregnancy***** | 13% | 7.7% | 0.06 | Not available |

Table Legend *as reported by Central Statistics Office 2016 (205), Ireland and HPO, HSE (2016) (7) **this figure is for all females, not mothers, *** as reported in the Growing Up in Ireland Survey, *p-value* significance .05

# CHAPTER FIVE:
# THE EXPRESS STUDY PART 2

(Exploring women's perceptions and feelings surrounding childbirth)

(Paper 4: Pregnancy outcomes Paper)

# 5.0 PREGNANCY OUTCOMES IN WOMEN WITH SEVERE FEAR OF CHILDBIRTH (PAPER 4)

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## 5.1 Prospective cohort study

The prospective cohort study is presented in this chapter. The paper is presented in the final manuscript format, which was published in the Journal of Psychosomatic Research in March 2019.

## 5.2 Abstract

**Objective**

To compare pregnancy outcomes for women with and without severe fear of childbirth (FOC) reported in the second trimester of pregnancy.

**Methods**

In a prospective cohort study, 389 singleton pregnancies were followed up using medical records of women who participated in a study in Cork, Republic of Ireland. Fear of childbirth was measured using the Wijma Delivery Experience Questionnaire Part A (W-DEQ A). Severe FOC was defined as a W-DEQ A score ≥85; moderate FOC was W-DEA 66-84 and low FOC, W-DEQ A 0-65. Outcome measures were birthweight, birthweight centile, gestational age, and Apgar scores at 1 minute and Apgar at 5 minutes. Linear regression was used to assess the association between FOC and each outcome measure with adjustment for maternal age, smoking, parity and marital status.

**Results**

There was no statistically significant difference in mean birthweight (mean difference = -0.03; [95% CI: -444.69, 315.82]), mean birthweight centile (mean difference= 0.03; [95%CI: -15.97, 23.53]), or mean gestational age (mean difference= -0.06; [95%CI: -11.69, 4.82]) in women with severe FOC compared with women with low FOC. In the adjusted models, there was only a slight correlation between severe FOC and Apgar scores at 1 minute (mean difference= -0.09 [95%CI: -1.28, 0.32]) and Apgar scores at 5 minutes (mean difference= -0.18 [95%CI: -1.16, 1.08]).

## Conclusion

While a slight association was noted between severe FOC and Apgar scores, overall findings of this study are reassuring and could inform educational interventions which may alleviate FOC. Awareness of FOC for health care professionals is vital to consider women's well-being.

## Study Highlights

- Only one study has previously investigated the relationship between FOC and pregnancy outcomes, but this study did not measure FOC using a validated questionnaire
- No association between severe FOC (W-DEQ ≥85) and birthweight, birthweight centile and gestational age.
- Findings of the present study are reassuring for mothers and health care professionals.

## 5.3 Introduction

Fear is a primal and basic emotion experienced universally (39). Fear exists on a spectrum, ranging from worries and minor fears to high fear, and severe phobic fear of childbirth (FOC) (73). Severe FOC impacts women's experience of pregnancy, manifesting in sleep disturbance and physical complaints (108, 147, 209). A Swedish study reported that 80% of pregnant women express some level of FOC. Thus it could be considered normal (46), but a recent meta-analysis suggested that up to 14% of pregnant women could experience severe FOC worldwide (77).

FOC is categorised under the general umbrella of anxiety disorders in pregnancy (30) but is considered a psychological domain in its own right (73). A meta-analysis (210) examining the difference between trait fear and trait anxiety concluded that fear has a distinct neurological mechanism, separate from anxiety and is, therefore, a separate emotion. Thus, various tools exist specifically to measure FOC (211). The Wijma Delivery Experience Questionnaire Part A (W-DEQ A) with a cut-off greater than 85 defining severe FOC is considered the gold standard (40). Psychometric analysis of the W-DEQ A (45) indicated the optimal cut-off value of 85 to detect fear of childbirth which is clinically relevant according to the psychiatric DSM-5 diagnosis of fear of childbirth with 100% sensitivity and 93.8% specificity in an Italian longitudinal study of nulliparous women (n=106).

In one study which previously examined the relationship between FOC and pregnancy outcomes (68), rather than using the validated tool (the W-DEQ A) to assess women's FOC levels, FOC was defined using the International Classification of Diseases code O99.80. This is a code allocated to women who attended dedicated clinics for FOC. The study (68) used data from the Finnish Medical Birth Register to look at all singleton births during the period 1997 to 2010 (n=788, 317). Findings of this study

concluded that both nulliparous and multiparous women with FOC had an association with lower incidence of low birthweight, small for gestational age babies, preterm birth and low Apgar score at one minute (68). While the sample size was large, the definition of FOC used is a limitation, since it restricts the results to those who were diagnosed or who requested a CS and were thus referred to phobia clinics and excluded those who attended primary care. It is possible that a true association was not captured due to an underestimation of the incidence of FOC using the ICD-10, thus using the W-DEQ A ≥85 is a more robust definition. A study by Adams et al (2012) examined the duration of labour in women who intended vaginal delivery with severe FOC and concluded that duration of labour was longer in women with FOC than in women without FOC (94).

Various factors may contribute to the possibility of adverse pregnancy outcomes in women with FOC. FOC may be associated with increased risk of Caesarean Section (212), unintended pregnancy, intimate partner violence (61) and a history of sexual abuse (adult or childhood) (62, 213). Some evidence proposes there is a relationship between a history of childhood sexual abuse and preterm birth (214), and intimate partner violence has been correlated with low birthweight and preterm birth (215). Moreover, unintended pregnancy could mean that women are less likely to have modified lifestyle behaviours such as smoking and alcohol consumption in early pregnancy, which are well-established as deleterious (216). Therefore, the aim of this study was to compare the risk of adverse pregnancy outcomes for women with severe FOC as measured using W-DEQ A≥85 during pregnancy compared to women with lower levels of FOC.

## 5.4 Materials and Methods

This was a prospective cohort study of 389 women recruited in a maternity unit in the Republic of Ireland. The study primary aims were to establish the prevalence and risk factors of FOC in an Irish context (217). A convenience sample of women attending routine antenatal care were recruited by a research midwife undertaking doctoral studies, and by undergraduate students, who were trained by the midwife to recruit participants, in 2015 and 2016. Findings and full recruitment details are published elsewhere (217). Full ethics approval was obtained from the Cork Research Ethics Committee for the Teaching and Learning Hospitals [ECM 4 (06/01/15) and ECM 3 (03/03/15)] (Appendix 6).

Inclusion criteria were; pregnant women ≥ 18 years, 12-24 weeks' pregnant and booked to give birth in a large university-based tertiary maternity hospital (approximately 8,000 births annually). Exclusion criteria were; women who self-determined they had insufficient English. Questionnaires were completed in clinics after research assistants gained written informed consent. Women were invited to provide their medical records number to allow follow-up. Each woman completed a questionnaire including socio-demographic and obstetric questions, and the W-DEQ A. The W-DEQ A (40) consists of 33 questions using a Likert scale. A total score was calculated; with scores between 0 and 165 possible, scores 0-65, low fear, ≥66, moderate fear, and a score ≥85 defining severe FOC (40, 147) (Appendix 4 and 5). In Ireland at the time of the study, there were no phobia clinics available to women with FOC and a formal diagnosis of FOC would be unusual due to a lack of awareness of perinatal mental health (22).

Of 690 women invited to participate, 451 gave consent to postnatal data collection (65%) (Figure 5-1). Women who had incomplete W-DEQ A scores (n=29), stillbirths (n=2) and miscarriages (n=1) were excluded due to incomplete datasets, and 21 women were lost to follow-up. For the final analysis, we excluded twin pregnancies (n=9), limiting to singleton pregnancies, in order to increase homogeneity of the sample. Stillbirth was defined per the World Health Organisation (WHO) definition (218) as the birth at, or after 28 weeks gestation of a baby with no signs of life. Although there are various definitions of miscarriage, in this study, miscarriage was defined as spontaneous fetal loss, from conception to 24 completed weeks gestation (219). Thus, the final study population consisted of 389 women.

Pregnancy outcome data were extracted from medical records by hand, directly from medical records where possible, or from delivery logbooks and e-health record (Maternal and New-born-Clinical Management System) as necessary in July 2017 into a postnatal record sheet (Appendix 7). Birthweight centiles were calculated using a customised centile calculator for Irish mothers (220). Outcome data were entered into a secure encrypted SPSS file by the first author.

The following pregnancy outcomes were investigated for their association with severe FOC; birthweight in grams, birthweight centile, gestational age in days, and Apgar scores at 1 minute and 5 minutes.

Statistical analysis was performed using SPSS Version 22.0 Software programme (Chicago, USA). Continuous variables were tested for normality using histograms and box plots and described using means and standard deviation (SD) if normally distributed, and median and interquartile range (IQR) if not normally distributed. Due to the non-normal distribution of the data, a non-parametric technique (Kruskal-Wallis

test) was used to test the hypothesis in relation to Apgar scores. Analyses were conducted separately for nulliparous and multiparous women. A linear regression model was performed to investigate the relationship between antenatal exposure to FOC and neonatal outcome (birthweight, birthweight centile, gestational age, and Apgar scores). Models were adjusted for potential confounding factors: maternal age (<35 years vs >=35 years), marital status (partner vs no partner), smoking (smoker vs non-smoker) and parity (nulliparous vs multiparous). Results were reported using the mean difference and 95% confidence intervals (CIs). For the comparison of normally distributed continuous variables, the independent t-test was used and Mann-Whitney U Test was performed for non-normally distributed data. An overall significance level $p \leq 0.05$ was considered to be statistically significant and $p \leq 0.05$ also considered significant for individuals mean difference of each analysis.

## 5.5 Results

In the final cohort, eighteen women (4.6%) had W-DEQ A ≥85, 103 (26.5%) women had W-DEQ A ≥66, and 268 (68.9%) women had W-DEQ A ≤65. Mean W-DEQ A score for the whole sample was 55.42 (SD= 18.43) (Figure 5-1). Women under 25 years had the highest mean W-DEQ A score (60.53, SD=17.72). Married women had a lower mean W-DEQ A score (54.87, SD=18.37) when compared with single women (60.52, SD=18.49). Nulliparous women had a higher mean W-DEQ A score (59.17, SD=16.64) when compared with multiparous women (52.93, SD=19.73). There was no difference in mean W-DEQ A score in women with no pregnancy loss (55.67, SD= 17.96) versus those with one pregnancy loss (55.71, SD= 17.79). Women with two or more pregnancy loss had a slightly lower W-DEQ A score (53.24, SD=22.49).

The mean birthweight in the total sample was 3521g (SD=542.41), mean birthweight centile was 44.86 (SD=29.04), median gestational age was 279 days (IQR=12), median Apgar score at 1 minute were 9.00 (IQR=1), and median Apgar score at 5 minutes were 10.00 (IQR= 1) (Table 5-2). In the exposure group (W-DEQ A≥85), birthweight, mean gestational age, median Apgar score at 1 minute and Apgar score at 5 minutes were similar overall (Table 5-2). There was an increase in the mean birthweight and birthweight centile for nulliparous women with severe FOC (n=7), 3786g (SD=415.19), 45.59 (SD=24.39), in comparison with nulliparous women with low exposure 3386g (SD=562.08), 36.17, (SD=25.97), but the number of women in this group is too small to be reliable. Apgar score at 1 minute and Apgar score at 5 minutes were similar in all groups except the severe FOC group, which had a median Apgar score at 1 minute of 8.11 and median Apgar score at 5 minutes of 9.11.The results of the linear regression showed a significant correlation between the exposure (severe FOC) and Apgar scores at 1 minute (mean difference= -0.09 [95%CI -1.28, 0.32]) and Apgar scores at 5 minutes (mean difference= -0.18 [95%CI: -1.16, 1.08]) when adjusted for possible confounders (Table 5-3).

When labour and delivery outcomes were compared for women with W-DEQ A≥85 versus those with W-DEQ A 0-84, there was no statistical difference in use of epidural analgesia, induction of labour or Caesarean Section (Table 5-4).

## 5.6 Discussion

Overall, there was no evidence of an association between FOC and birthweight, birthweight centile, or gestational age. There was a statistically significant difference in relation to severe FOC and Apgar scores, however, this association is not clinically relevant. This study rejects our hypothesis that there is an association between exposure to severe FOC and adverse pregnancy outcomes.

One possible explanation of this finding that FOC may not be associated with negative outcomes is that women have increased opportunities during the second trimester to ask doctors and midwives questions, which may alleviate FOC and provide reassurance, rather than earlier on in pregnancy, when typically women have few antenatal appointments.

Only two previous studies (68, 94), to our knowledge, investigated a relationship between FOC and pregnancy outcomes. Our study confirms the findings of this large population-based epidemiological study (68) conducted using the Finnish Medical Birth Register which found no relationship between severe FOC and pregnancy outcomes. However, the Finnish study did not use the validated W-DEQ A tool to measure FOC and reported other pregnancy outcomes which we did not, such as incidence of low birthweight (<2500g), small for gestational age babies, and preterm birth.

### 5.6.1 Strengths and Limitations

To our knowledge, the present study is the first to investigate FOC and pregnancy outcomes using the W-DEQ A. Data were complete for the majority of variables.

Study limitations must be acknowledged. The W-DEQ A was measured once, in the second trimester, but FOC may be triggered at any point during pregnancy, thus a study which measured FOC in the first and/ or third trimester may find different results. There was a high proportion of women who did not consent to follow up. The study used a convenience sample which limits the generalizability of the findings. The sample consisted of mainly Caucasian women, therefore a study including a more heterogeneous sample or women with a different ethnicity may result in different findings. The analysis was not adjusted for potential confounding factors related to pregnancy complications or high risk pregnancy. It must be acknowledged that the number of women with severe FOC in the sample were small (n=18), therefore the study was not adequately powered which led to wide confidence intervals. However, the prevalence of women with FOC (4.3%) in this study is similar to the findings of previous studies in other countries which also found a prevalence of approximately 5% (77). Finally, the Finnish study (68) reported other pregnancy outcomes which we did not, such as incidence of low birthweight (<2500g), and small for gestational age babies.

## 5.7 Conclusions

This study suggests maternal exposure to severe FOC in the second trimester of pregnancy has no adverse impact on birth weight, birth weight centile, and gestational age or Apgar scores. Findings of this study are reassuring and may be useful to inform women and clinicians, adding to our limited understanding of severe FOC in an Irish context, highlighting similarities between Finnish and Irish populations. Awareness of FOC in health care professionals is vital to integrate management of FOC in antenatal care and enhance emotional support for women, which may result in a reduction in medical interventions and Caesarean Section rates. Further research should focus on investigating pregnancy outcomes in othr countries and in different ethnic groups. In addition, future studies should evaluate the pregnancy outcomes of women with FOC in the first or third trimester.

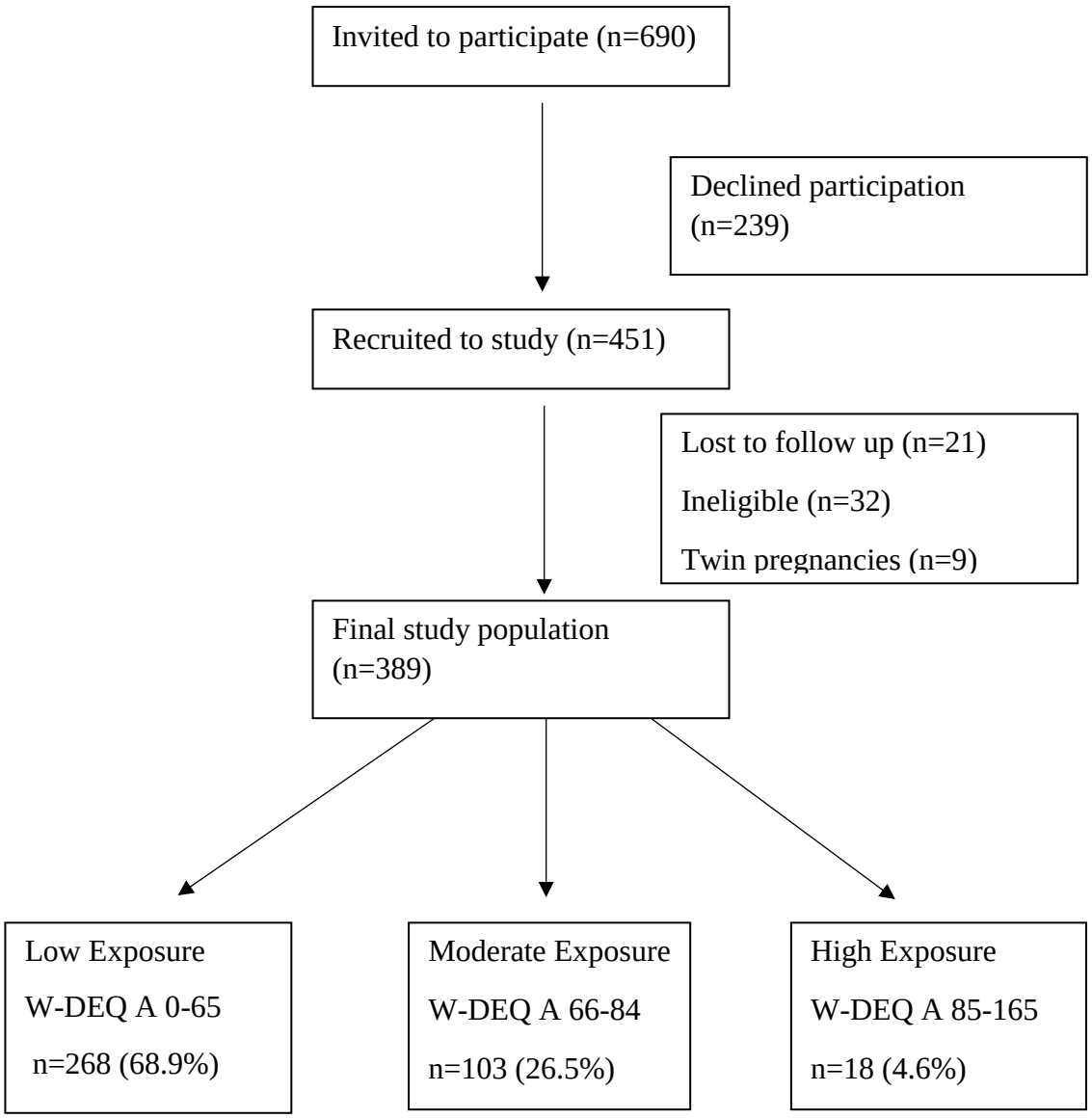


**Figure 5-1. Flow chart of study recruitment**

## Table 5-1. W-DEQ A score by Maternal Characteristics

| Variable | n (%) | W-DEQ A Score (mean, SD) |
|---|---|---|
| Infant Gender | 389 (100.0) | |
| Male | 186 (47.8) | 56.22 ±17.37 |
| Female | 180 (46.3) | 54.68±19.40 |
| Missing | 23 (5.9) | |
| Maternal Age | 389 (100.0) | |
| <25 | 34 (8.7) | 60.53±17.72 |
| 26-30 | 87 (22.4) | 57.13±18.85 |
| 31-35 | 183 (47.0) | 53.67±17.69 |
| 36-40 | 67 (17.2) | 57.82±18.37 |
| >40 | 15 (3.9) | 43.53±18.75 |
| Unknown age | 3 (0.8) | |
| Smoking Status | 389 (100.0) | |
| Smoker | 28 (7.2) | 56.21±57.00 |
| Non-Smoker | 357 (91.8) | 55.20±18.37 |
| Unknown smoking status | 4 (1.0) | |
| Marital Status | 389 (100.0) | |
| Married/ Co-Habiting | 358 (92.0) | 54.87±18.34 |
| Single | 29 (7.5) | 60.52±18.49 |
| Unknown marital status | 2 (0.5) | |
| Parity | 389 (100.0) | |
| 0 | 145 (37.3) | 59.17±16.64 |
| 1 | 138 (35.5) | 52.93±19.73 |
| 2 | 72 (18.5) | 52.42±18.68 |
| 3 | 23 (5.9) | 54.04±14.85 |
| ≥4 | 5 (1.3) | 56.33±17.36 |
| Unknown parity | 2 (0.5) | |
| Pregnancy Loss | 389 (100.00) | |
| 0 | 270 (69.4) | 55.67±17.96 |
| 1 | 77 (19.8) | 55.71±17.79 |
| 2 or more | 36 (9.4) | 53.24±22.49 |
| Unknown | 6 (1.5) | |

**Table Legend:** SD=Standard Deviation

**Table 5-2. Gestational age, birthweight, birthweight centile and Apgar scores by exposure to fear of childbirth**

| Variable | Gestational Age, days median, IQR (n) | | | Birthweight, g mean, SD (n) | | | Birthweight centile mean, SD (n) | | | Apgar at 1 minute median, IQR (n) | | | Apgar at 5 minutes median, IQR (n) | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Total Sample | Nulliparous women | Multiparous women | Total Sample | Nulliparous women | Multiparous women | Total Sample | Nulliparous women | Multiparous women | Total Sample | Nulliparous women | Multiparous women | Total Sample | Nulliparous women | Multiparous women |
| **Overall Sample W-DEQ 0-165** | 279.00, 12 (389) | 280.50, 14 (120*) | 278.00, 10 (266) | 3521.13± 542.41 (389) | 3421.84±552.85 (122) | 3568.48± 532.49 (266) | 44.86±29.04 (389) | 35.79±5.90 (120*) | 49.12±29.44 (265*) | 9.00, 0 (389) | 9.00, 0 (122) | 9.00, 0 (264*) | 10.00, 1 (389) | 10.00, 1 (122) | 10.00, 1 (264*) |
| **Low Exposure W-DEQ A 0-65** | 278.00, 11 (268) | 280.00, 15 (76*) | 277.00, 10 (189) | 3529.05± 562.08 (268) | 3386.54±599.56 (78) | 3590.45± 536.64 (189) | 46.16±29.01 (268) | 36.17±25.97 (76*) | 50.37±29.20 (189) | 9.00, 0 (268) | 9.00, 0 (78) | 9.00, 0 (187*) | 10.00, 1 (268) | 10.00, 0 (78) | 10.00, 1 (187*) |
| **Moderate Exposure W-DEQ A 66-84** | 280.00, 11 (103) | 284.00, 12 (37) | 278.25, 11 (65*) | 3492.62± 478.62 (103) | 3427.03±448.25 (37) | 3529.39± 494.33 (66) | 39.92±28.73 (103) | 33.19±26.23 (37) | 43.75±29.58 (65*) | 9.00, 0 (103) | 9.00, 0 (37) | 9.00, 0 (66) | 10.00, 1 (103) | 9.00, 1 (37) | 10.00, 1 (66) |
| **High Exposure W-DEQ A 85-165** | 281.00, 16 (18) | 285.00, 8 (7) | 274.00, 26 (11) | 3566.39± 608.58 (18) | 3787.86±415.19 (7) | 3425.45± 685.57 (11) | 54.09±28.27 (18) | 45.59±24.39 (7) | 59.50±30.31 (11) | 9.00, 1 (18) | 9.00, 0 (7) | 9.00, 1 (11) | 9.00, 1 (18) | 9.00, 1 (7) | 9.00, 1 (11) |

**Table Legend:** SD=Standard Deviation, W-DEQ A= Wijma Delivery Experience Questionnaire Part A, *=missing data

**Table 5-3. Results of linear regression predicting gestational age, birthweight, birthweight centile and Apgar score**

| Variable<br>N | Gestational Age, days | | Birthweight, g | | Birthweight Centile | | Apgar at 1 minute | | Apgar at 5 minutes | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Co-efficient (95%CI) | | Co-efficient (95%CI) | | Co-efficient (95%CI) | | Co-efficient (95%CI) | | Co-efficient (95%CI) | |
| | Adjusted | Unadjusted | Adjusted | Unadjusted | Adjusted | Unadjusted | Adjusted | Unadjusted | Adjusted | Unadjusted |
| Overall Sample (continuous) W-DEQA 0-165 N=389 | 0.04 (-0.09, 0.14) | 0.06 (-0.03, 0.10) | 0.12 (-1.94, 9.69) | 0.02 (-2.39, 3.48) | 0.11 (-0.11, 0.45) | -0.11 (-0.18, 0.14) | -0.04 (-0.01, 0.01) | -0.06 (-0.01, 0.01) | 0.36 (-0.01, 0.01) | -0.09 (-0.01, 0.01) |
| Low Exposure W-DEQ A 0-65 n=268 | - | - | - | - | - | - | - | - | - | - |
| Moderate Exposure W-DEQ A 66-84 n=103 | 0.08 (-2.23, 6.43) | 0.11 (0.27, 5.54) | -0.09 (-305.61, 92.91) | -0.03 (-161.42, 83.87) | -0.14 (-19.68, 1.01) | -0.10 (-13.29, -0.18) | 0.06 (-0.27, 0.56) | 0.04 (-0.15, 0.36) | -0.07 (-0.34, 0.14) | -0.02 (-0.18, 0.11) |
| Exposure W-DEQ A 85-165 n=18 | -0.06 (-11.69, 4.82) | -0.06 (-8.75, 2.37) | -0.03 (-444.69, 315.82) | 0.02 (-210.22, 305.13) | 0.03 (-15.97, 23.53) | 0.07 (-4.14, 23.51) | -0.09 (-1.28, 0.32) | -0.11 (-1.16, -0.08) | -0.18 (-1.03, -0.12) | -0.16 (-0.81, -0.19) |

**Table Legend:** W-DEQ A= Wijma Delivery Experience Questionnaire Part A

Adjusted for Age, Marital Status, Parity, Smoking

**Table 5-4. Comparison of labour and delivery outcomes of women with and without a severe fear of childbirth**

| Labour and delivery outcome | W-DEQ A ≥85, n (%) | W-DEQ A ≤84, n (%) | p |
|---|---|---|---|
| **Epidural analgesia** | 7 ( 38.8) | 140 ( 37.73) | 0.39 |
| **Induction of labour** | 5 ( 27.77) | 130 (35.04 ) | 0.57 |
| **Pre-labour Caesarean** | 5 ( 27.77) | 44 ( 11.85) | 0.06 |
| **Caesarean in labour** | 4 (22.22) | 53 (14.2 ) | 0.31 |

**Table Legend:** W-DEQ A= Wijma Delivery Experience Questionnaire Part A
$p<0.05$= significant

# CHAPTER SIX:

# 6.0 A META-SYNTHESIS OF WOMEN'S EXPERIENCES OF INTERVENTIONS FOR FEAR OF CHILDBIRTH IN THE PERINATAL PERIOD (PAPER 5)

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## 6.1 Meta-synthesis

The meta-synthesis is presented in this chapter. The paper is presented in draft manuscript format (unpublished).

## 6.2 Abstract

**Background**

Fear of childbirth (FOC) can have an adverse impact on women's lives in pregnancy, the puerperium and beyond. Little is known about the experiences of women who engage with interventions for FOC and how they navigate childbirth.

**Methods**

A meta-synthesis was performed starting with a comprehensive search of relevant databases (CINAHL Plus, MEDLINE, PsycINFO, MIDIRS, Pubmed, EMBASE, ProQuest (including: ProQuest Central, ProQuest Dissertations & Theses, Australian Education Index, Social Science Premium Collection), The Cochrane Library, and the International Clinical Trials Registry) for qualitative research studies describing women's experiences of interventions for FOC. In total, following appraisal, six qualitative studies were eligible for inclusion. The findings were integrated using thematic synthesis for the final stages in the analysis.

**Findings**

One overarching theme "Ownership of Childbirth" and three analytical themes "Facing the fear", "Feeling empowered", "Managing the fear with a sense of security" were generated through the synthesis. There were no studies outside of Scandinavia located.

## Conclusions

This meta-synthesis provides a new analytic framework to describe the process of moving from fear to "Ownership of childbirth". FOC is experienced as a burden which is difficult for women to communicate. The first step in the process appears to be acknowledging and identifying the individual's fears. Women can be empowered to self-manage FOC, but may be influenced by external factors such as the support of partners and staff. This meta-synthesis provides further evidence of the need for compassionate, respectful maternity care. Further research is vital.

Statement of significance

### Issue

- Our search did not identify a meta-synthesis on the experiences of women who engaged with interventions for FOC. Therefore, this meta-synthesis aimed to address this knowledge gap.

### What is already known

- FOC is poorly defined and encompasses several types of anxieties and fear in childbearing women.
- Navigating childbirth is challenging for women with FOC.

### What this paper adds

- This meta-synthesis provides a novel analytical framework of women's experiences of engaging with interventions for FOC and navigating the birth process.

- Highlights significant gaps in the literature suggesting an urgent need for further research studies, particularly outside of Scandinavia.

## 6.3 Introduction

Fear of childbirth (FOC) is a specific, distressing condition which impacts women's everyday lives (78). Approximately 80% of women (46) experience FOC, ranging from normal anxieties and worries in the perinatal period to Pregnancy Specific Anxiety (PSA), to a severe phobic fear, termed tocophobia (37, 78, 211). PSA relates to fears, worries and anxiety related to pregnancy and birth, and may overlap with FOC (37). According to a systematic review and meta-analysis, the prevalence of FOC in pregnant women worldwide was 14%, and in a subgroup analysis according to parity it was 16% in nulliparous women versus 12% in multiparous women (77). Moreover prevalence appears to be increasing over time (211). In addition, prevalence studies have not included women who do not get pregnant or who choose abortion as a result of tocophobia.

While many women experience FOC, and it is well-recognised that comprehensive maternity care should provide for women with FOC, the construct is not well understood, and provisions in maternity services for women with FOC has been lacking. National surveys in Sweden and the UK reported disparity in the availability of services, and varied approaches, with different health care professionals leading the care (27, 221). Although fear is a distinct emotion from anxiety, FOC is categorised under the umbrella of anxiety disorders (37, 68). Based on expert consensus rather than evidence, NICE guidelines (CG 192) recommend universal screening for anxiety in pregnancy (222) which has not been widely adopted, and countries do not routinely screen for FOC (37, 58). Universal screening for anxiety anticipates early intervention and the prevention of other perinatal or co-morbid mental conditions. However, it is

not likely that screening for anxiety would identify women with FOC, which is a separate, although poorly defined, concept (30, 222).

Both PSA and FOC may be associated with fatigue and sleep deprivation (37, 50, 150, 173, 223). Furthermore, there is growing evidence of the association between FOC and heightened pain perception in labour, lower pain tolerance, greater use of epidural analgesia in labour, longer duration of labour (57, 73) and increased likelihood of CS (68). In the postnatal period, women with FOC are more likely to report a negative birth experience (76, 224), develop PTSD (79, 194) and have poor partner relationships (194). Ultimately, women with FOC may decide to avoid pregnancy (225) or in women with secondary FOC, decide to have no further children (37, 75, 226).

Moreover, studies suggest that FOC is linked with long-term adverse infant outcomes. A large UK longitudinal study (n=7,448) reported strong and significant links between high maternal general anxiety and children with elevated behavioural and emotional problems at age 4 (227). Mothers with high levels of anxiety at 32 weeks gestation were more than twice as likely to have children with elevated behavioural and emotional problems at age 4 which remained significant when antenatal depression was included as a covariate (227). Furthermore, elevated antenatal anxiety was associated with hyperactivity/ inattention in boys and total behavioural/ emotional problems in both boys and girls (227). Despite increasing recognition of the impact of FOC on health and well-being, to date, research into FOC, anxiety and the effectiveness of perinatal interventions has been neglected (20).

Psycho-social risk factors of increased FOC include; low birth self-efficacy, anxiety, history of depression, history of sexual abuse, partner dissatisfaction, previous negative birth experience, and previous operative births (32, 228, 229). Socio-demographic risk factors include; younger maternal age, lower income, lower education, and low social support (32, 68). Women who experienced FOC in a previous pregnancy or a previous operative birth are at significant risk of experiencing FOC in a subsequent pregnancy (229).

A qualitative evaluation when conducting trials of interventions is important, but there is a paucity of qualitative evidence to date. Only one previous meta-synthesis in relation to women with FOC was located (58). The study by Sheen *et al.* (58) aimed to identify and synthesise the key elements of FOC reported by women and included 25 papers from 24 studies from 12 countries, mainly Swedish and Australian. Based on the findings of the study, Sheen *et al* (58) suggested enhancing tolerance of uncertainty, developing confidence, self-efficacy and ability to cope with labour may be critical aspects to consider when developing interventions for women with FOC. However given the aim of the study, these conclusions may extend beyond the scope of the study. Furthermore, out of four systematic reviews aiming to investigate the effectiveness of interventions offered to women with FOC (37, 223, 230, 231), only two systematic reviews (223, 231) aimed to include qualitative data representing the views of women. One systematic review (231) did not locate any studies in the systematic search and, the other (223) located three qualitative studies, but details of the qualitative findings lacked detail in the narrative of the systematic review. Thus, very little is currently known about how women with FOC experience interventions offered to them.

The majority of trials focussed on a quantitative measure of FOC and the final preferred mode of birth as a primary outcome (CS or vaginal birth). For example, an RCT from Finland (n=4575) of a group psycho-education with relaxation intervention in nulliparous women, identified a reduction in the number of CS and fewer postnatal depressive symptoms as well as a reduction in women with severe FOC (232), and an Australian RCT of telephone psycho-education by midwives similarly reported positive quantitative outcomes of reduced FOC and improved childbirth self-efficacy (116). Interventions included in the systematic reviews were; psycho-education by midwives, hypnotherapy, and CBT, or combinations of these interventions (37, 223, 230, 231). While the systematic reviews revealed a plethora of ongoing trials, as yet unpublished, exploring the use of other interventions including, Eye Movement Desensitisation and Reprocessing (EMDR), Mindfulness, Music Therapy, Yoga, and the use of a Snoezelen (sensory) room (223), there was no evidence of a qualitative component of these studies.

The WHO (206) recommendations for non-clinical interventions to reduce unnecessary CS are based on findings from an unpublished qualitative systematic review, which further highlights the paucity of published qualitative data in the field. The findings of this report suggest that women want consistent information, in various different formats including paper literature, along with emotional support if necessary when discussing childbirth and information given by midwives should not provoke anxiety. Thus, there is a dearth of published qualitative evidence in the field.

The aim of this meta-synthesis is to address this knowledge gap, focussing on the experiences of women who engaged in interventions for FOC in the perinatal period, providing a novel analytical framework which may promote a meaningful understanding of the experience of engaging with interventions for FOC for women and health care professionals.

## 6.4 Research Question and Purpose of the Meta-Synthesis

Developing a clear research question is a crucial step at the outset of the meta-synthesis process, therefore, having identified the need for the study, the following research question was developed:

> *"How do women with FOC experience interventions for FOC in the perinatal period?"*

The purpose of the study was to aggregate the individual findings of qualitative studies related to women's experiences of interventions for FOC in the perinatal period, in order to develop new meaningful interpretations. We considered a woman to be in the perinatal period up to two years post birth, since FOC can occur at any time during the antenatal or postnatal period, or exist along a continuum of this period (229). From a psycho-social perspective, a mother may be considered to be in the perinatal period until she achieves a maternal identity and develops confidence and competence as a new mother in the post-natal period (2). Thus, duration may vary depending on the individual, the infant, family and environmental factors. For example, if the mother has low social supports, has a pre-term infant or if the infant has special needs, the duration may be considerably increased (2).

To our knowledge, there is no meta-synthesis of qualitative evidence in relation to how women experience interventions for FOC in the perinatal period to date. Thus, there were three specific objectives of this meta-synthesis; 1) to systematically search and appraise the qualitative evidence on women's experiences of interventions for FOC in the perinatal period, 2) to synthesise women's experiences of interventions for

FOC collectively by interrogating data and going beyond the individual relevant qualitative study findings to a higher level of analysis, by developing descriptive themes, interpretation and conceptual synthesis 3) to interpret and discuss the findings of the meta-synthesis which has the potential to generate new understandings which may inform the development of future interventions.

## 6.5 Method

Meta-synthesis allows the researcher to extend beyond the original data in the primary qualitative research studies by interpreting analogies between the accounts and developing analytical themes using key metaphors and organisers (233). Williams and Shaw outlined five consecutive stages of the meta-synthesis process (Table 6-1) (234, 235). Thematic synthesis is useful when conducting meta-synthesis involving qualitative studies about interventions (236).

### 6.5.1 Epistemology and Reflexive note

In line with the 'critical realist' approach, which means that knowledge of our reality is mediated by individual perceptions and beliefs (237), at the outset of this review, any existing beliefs which may impact the data analysis were documented to limit the influence of these beliefs on findings. The main researcher is a midwife who believes that continuity of midwifery carer benefits all women and in particular benefits women with a fear of childbirth. In addition, in order to limit the effects of these beliefs, there was a conscious effort to seek any disconfirming data in this area during the analysis. The researcher kept field notes during the process of the synthesis and consulted the other authors as 'critical friends' during the meta-synthesis process (Appendix 9).

### 6.5.2 Developing a research question and identifying relevant research articles

This review was undertaken using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA Guidelines) (238) and was registered on the International prospective register of systematic reviews (PROSPERO ID: CRD42017068202), however, due to the iterative nature of meta-synthesis, this protocol acted as an initial guide for the authors and was refined during the process of the review.

The following sub-questions were developed to be used as an *a priori* framework in the final stage of the synthesis:

1. *How did women feel before experiencing the intervention for fear of childbirth?*
2. *How did the women feel after experiencing the intervention for fear of childbirth?*
3. *What interventions are perceived as helpful by pregnant women with fear of childbirth?*
4. *How did women feel about the interventions offered to them for fear of childbirth?*
5. *Was the intervention acceptable to women?*
6. *Were women satisfied with the intervention for fear of childbirth?*
7. *Who supported women to cope with fear of childbirth?*
8. *What was good about the intervention?*
9. *How could the intervention be improved?*

### 6.5.3 Search Strategy

A systematic search of five relevant electronic databases was conducted on 8th May 2018: CINAHL Plus, MEDLINE, PsycINFO, MIDIRS, and Pubmed as depicted in the PRISMA flowchart. A subsequent search of additional relevant databases was conducted on 16th August 2018; EMBASE, ProQuest (including ProQuest Central, ProQuest Dissertations & Theses, Australian Education Index, Social Science Premium Collection), The Cochrane Library, and the International Clinical Trials Registry, and a hand-search of the bibliographies of the relevant studies. The following search terms were used:

*"Pregnancy-specific anxiety", "high childbirth-related fear", "intense fear", "high childbirth fear", "high levels of childbirth fear", "severe childbirth fear" and "severe FOC", "childbirth anxiety", "birth anxiety", "morbid fear",* or women who attended an intervention for fear of childbirth.

Inclusion criteria:

- All published original studies using qualitative methods that describe women's experiences of interventions for FOC in the perinatal period published in peer-reviewed journals.
- Studies presenting qualitative data assessing interventions to improve FOC.
- Study participants were women with FOC.
- Dissertations or theses presenting qualitative data assessing interventions to improve FOC.

Exclusion criteria:

- No intervention present.
- Opinions of partners, midwives or health care professionals.
- Women with physical co-morbid health issues, i.e. Assisted Reproductive Therapy, previous pregnancy loss, high-risk pregnancy or known pregnancy complications.
- Women with co-morbid mental health issues were not excluded.

### 6.5.4 Search Outcome

A flow diagram following the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) is portrayed in Figure 6-1. The results of the primary search revealed 2952 studies. Duplicates were removed, leaving 1542 studies to be screened. Initially, titles were screened, and 1,471 studies were excluded at this stage. A further fifty-one studies were excluded after reviewing both title and abstract since they were not related to the subject of interest. The full text of 20 papers were screened, and 12 of these were then excluded (reasons for exclusion are in Figure 6-1), thus a total of 8 papers that reported women's experiences of interventions for FOC in the perinatal period (157, 239-245).

### 6.5.5 Appraisal of studies for research quality

At this stage of the meta-synthesis study, quality was appraised independently by two authors (MOC and PL-W), using the CASP criteria for qualitative research (246). Using this tool involves two initial screening questions which identify the aims of the research and subsequent suitability of qualitative methods for the purpose of the research (246). The original eight studies met this screening criterion (Table 6-3). Following this initial screening, rather than rigidly applying criteria to evaluate the research, (247), the studies were further appraised using a list of questions related to the trustworthiness, theoretical considerations and practical considerations or technical factors (246).

Six full-text papers were deemed to be of sufficient quality (Table 6-3) and two studies were excluded at this stage due to methodological limitations of the study and inadequate data useful to the review question (241, 242) (Figure 6-1 and Table 6-5). In the studies which were excluded, there was a lack of rigorous data analysis or a lack of reflexivity identified; this may be explained by the strict word limit imposed by journals.

### 6.5.6 Final selection of studies

At the outset, all the potentially relevant studies were read and reviewed in full. These studies revealed various experiences of women who had attended different interventions for FOC in the perinatal period. In total, six papers met the inclusion criteria after quality appraisal (146, 239, 240, 243-245), the studies were published between 2010 and 2018 and included four different interventions for women with FOC in the perinatal period. However, the details of the intervention were not clear in every study. Three Norwegian studies (240, 244, 245) were eligible for inclusion. On scrutinising these studies for details of the intervention used, it became apparent that the women all participated in the same continuity of care team midwifery intervention which is described in another paper (248) but, the five women in the Ramvi study (240) are separate to the thirteen women included in Lyberg (a) and (b) (48, 53). The other three papers were Swedish and included various interventions with combinations of approaches as follows (146, 239, 243). One study reported on an intervention which consisted of eight weeks of Internet-based CBT (iCBT) involving psycho-education, cognitive restructuring, exposure (both imaginary and involving a visit to the labour ward), & relapse prevention (146). One paper reported on an intervention which comprised five weeks of art therapy (individual, group or both) in combination with a

specialist midwifery team, which involved a visit to the birth environment and review of past notes as relevant (239). One study reported on midwife-led counselling which involved information giving on the birth process, learning techniques to cope with labour, visits to the labour ward and review of the birth notes as necessary for women who had a negative previous birth experience (243). Four of the studies included continuity of midwifery care as part of the intervention (239, 240, 244, 245) (Table 6-2).

### 6.5.7 Generating themes within and across studies

All text labelled findings and all text within the findings sections of the studies was considered data and extracted for the initial descriptive coding by the first author (233, 234, 236). Codes were generated by combining similar ideas across texts. Initially, the inductive coding of women's experiences of interventions for FOC in the perinatal period was not restricted to an *a priori* framework which allowed the researcher to recognise new ideas from the data (233). Based on the data, the coding categories were sorted into 1) before the intervention; 2) during the intervention; 3) after the intervention 3) elements of interventions perceived as helpful; 4) external factors and 5) women's suggestions for the improvement of interventions for FOC. Descriptive themes were generated by hand and then input to a new file using NVIVO PRO 11 software. Subsequently, the descriptive themes were examined for similarities and differences and grouped across the studies (233). The authors continued to participate in the iterative process of the generation of descriptive themes using NVIVO, with the second author (PL-W) acting as a 'critical friend' (See Appendix 9).

### 6.5.8 Synthesis of themes to refine meaning and new analytical themes

An external *a priori* framework consisting of research question and sub-questions, to interrogate the descriptive synthesis was applied to create analytical themes, a crucial step in thematic synthesis which ensures that findings 'go beyond' the original research findings (233, 234) (Table 6-6). The second author (PL-W) continued to act as a 'critical friend' in the process of developing analytical themes by scrutinising the analysis and promoting reflection and a deeper exploration of alternate interpretations of the synthesis (234). Finally, for the second and third order interpretation, the authors discussed the themes and subthemes which were generated through the synthesis, considering the results to ensure they were grounded in the original data (233, 234).

## 6.6 Results

The characteristics and key information from studies included in the meta-synthesis are presented in Table 6-2.

From the included studies, 118 women of mixed parity participated, 103 of these participated in face to face interviews and 15 women documented statements online. The studies used different definitions of FOC; two studies used W-DEQ A≥85 (146, 239), one used FOBS≥60 (243) and in the other three studies women self-reported FOC (240, 244, 245). In two studies (146, 239) the experiences of women before and after the intervention were ascertained, the other studies interviewed women in the postnatal period between two months and 1.5 years postnatal.

This meta-synthesis of studies focussing on women's experiences of interventions for FOC in the perinatal period resulted in one final overarching theme, "Ownership of Childbirth". This title demonstrates that women needed to gain control in order to feel

ownership of childbirth and "Birth on her own terms" by ensuring that caregivers were aware of individual needs during labour and birth:

*"The only way I could gain control was to be clear about what I wanted them to be in control of. (R9, first baby)" (Participant in Midwifery counselling)* (243)

Once women felt they were listened to and were empowered to take an active role in decision-making during the birth process, this also led to "Ownership of Childbirth" as can be seen in the following quote:

*"The midwives were open to the idea of a caesarean if I wanted one. They never forced us to go through a vaginal birth if we did not want to. The midwife said: caesarean can be one birth alternative. I was very afraid, and that helped me to sleep at nights." (Participant in Team Midwifery intervention) (*53)

When this woman felt she had "Ownership of childbirth", it gave a sense of security, calm and reassurance.

This overarching theme is comprised of three analytical themes, 1) Facing the fear, 2) Feeling empowered, and 3) Managing the fear with a sense of security. Each of these analytical themes is made up of subthemes as portrayed in Table 6-4.

### 6.6.1 Theme 1: Facing the fear

The process of women with FOC moving from experiencing FOC as a burden which they felt unable to express, to facing up to the fear is reflected in the first analytical theme "Facing the fear". Facing the fear was a crucial step in the overall journey to "Ownership of Childbirth". Facing the fear was encompassed in the subthemes, "Acknowledging the fear" and "Identifying the fear".

*6.6.1.1 Subtheme: Acknowledging the fear*

In the primary studies, the women found it difficult to communicate the emotion of fear with their midwife, doctor, or even their partner with the result that the fear was experienced as a burden.

*"You do not talk to everyone about your anxiety. I had a person (midwife) I could phone, and one of them was always on duty. That certainty was good enough for me. They focused on and confirmed my emotional dimension, and it gave me the security I needed."* (*Participant in Team Midwifery*) (245)

A woman in the midwife counselling group similarly expressed difficulty in communicating the fear to others. It appeared that "Acknowledging the fear"was a major step for her that helped her to face and process FOC.

*"If you get to put it into words, it exits the body, and you can ground your thoughts in some way and then you can let it go." (Participant in Midwife Counselling)* (243)

In the case of women with a previous negative birth experience, traumatic experiences left deep emotional impressions on women which led to an extreme FOC. In this case the woman was reluctant to acknowledge or face up to her fear. Instead she put up a barrier or 'impenetrable wall' to any advice from health care professionals perceiving a CS as the only solution.

*"During the third pregnancy, her anxiety became so insurmountable that she thought she would not survive the birth: "Yes, I was really very withdrawn, sad, and cried a lot." In conversations with the midwife from the project, Ruth said that it was "very hard to dig it all up again" with questions about "why and how and can't you give it*

*a try?" She later explained that "I had built a wall around myself that was impenetrable to any input" and that all she wanted was a Caesarean section..... I would have sacrificed the child in order not to give birth. The episode when I was told that I had to give birth was awful. I felt as if I was going to die and the doctor was so tough when he said it. I felt that he was angry." (Participant in Team Midwifery)* (240)

For some women, the intervention helped them to communicate the fear, as can be seen in this case.

> *"Before it felt like a lump in my throat because I wasn't able to communicate the difficult feelings" (Participant in Art Therapy*) (239)

Thus, it appears that women find it difficult to face their fear and communicate it with others which can lead to symptoms of withdrawal and severe anxiety. There were several examples in the studies where the woman's needs were not met and she felt there was a lack of sensitivity or compassion from the health care professional when FOC was expressed. Thus, as well as women "Acknowledging the fear", health care professionals also need to "Acknowledge the fear" and take it seriously.

*6.6.1.1 Subtheme: Identifying the fear*

Identifying the specific fear was important for women with FOC in the process of facing the fear. For example, many women in the studies feared being left alone in labour. This woman in the iCBT group before the intervention said;

*"But what are the others doing? The ones who should help me..."(Woman 13 before treatment iCBT)* (59)

The art therapy was described as a visual aid which helped women to identify, articulate or express the fear which they were unable to before the intervention.

*"It helped me to visualize much more clearly the things which I did not know how to put into words or really express what it was that I felt." (Participant in Art Therapy) (239)*

By "Identifying the fear", health care professionals could respond to the woman's needs. Women articulated the wish for non-judgemental attitudes from health care professionals. When women shared the cause of the fear and felt listened to, this helped women in "Facing the fear".

*"She (the midwife) knew what I was afraid of. I had an appointment and could talk about it before the birth. The team of midwives had time to focus on the birth and my feelings about it. They knew what they were talking about, and I knew that they would be there when it was time for the birth and could influence the birth process." (Participant in Team Midwifery)(235)*

In the Team Midwifery study by Ramvi *et al.* (240), one woman revealed that poor communication between partners during pregnancy had a negative impact on their relationship. The women in the studies described how openly discussing and articulating their specific fears about childbirth with their partner helped them to understand and be taken seriously. As one woman who participates in the art therapy intervention articulated:

*"It also made it easier to talk to my husband. Before it was difficult to put it into words. He knew that I was scared, but not how I was scared, how it really was for me. Then you could talk about this, and it made it easier even for him to understand" (Participant 17, Art Therapy) (239)*

Facing up to the fear by identifying it facilitated the dialogue and helped the woman's partner gain a better understanding of how they felt.

### 6.6.2 Theme 2: Feeling empowered

The next analytical theme "Feeling empowered" reflected the experience of the majority of women who attended interventions for FOC". This comprised two subthemes. "Internal agency (the self)" and "External factors". "Internal agency" refers to the woman's self-awareness, growing in self-belief, ability to self-advocate and personal sense of control. "External factors" refers to whether health care professionals and partners are engaged and supportive of the woman as well as other broader external factors such as the environment in which she is birthing in and the philosophy or ethos of the unit.

#### *6.6.2.1 Subtheme: Internal Agency*

When women developed their sense of "Internal agency", they moved to a position of stronger self-confidence overall, facilitating more control and more certainty in the process of birth. Learning techniques to cope in labour and having a better understanding of what to expect, helped them "Grow in self-belief", gain agency and control. Ultimately, they felt empowered. For example in the midwife counselling intervention it was observed that;

*"sense of control appeared when the women felt they could manage pain with the different techniques they acquired." (243)*

This was also seen in participants of the iCBT intervention;

*"Prior to therapy, most women describe anxiety, uncertainty and loneliness, whereas after treatment they offer narratives with less uncertainty."* (59)

Through the interventions women gained emotional strength which was an important aspect in facilitating women's sense of self or "Internal agency". This can be seen in who attended the art therapy intervention. Feelings of increased self-confidence and self-awareness were positive outcomes of this intervention.

*"The participants gave voice to feelings of increased self- reliance, self-confidence and self-awareness that became useful tools for the impending birth." (Participant in Art Therapy) (239)*

Their new found self-confidence was evident through their art.

*"I made a special image that portrayed just how I felt that day. There was a lot* of power *in that image. I saw that this is ME – in a way. It was a mammoth – gigantic, earthbound and self-confident. I'm quite proud of that. I could almost consider* framing it – *actually." (Participant 14, Art Therapy) (239)*

Similarly, women who participated in the iCBT intervention appeared to develop a sense of "Internal agency". Women described finding emotional strength and new found power as well as feeling calm, confident and ready for the birth, which was empowering.

*"I feel calm and confident. I feel a quiet kind of expectation about what is to come. I'm not thinking so much about what's going to happen during the next hours, but focusing on being here and now. I'm focusing on my breathing and relaxing my body. I'*m ready, *my bag is prepared and waiting." (Woman 7 after treatment)" (iCBT) (59)*

*"A complete focus on fear as well as anxiety and hopelessness has been replaced by an expectation that reflects more confidence." (Participant in iCBT) (59)*

In the same way, women in the midwife counselling intervention described the development of self-efficacy as a positive result of the intervention. Discussions with the midwives in the team midwifery intervention were helpful in developing a sense of "Internal agency".

*"She asked for a Cesarean section, but supportive conversations with one of the midwives from the Team Midwifery project led to a turning point. She was given the opportunity to express her feelings, reflect, and move forward in a process toward giving birth. After the birth, Ann said: "I actually have a feeling that I managed this well." (Participant in Team Midwifery), (240)*

Positive emotions related to the baby arising as a result of the interventions contributed to the feeling of "Internal agency". This was seen in the case of women who attended iCBT and art therapy interventions (157, 239), the interventions helped women to develop a bond with their baby by visualising them which helped them form positive anticipation of the birth. This is evident in the following quotes from women in the studies.

*"I feel a nervous expectation, a kind of positive thrill that I soon will be able to meet the person I've been carrying around for 9 months." (Woman 6, after treatment, iCBT) (157)*

*"The image of the child was clarified and positive emotions arose, allowing the bonding process to start." (Participant in Art Therapy) (239)*

Thus, "Internal agency" was an important factor for women which helped them develop their confidence as a new mother and begin the process of bonding with their baby.

*6.6.2.2 Subtheme: External Factors*

The experience of women depended on "External factors" related to the attitudes of health care professionals and partners, as well as broader social, and cultural factors such as the underpinning philosophy or ethos of the birth unit. The importance of communication was described in all of the studies (239, 240, 243-245). The only study in which this was not evident to the same extent was in the study by Nieminen *et al.* (157) which focussed on the use of internet CBT. There was limited real interaction between the woman and the therapist in this particular intervention, women did homework and received feedback for each session, but contact did not go beyond this.

A woman-centred ethos and a respectful, trusting relationship with the midwife was a crucial aspect of the process of moving from fear to "Ownership of childbirth". In the studies, it was obvious that when women felt they were listened to, understood and that the fear was taken seriously by health care professionals, this helped a trusting relationship develop. Health care professionals had to be willing to engage in a discussion about FOC and the woman's wishes for the birth in order to achieve "Ownership of Childbirth".

*"A majority of the women in the study described the dialogue with the midwife as a contributing factor for strengthening the women's belief in themselves." (Participant in Midwife Counselling), (243)*

When health care professionals appeared engaged and supportive, women appeared to feel in control, which led to a positive experience.

*"It was obvious that they had read my journal and my letter of delivery. They totally knew what I wanted [...] and were very empathetic, great. (Participant 10, second baby)." (Participant in Midwife Counselling) (243)*

In contrast, in the art therapy intervention (239), women reported that abusive encounters with health care professionals or neglect could be traumatic, leaving deep emotional scars.

Responding to and identifying women's individual needs was supportive. This can be seen in this quote from a woman who participated in the team midwifery intervention:

*"The midwives were open to the idea of a caesarean if I wanted one. They never forced us to go through a vaginal birth if we did not want to. The midwife said: caesarean can be one birth alternative. I was very afraid and that helped me to sleep at nights." (Participant in Team Midwifery) (245)*

A sense of disempowerment was apparent in some cases which could be related to external factors such as the ethos of the birth environment or the philosophical approach of the health care providers. One woman in the Team Midwifery intervention (245) appeared disempowered. She reported that she was *"not considered the expert despite giving birth three times before".*

Similiarly, in another study (240), the stories of five women who had a vaginal birth despite requesting a CS were described. The women described not feeling listened to or being heard, despite being part of the Team Midwifery intervention. In spite of attending the team midwifery intervention for FOC, the obstetrician was not willing to engage with women in the discussion about FOC, with the result that the women felt disempowered in decision-making about childbirth. Subsequently, some women had traumatic birth experiences.

On the other hand, women in the other Team Midwifery intervention (244, 245) described that feeling listened to and understood, the emotion of fear was validated and reassurance provided. In this intervention (244, 245), the midwife was valued since she acted as an advocate for the woman when she was in labour. These midwives were described as giving extra time, going beyond the expectations of women and providing critical emotional as well as practical support, providing respectful, woman-centred care, as can be seen in the following quotes (244, 245).

*"My midwife was so very professional and competent. Although I had a difficult birth and a lot of pain she looked after and respected me and I trusted her fully. She said the right things and also managed to say no to other people who wanted to follow the birth with whom I felt uncomfortable." (Participant in Team Midwifery) (245)*

*"I knew the midwife would help me and that I could choose the mode of delivery. I knew that if I requested a caesarean I could have one, but I wanted to give birth in a natural way. The team gave me a sense of security, we worked together, they took great responsibility and were prepared for a traumatic birth.'' (Participant in Team Midwifery) (245)*

Other "External factors" which could influence feeling empowered, therby influencing FOC, are supportive partners and peers. When partners took an active role in the labour process, women in three of the studies (157, 239, 243) found this helpful. Finally, communicating with other women who felt similarly helped women to normalise the fear and process it (239). Within a group art therapy situation, the women said that being grouped with women at a similar gestation and parity was beneficial (239). So, while interventions for FOC benefitted women by developing her sense of "Internal

agency", "External factors" had the potential to impede women's experience by disempowering them.

### 6.6.3 Theme 3: Managing the fear with a sense of security

This theme portrays how women emerged from the interventions "Managing the fear with a sense of security". After most interventions, women described feeling calm, safe and hopeful once they understood and reflected on the cause of the fear (157, 239, 243, 244).

#### *6.6.3.1 Subtheme: Coping in times of uncertainty*

Women with FOC viewed birth as a situation where they lacked control and ownership of childbirth. The midwife was viewed as in control of the birth, thus women worried about the credibility, competence and availability of the midwife. In addition, women were fearful of not being treated with dignity during the birth process. Interventions helped women to develop confidence in both themselves and the staff, helping them to "Cope in times of uncertainty". A feeling of security was a crucial aspect provided by the team midwifery intervention which helped women tolerate uncertainty. This sense of security was cultivated through developing a trusting relationship and having a belief in the competence of health care professionals which helped women with "Coping in times of uncertainty". The following quote highlights how women perceived staff prior to the iCBT intervention:

*"In the descriptions before treatment, many women depict the staff as absent and distant. They describe the staff as not listening to their questions and as being busy with other patients. Quite the opposite, in the narratives after treatment, the staff is described as present, supportive and trustworthy." (Participant in iCBT intervention)* (59)

The value of a trusting relationship in providing a sense of security through emotional support was seen in this quote:

*"I'm sure I could have managed it psychically but not mentally without the support of the midwife. She was my voice all through the birth. She was totally in control, I could trust her and she guided me carefully through the birth despite the fact that it was unpredictable." (Team midwifery) (42)*

The interventions appeared to help women prepare emotionally for the birth process which also helped them "Coping in times of uncertainty" as was seen in the following quote from a participant in the Midwife Counselling intervention:

*"You were more prepared that way. And that may have affected that I felt more at ease when things didn't go as expected. Perhaps a bit more at ease in times of uncertainty." (R8, second baby, Participant in Midwife Counselling) (243)*

Women moved from feeling that they would be unable to cope with labour pain prior to the intervention, to viewing labour pain as having a purpose after the intervention which helped them "Cope in times of uncertainty". This can be seen in the following quote:

*"That I could focus on the pain and that was the reason for me being there, so, yeah, I believe so, absolutely. Then you could relax in a different way." (R14, first baby, Participant in Midwife Counselling) (243)*

In the midwife counselling intervention, the presence of the midwife at the birth was described as calming, and in contrast, if they were left alone, women described feeling insecure and isolated (243). Some women expressed that midwifery support was crucial when their partner was not so supportive during labour (243). Thus,

interventions helped women to cope with the uncertainty of childbirth by providing a sense of security for women.

*6.6.3.2 Subtheme: Reframing the emotions about childbirth*

Prior to the interventions, women with FOC tend to avoid talking about birth and birth preparation (249). The midwife counselling intervention gave women the opportunity to "re-frame their emotions about childbirth" via discussion, having their questions answered, getting practical information and developing practical tools for the birth.

*"So I think that I have the tools to cope when I'm there. And I have realised that I do not have to study non-stop, I'm still with it. [ . . . ] I can focus on other things now." (Participant 13, first baby, Midwife Counselling) (243)*

Learning practical techniques during the intervention helped women to manage the fear, helping to feel calmer and improving the sense of safety and gain hope.

*"I believe it [the information received by the counselling midwives] may have had an impact as I knew beforehand how it might develop on different levels, and that made me feel calmer when I arrived." (Participant 14, first baby, Midwife Counselling) (243)*

After the iCBT intervention *(146)* this woman's emotions about the upcoming birth were re-framed in a more positive way. She viewed herself as active in the birth process, having the confidence, ability and skills to cope with labour and birth.

*"Woman 7 summarises how she views the situation after treatment, describing herself as an active subject while giving birth; she is prepared and confident, focusing on the present, on her body and her breathing." (Participant in iCBT intervention) (146)*

In some cases, the fear still remained after the interventions, but the woman felt she could control the emotion of fear using practical techniques she had learned. In the midwife counselling intervention, the women described practical skills for coping with the fear such as relaxation and breathing exercises, visiting the labour ward and listening to your body in labour (243). Three of the interventions conveyed that birth preparation was crucial for women with FOC (157, 243, 245). Gaining knowledge empowered women to take an active role in the birth process rather than perceiving themselves as the passive recipients of care, helping them to manage their fear. In some cases, the fear didn't disappear, but rather women learned to manage it as can be seen in this case:

Women who had a previous negative birth experience had specific individual needs during the intervention to re-frame the emotions about childbirth. Gaining knowledge about the previous birth by reviewing the previous birth notes helped them to reconcile it. Women expressed that understanding what happened in the previous birth was helpful in moving forward and 'handling' the upcoming birth.

*"The possibility to talk about their experiences with the midwife, who had knowledge of birthing and could give explanations of the course of birth, provided an opportunity to reconcile and then prepare for the upcoming birth." (Participant in Midwife Counselling) (243)*

*"I could probably better understand how to handle it, going forward. (Participant in Midwife Counselling) (243)*

*"The fact that I could listen to my body and that it was easier to gain, to stay in control obviously if you listen to what the body wants instead of panicking over the pain and resisting. (Participant 6, second baby, Midwife Counselling)." (243)*

Thus, these insights into women's experiences of interventions for FOC highlight the importance of a sense of security to enable them "Coping in times of uncertainty" and "Re-framing the emotions about childbirth".

## 6.7 Discussion

The findings of this meta-synthesis are framed in the process of women with FOC moving from fear, to "Ownership of Childbirth", within six qualitative studies. The three analytical themes and subthemes of this process has offered a novel analytic framework for the process of moving from fear to "Ownership of Childbirth". This framework adds to the existing knowledge about how women who engage with interventions for FOC, experience the interventions and navigate birth.

From the meta-synthesis, "Facing the fear" emerged as a theme and would seem to be an important step for women with FOC in engaging with interventions. This occurred through first of all, feeling able to divulge FOC as an issue, secondly FOC being acknowledged as an issue, and thirdly, identifying the nature of FOC. FOC was experienced as a burden which was difficult to communicate, thus it was essential that women could put it into words. When women finally revealed FOC, it was helpful when women felt that midwives and doctors understood, acknowledged and validated FOC. Women also appreciated having an opportunity to ask questions and discuss their birth preferences. This was particularly evident in the team midwifery (240, 244,

245) and midwife counselling interventions (243). This builds on previous work by Striebech *et al* (223) which recommends a one on one conversation to discuss women's fears and Fenwick *et al* (89) who recommended woman-centred models of care sensitive to identifying women's fears, and working with women to promote a positive birth experience.

The second analytical theme was that women could "Grow in self-belief and feeling empowered" when they engaged with interventions for FOC. "Internal agency" was a subtheme of "Growing in self-belief and feeling empowered" which was generated through the meta-synthesis. It was important for women to take an active role in their own birth to facilitate increased control and knowledge about what to expect. Gaining knowledge through interventions facilitated women to develop practical skills to manage their fear and empowered them to have a sense of control over their decisions and choices during birth. First-time mothers learned what to expect in labour and women who had a previous negative birth experience were helped to understand and reconcile their previous birth. Furthermore, women learned techniques such as relaxation and breathing to help them cope with labour pain. This finding is in line with reports from the WHO which recommend health education as an essential component of antenatal care, recognising that women find learning information about birth empowering (206). However, while relevant information is important, it is crucial that women are also supported in enhancing their self-belief to birth on their own terms. Through the interventions, women developed emotional strength and self-awareness. This finding also broadly supports the work of other research studies in the area (58, 89, 223, 250) which suggest that women may have low self-esteem and commonly fear loss of control during the birth. Increasing sense of control and taking

an active role in the birth is therefore a central aspect of interventions for FOC. “Feeling empowered” was particularly evident through the iCBT (146) and art therapy interventions (239), whereas in the midwifery continuity of care interventions (240, 244, 245), it could be seen that women tended to focus on the competence of the midwives and the trusting relationship, rather than building their own self-confidence.

The subtheme “External factors” provided an insight into basic issues such as the willingness and sensitivity of staff to FOC which may help or hinder women’s self-confidence. Good communication was crucial. Women with FOC need reassurance, validation of the fear, an advocate in labour who knows their birth preferences and understands their fear. This finding was consistent with the literature. Sheen *et al.* (58) also found external factors which could moderate FOC in their meta-synthesis. Examples include the attitudes of staff, willingness to listen, judgemental staff, and a negligent encounter with staff, which may be due to staff stress. There were various external factors which could be controlled; a known midwife or trusting relationship with the health care professional, validation of the fear, feeling listened to, partner prepared and supportive and, being involved in decision-making during the birth process. Our meta-synthesis revealed that overall, while the majority of women had a positive experience of midwifery continuity of care, in contrast to previous findings, despite midwifery continuity of care, some women had negative encounters with obstetricians who were not sensitive to their needs and women felt disempowered as a result. This may be due to a difference in philosopy or ethos. A woman-centred ethos, based on respectful care is a pivotal aspect of empowerment.

The third analytical theme “Managing the fear with a sense of security” describes how women may handle the fear. The midwife was a critical, valuable source of support for women to help women “cope in times of uncertainty”. This involved both emotional and psychological support, and practical, professional support in the perinatal period, helping the women to regain emotional strength in some cases. The interventions helped women “re-frame their emotions about childbirth” by perceiving the midwife as a skilled, competent clinician who wanted the woman to have a positive birth experience, which was important in providing women with a sense of security. Knowing the midwife who would be with them in labour helped women to feel calm and safe. Involving the partner in the labour and birth process was reported to be beneficial. The role of the midwife became increasingly significant when partners were not as involved in the birth process. This finding corroborates the findings of a qualitative systematic review by Downe *et al.* (251) which reported that women want a safe, supportive, kind, respectful and responsive intrapartum care. The review (251) concluded that most women want a positive birth experience and value safety and psychosocial well-being. It is important for maternity care systems to acknowledge that women may have individual requirements, related to the reason for FOC or co-morbidities.

In line with this, the present meta-synthesis provides evidence that interventions for FOC, and maternity care in general, needs to be designed to meet the individual needs of women (physically, psychologically and emotionally). The majority of women revealed a positive experience of the art therapy intervention (239) which took a multi-dimensional, individualised psycho-social approach depending on each woman’s wishes, and no negative effects were reported. Ultimately, most women managed to handle the fear once they had a sense of security, which helped them to cope with the

uncertain outcome of childbirth. This finding is consistent with that of Sheen *et al* (58) who describe the intolerance of uncertainty as a key characteristic of women with FOC suggesting that enhancing tolerance of uncertainty may reduce FOC.

Data from a small Swedish feasibility study (252) (n=8) suggests that midwifery continuity models of care are beneficial for women with FOC with women reporting reduced FOC and high satisfaction. Data from this study (252) was quantitative, whereas our study has provided an in-depth qualitative analysis. Doctors and midwives need to be competent in addressing FOC. It was important to realise that FOC didn't disappear for all women, but rather most women learned to manage the fear. Thus, the findings of the present meta-synthesis are further evidence of the need for compassionate care for women in maternity care. There is no information about women who chose not to participate in the Team Midwifery and midwife-counselling interventions (243). Therefore it could be postulated that the interventions were not acceptable to some women.

### 6.7.1 Strengths and Limitations

This is the first study, to our knowledge, using this method to identify, bring together and make sense of the available literature, developing a new understanding of women's experiences of interventions for FOC. This meta-synthesis has several strengths, such as the development of a clear research question, the use of a robust, rigorous search strategy across multiple relevant databases, and reporting the search via the PRISMA flowchart. Quotes from the primary research studies were used to generate 'rich description' and ensure that our results were grounded in the original data, remaining true to the source which is an important strength of the study. (253).

Moreover, details of the analysis are transparent through tables describing the included studies and how the themes were generated, which strengthens the trustworthiness and credibility of our study (253). Furthermore, the researchers kept a reflexive journal during the process of the synthesis in order to document their decision-making process throughout the analysis to maintain a high standard when conducting the meta-synthesis (253). However, limitations of our study must be considered.

The individual studies were limited by a few methodological issues. One mixed-method study (157) was included, and it could be argued that the data was not rigorously collected. However, due to the limited available evidence, it was deemed that the data included in this paper was meaningful and important to answer the research question. Two mixed method studies were excluded (241, 242) due to methodological concerns when appraised. In order to avoid this, future qualitative studies need to clearly report their analysis and qualitative methodologies when presenting their data. Finally, the studies included were undertaken in high-income countries, therefore the findings are limited in their generalisability to other settings.

## 6.8 Conclusion

This meta-synthesis has generated a new interpretation of how women experienced interventions for FOC. Our synthesis framed the process of moving from fear to "Ownership of childbirth", usually through growing in self-belief in their ability to give birth when women were facilitated to birth on their terms in a respectful, woman-centred and safe environment. Health care professionals are key messengers who can improve or worsen FOC in women. Thus, improved awareness and understanding of FOC is critical in maternity care. Overall, women were satisfied with the interventions

included in the review, apart from one team midwifery intervention (240), where some women felt that they were not listened to or understood. In conclusion, this meta-synthesis provides the evidence for the need for the design and evaluation of future interventions, policies and practice in this area of maternity care. Future research involving service-users at the outset is imperative to explore developing and investigating interventions which may be tailored to the individual needs of women with FOC. Furthermore, there is a paucity of research as the available evidence was predominantly from Scandinavian countries, thus more research is warranted.

## 6.9 Implications for practice

There are several findings from this meta-synthesis which may have implications for the future design of interventions, policies and practices to support women with FOC. Interventions need to be designed to meet the needs of the target population (in this case women with FOC). Thus, examining how women experience the intervention, what was good about it and what helped is very valuable information. Ideally, the design of trials should be collaborative and include meaningful patient and public involvement (PPI) at the outset to identify the needs of the population, what is appropriate and acceptable (254). Therefore, early involvement of service users in the development of clinical trials of interventions for FOC is a key recommendation of this review.

Self-management of FOC is an important aspect of interventions. Health care professionals need to ensure that women with FOC and their partners are equipped with information about what to expect and help them to develop their self-efficacy for

birth. Women valued the support of staff, however, short staffing, stressed staff or staff that lack awareness or knowledge about FOC might negatively impact the experience of women with FOC and cause further trauma. Thus, this issue may be addressed by educating health care professionals to ensure that they have the necessary knowledge and skills to provide sensitive, non-judgemental care for women with FOC. Women need compassionate, respectful care and staff to be supportive of them, regardless of how they choose to birth their baby.

## 6.10 Ethics approval

This is a meta-synthesis of published qualitative research. Studies included had ethical approval.

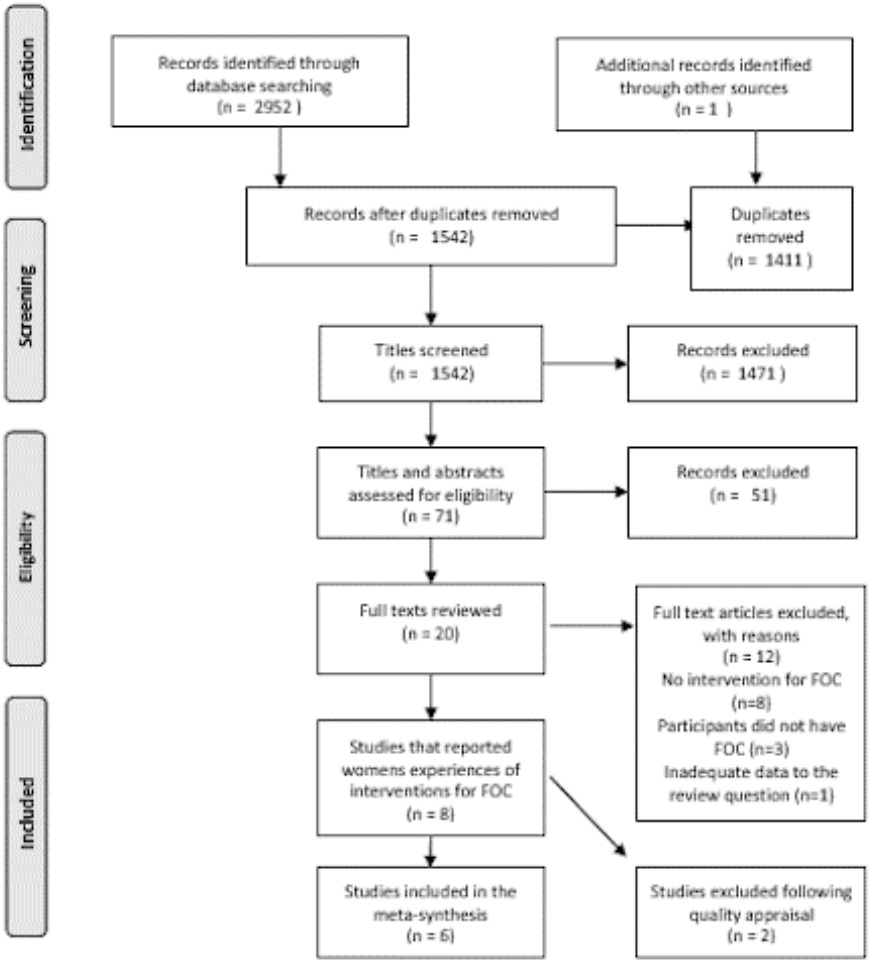


**Figure 6-1. PRISMA Flowchart of search strategy results**

**Table 6-1. Meta-synthesis steps using thematic synthesis (235)**

| | |
|---|---|
| Developing a research question | |
| Identifying relevant articles | |
| Quality appraisal of the research studies | |
| Synthesising the studies: Thematic synthesis | Developing descriptive themes (by extracting data, coding text and developing descriptive themes) |
| | Interpretation and conceptual synthesis |

## Table 6-2. Characteristics of included studies

| Authors and country | Study Aims | Participants (n) | Study Design | Description of intervention | Study Definition of FOC | Data Collection | Data Analysis | Main Findings |
|---|---|---|---|---|---|---|---|---|
| **Lyberg et al (a)**<br><br>**2010**<br><br>**Norway** | To gain a deeper understanding of women's experience of FOC.<br><br>To describe participant experiences of a midwifery continuity of care intervention for women with FOC. | N=13 women‡<br><br>1-1.5 years after the birth<br><br>Aged 25-37 years | Hermeneutic | Intervention: Team midwifery continuity of care, a feeling of security, identify individual needs and offer practical, informational and emotional support throughout pregnancy, childbirth and the perinatal period for women with FOC. One of the midwives was also a mental health nurse. All 4 midwives on the team were dual qualified nurse-midwives with minimum 2 years maternity experience and familiar with working with women with FOC. The midwives attended 30 hours group supervision.<br>Mothers & fathers invited to a brief training programme prior to the birth. | Self-reported FOC | Semi-structured individual interviews conducted face to face using a dialogue approach | Interpretive content analysis | *One main theme:*<br>The woman's right to ownership of the pregnancy, childbirth and postnatal care as a means of maintaining dignity.<br><br>**Theme 1) Being aware of barriers and reasons for fear**<br>*Subthemes in Theme 1:*<br>Fear due to traumatic memories<br>Being trapped – no other alternative<br>Lack of professional competence<br>Not being included in the decision-making and not having ownership of the birth<br>Spiritual and emotional experiences of the birth<br>Lack of emotional capacity<br>Fear for the unborn child<br>Relationship with the midwife and others<br><br>**Theme 2) Being prepared for childbirth**<br>*Subthemes in Theme 2:*<br>The need to be involved and supervised<br>The need to know the midwife-versus the feeling of being intruded upon<br>The Body-in-labour<br>Individual care and birth plan<br><br>**Theme 3) Being confirmed and treated with dignity by the midwife.**<br>*Subthemes in Theme 3:*<br>Guided by the team midwife<br>The meaning of the presence of a familiar midwife during childbirth<br>Increased self-esteem and professional development |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Lyberg et al. (b)**<br><br>**2010**<br><br>**Norway** | To describe midwives supervisory styles and leadership role as experienced by women with a severe fear of childbirth. | N=13 women‡<br><br>1-1.5 years after the birth<br><br>Aged 25-37 years | Explorative | Intervention: Team midwifery continuity of care, a feeling of security, identify individual needs and offer practical, informational and emotional support throughout pregnancy, childbirth and the perinatal period for women with FOC. One of the midwives was also a mental health nurse. All 4 midwives on the team were dual qualified nurse-midwives with minimum 2 years maternity experience and familiar with working with women with FOC. The midwives attended 30 hours group supervision.<br>Mothers & fathers invited to a brief training programme prior to the birth. | Self-reported FOC | Semi-structured individual interviews conducted face to face using a dialogue approach | Interpretive content analysis | **Theme 1) Creating a trusting and caring relationship;**<br><br>*Subthemes:* being sensitive to individual needs & wishes, acting in accordance with & responding to individual desires & needs, ability to provide hope & confirmation;<br><br>**Theme 2) Demonstrating problem-solving capacity;**<br><br>*Subtheme:* being understanding and explaining the reasons for a fear of childbirth<br><br>**Theme 3) Showing willingness, preparedness & courage to provide support, which reflected the midwives long & multi-facetted clinical experience as health care professionals.**<br><br>*Subtheme:* showing involvement and demonstrating courage to handle acute situations beyond normal routines. |
| **Ramvi et al**<br><br>**2011**<br><br>**Norway** | To investigate the experience of women who requested a caesarean section due to fear, but who gave birth vaginally despite this fear. | N=5 women<br><br>Women who attended the intervention and an individual consultation with 1 of 4 midwives on at least 3 occasions before birth. | Narrative | Intervention: Team midwifery continuity of care, a feeling of security, illuminate individual needs and offer practical, informational and emotional support throughout pregnancy, childbirth and the perinatal period for women with FOC. One of the midwives was also a mental health nurse. All 4 midwives on the team were dual qualified nurse-midwives with minimum 2 years maternity experience and familiar with working with women with FOC.<br>The midwives attended 30 hours group supervision. | Self-reported FOC | Narrative individual face to face interviews in two sessions. | Biographical, narrative, interpretive method (BNIM) | *3 key conclusions:*<br><br>1 Health professionals must accept the fear of birth, without demanding to understand what is "behind" the fear.<br><br>2 Obstetricians and midwives have to listen to women and help to contain their strong emotions regarding their forthcoming experience of giving birth.<br><br>3 Health professionals should help to contribute to a safe relationship, allowing for a real dialogue about how the pregnancy, birth, and postnatal period should be conducted in the best |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | Mothers & fathers invited to a brief training programme prior to the birth. | | | | possible way for both the mother and the baby. |
| **Nieminen et al**<br><br>**2015**<br><br>**Sweden** | To describe the expectations concerning imminent childbirth before and after 8 weeks of Internet-based cognitive behavioural therapy (ICBT) among nulliparous women with severe FOC | N=15 women<br><br>Nulliparous women who completed the whole programme.<br><br>Mean age 29.5 years.<br><br>Exclusion: parous women, women who did not meet the criteria for the intervention (W-DEQ A<85) | Thematic analysis | Intervention: ICBT for severe FOC weekly for 8 weeks (started 18 to 30 weeks gestation). The module consisted of psycho-education, cognitive re-structuring, exposure both imaginary and *in vivo*, & relapse prevention. Participants got homework and feedback weekly. | W-DEQ A≥85 (Majority had W-DEQ A≥100) | Open-ended questions over the internet (written text) | Thematic analysis | *My own role*<br>**Theme 1**—Fear: from hopelessness with anxiety, uncertainty and loneliness to simultaneous doubt and hope<br>**Theme 2**—Self-confidence: from lacking self-confidence to being an active subject<br>**Theme 3**—Coping: from avoidance of, to active coping with labour<br><br>*The role of others*<br>**Theme 4**—Partner: from being uncertain to being an active, supportive person<br>**Theme 5**—Staff: from being unavailable to being supportive and helping<br><br>*Attitudes towards the baby*<br>**Theme 6**—The baby: from only focusing on the baby after the nightmare is over to focusing on the baby during all stages of labour and delivery |
| **Wahlbeck et al**<br><br>**2017**<br><br>**Sweden** | Women's experience of treatment by art therapy for severe FOC. | N=19 women<br><br>Women who took part in the intervention; 3 months after the birth (2011-13).<br><br>Aged 27-41 (mean age 32)<br><br>10 nulliparous<br>9 parous women<br>2 single mothers | Phenomenology<br><br>Hermeneutic | Intervention: Art therapy for FOC (28 to 36 weeks gestation) for 5 weeks.<br>Individual, group & both group & individual.<br>Support from a specialist midwifery team- discuss fears, counselling, information about birth, visit to the birth environment & review of past case notes if relevant | W-DEQ A≥85 | Semi-structured face to face interviews.<br>18 at home, 1 in the hospital, 1 in the art therapy room | | *Overarching Main theme: Gaining hope and self-confidence*<br><br>3 main themes:<br>**Theme 1: Carrying heavy baggage describes women's fear**<br><br>Subthemes:<br>Fear of hospital and physical damage to self and the baby<br><br>Being unable to identify oneself as a mother<br><br>**Theme 2: Creating images as a catalyst for healing**<br><br>Subthemes:<br>Uncovering and verbalizing hidden feelings |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | Excluded: women with a psychiatric diagnosis, non-Swedish speaking, history of substance abuse, or had physical obstacles for normal birth/ | | | | | | Sharing the burden with others<br>Images became treasured article<br><br>**Theme 3: Acquiring new insights and abilities**<br><br>Subthemes:<br>Depositing the heavy baggage<br><br>Facilitating attachment to the baby |
| **Larsson et al**<br><br>**2018**<br><br>**Sweden** | To describe women's experiences of midwife-led counselling for childbirth fear | N=66 women<br><br>Women who participated in the intervention<br>Aged 24-38<br><br>18 nulliparous women<br>9 parous women (second or third baby) | Descriptive | Intervention: Midwife-led counselling | FOBS ≥60 | Telephone interviews at least two months after the birth | Thematic analysis | Overarching main theme: "Midwife-led counselling brought positive feelings and improved confidence in birth".<br>Theme 1: The importance of the midwife<br>Theme 2: A mutual and strengthening dialogue<br>Theme 3: Coping strategies and support enabled a positive birth<br>Theme 4: Being prepared for a future birth |

Table Legend: FOBS=Fear of Birth Scale, FOC=Fear of Childbirth; W-DEQ A=Wijma Delivery Expectancy Questionnaire Part A; ICBT=Internet-based Cognitive Behavioural Therapy, ‡ same study population

**Table 6-3. Appraisal of studies**

| First Author (Year of publication) | Clear Statement | Qualitative appropriate | Research Design | Sampling | Data Collection | Reflexivity | Ethics | Data Analysis | Discussion of findings | Value | Overall assessment of methodological quality |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Ryding (2003) | ☑ | X | ? | ? | ☑ | ? | ☑ | X | X | ? | Low |
| Lyberg (2010a) | ☑ | ☑ | ☑ | ☑ | ☑ | ? | ☑ | ☑ | ☑ | ☑ | High |
| Lyberg (2010b) | ☑ | ☑ | ☑ | ☑ | ☑ | ? | ☑ | ☑ | ☑ | ☑ | High |
| Ramvi (2011) | ☑ | ☑ | ☑ | ☑ | ☑ | ☑ | ☑ | ? | ☑ | ☑ | High |
| Nieminen (2015) | ☑ | ☑ | ☑ | ☑ | ☑ | ? | ☑ | ☑ | ☑ | ☑ | High |
| Wahlbeck (2017) | ☑ | ☑ | ☑ | ☑ | ☑ | ☑ | ☑ | ☑ | ☑ | ☑ | High |
| Larsson (2018) | ☑ | ☑ | ☑ | ☑ | ☑ | ☑ | ☑ | ☑ | ? | ☑ | High |
| Airo-Toivanen (2018) | ☑ | X | X | ☑ | ? | X | ☑ | X | X | ? | Low |

☑ Yes, methodologically sound; X, No or not methodologically sound; ?, can't tell whether it is methodologically sound

**Table 6-4. Thematic Synthesis: Concepts, themes and articles in which they were identified**

| Theme | Subtheme | Article |
|---|---|---|
| Facing the fear | Acknowledging the fear | 2, 4, 5, 6 |
| | Identifying the fear | 1, 2, 3, 4, 5, 6 |
| Feeling empowered | Internal Agency | 1, 2, 3, 4, 5, 6 |
| | External Factors | 1, 2, 3, 4, 5, 6 |
| Managing the fear with a sense of security | Coping in times of uncertainty | 1, 2, 3, 4, 5, 6 |
| | Re-framing the emotions about childbirth | 2, 3, 4, 5, 6 |

KEY: Articles numbered, 1= Lyberg (a) (2010), 2= Lyberg (b) (2010), 3= Ramvi (2011), 4= Nieminen (2015), 5= Wahlbeck (2017), 6= Larsson (2018)

**Table 6-5. Table of Excluded Studies and Reasons**

| First Author, Year | Reason |
|---|---|
| Melender, 2002 | No intervention for FOC |
| Ryding, 2003 | Methodological concerns/ inadequate data useful to the research question |
| Brown, 2010 | No intervention for FOC |
| Almeida, 2013 | [Translated] Not including women with FOC- included men and women with mental health issues. |
| Apaceida Ferreira, 2013 | [Translated] No intervention for FOC |
| Kapakian-Khasholian, 2013 | No intervention for FOC |
| Sahlin, 2013 | No intervention for FOC |
| Salomonsson, 2013 | No intervention for FOC |
| Martin, 2014 | No intervention for FOC |
| Faisal, 2014 | Not women with FOC/ No intervention for FOC |
| Greer, 2014 | Not women with FOC/ No intervention for FOC |
| Fenwick, 2015 | Inadequate data useful to the research question |
| Favrod, 2018 | Not women with FOC |
| Airo Tovanen, 2018 | Methodological concerns/ inadequate data useful to the research question |

## Table 6-6. Development of Themes and Subthemes

| **Theme 1**: Facing the fear? | | **Theme 2 :** Feeling empowered | | **Theme 3:** Managing the fear with a sense of safety | |
|---|---|---|---|---|---|
| ***Subtheme*** *Acknowledging the fear* | ***Subtheme*** *Identifying the fear* | ***Subtheme*** *Internal Agency* | ***Subtheme*** *External factors* | ***Subtheme*** *Coping in times of uncertainty* | ***Subtheme*** *Reframing the emotions about childbirth* |
| Communicating the fear was difficult | Fear of injury of infant | Developing self-confidence and self-efficacy | A real dialogue between clinician & woman | Viewing labour pain as having a purpose | Helped women to open up |
| Birth process viewed with uncertainty | Fear of loss of control | Gaining control over decisions and choices during birth | Birth discussion was opportunity to reconcile | Belief in the staffs competence and skills | Helped to feel calm, safe |
| Unable to picture parenthood | Feeling trapped during the birth | Gaining insight into reasons for the fear | Developing a trusting relationship | Able to gain a sense of control using techniques learned | Gained hope |
| Not being treated with dignity | Feeling vulnerable | Gaining more certainty | Felt listened to | Willingness of staff to provide support | Developing a trusting relationship led to a feeling of security |
| Lack of Agency | Being Left alone in labour | Thought process between sessions-getting feelings in order | Midwife was understanding | Emotional preparation | No worries or fears after the intervention |
| Negative self-image | Lacking emotional capacity | Turning negative thoughts around | Take fear seriously (is this midwives/clinicians?) | Feel safe in the uncertainty | Turning negative thoughts around |
| Midwife in control | Feeling unheard | Understanding the previous birth | Treated as an individual | | Visualising supportive staff |
| Competency and availability of the midwife | Not being treated with dignity | Learned techniques to cope | Working with other women helped to process the fear, sharing feelings, share problem | | |
| Previous Traumatic experiences left deep emotional impressions | | Visualising the baby | Supportive partner | | |

| | | | | | |
|---|---|---|---|---|---|
| Feeling trapped during the birth | | Painting promoted inner healing processes | Sensitivity to individual needs | | |
| | | Normalising the emotions of the fear | Visiting the labour ward | | |
| | | Managing the fear is emotional process | Taking an active role in decision-making | | |
| | | Developing power, pride | | | |
| | | Learning to trust in others and self | | | |
| | | Taking an active role in decision-making | | | |

Questions asked of the data

1. *How did women feel before experiencing the intervention for fear of childbirth?*
2. *How did the women feel after experiencing the intervention for fear of childbirth?*
3. *What interventions are perceived as helpful in maternity care by pregnant women with fear of childbirth?*
4. *How did women feel about the interventions offered to them for fear of childbirth?*
5. *Was the intervention acceptable to women?*
6. *Were women satisfied with the intervention for fear of childbirth?*
7. *Who supported women to cope with fear of childbirth?*
8. *What was good about the intervention?*

# CHAPTER SEVEN: DISCUSSION AND CONCLUSION

## 7.1 Summary of the main findings

The overall aim of this thesis was to undertake the first Irish exploration of tocophobia in pregnant women. Although there is growing research in the subject over the last twenty years, there is a dearth of research on tocophobia in Ireland. The majority of literature in this field originates in Scandinavia, thus in this thesis, the phenomenon of tocophobia was examined from an Irish perspective and in an Irish maternity setting. This work is important as the research field is relatively new. Furthermore, it is likely that there are cultural influences on FOC, so studies in different countries are needed in order to advance the existing knowledge and understanding of the topic.

This thesis included a literature review, a systematic review and meta-analysis of the worldwide prevalence of tocophobia, an Irish cross-sectional prevalence study and a prospective cohort investigating pregnancy outcomes of women with FOC. In the final study which comprises this thesis, a meta-synthesis of how women experience interventions for FOC was conducted, providing a new interpretation of how women with FOC process the fear and experience childbirth. The work in this doctoral thesis is significant as it has furthered our understanding of the phenomenon of FOC so that ultimately women may experience improved pregnancy outcomes, and health care professionals and researchers may have a better awareness and comprehension of FOC. In this chapter, the findings of the analyses, strengths and limitations of the thesis will be discussed and conclusions drawn.

## 7.2 Findings from the literature review

In the first part of this doctoral thesis, through a search of the literature, I identified that tocophobia is an important issue in maternity care which has adverse consequences for women's labour, birth and postnatal health and well-being, as well as both short and long-term consequences for infant outcomes. The aetiology of tocophobia was discussed and the possible risk factors. Tocophobia is complex and may arise secondary to personality characteristics, physical causes, social causes and cultural causes such as the influence of the media. In addition, a paucity of information in relation to how tocophobia is defined and the prevalence of tocophobia worldwide were ascertained. The management of tocophobia was discussed and it was suggested that an individual assessment is crucial since the causes are complex. Moreover, it was found that there is no definitive treatment of tocophobia, but working together with women, it is possible to achieve a positive outcome for women. Some women may require a CS, but for other women, there may be other appropriate plans which may help them have a vaginal birth.

## 7.3 Findings from the systematic review and meta-analysis

Thus, following the literature review, I performed a systematic review and meta-analysis of the global prevalence of tocophobia to assess how tocophobia was defined in the literature and provide a quantitative pooled estimate of the prevalence of tocophobia in pregnant women. The main finding of this study is that tocophobia is poorly defined and has been used as a label for a myriad of anxiety disorders during pregnancy, on a spectrum from low FOC to high FOC through to phobic FOC. Nevertheless, the terms FOC or tocophobia have been used interchangeably in the literature and appear to be used to describe emotional difficulties experienced by a significant minority of women, regardless of parity.

This meta-analysis found that the number of research studies in the field has increased exponentially since 2000. The majority of research was performed in Scandinavia, where the research originated. Thus a lot of the information about FOC is derived from Scandinavian populations. Crucially, no previous Irish prevalence study was located. The prevalence of FOC differs across countries, even when quantified using the same research tool. This suggests that other factors may influence FOC, for example, nuances such as personal beliefs, personality types, local obstetric norms and beliefs, and social supports. The W-DEQ A was the most commonly used tool to measure FOC, but even within this tool, different cut-offs were used to measure FOC. A W-DEQ A greater than 85 was found to be the most commonly used definition for FOC.

I performed a meta-analysis of 29 studies including 833,988 women to determine a global pooled-prevalence estimate, which resulted in an estimate of 14% (95%CI 0.12-0.16), but considerable heterogeneity was obtained ($I^2$=99.25%, $p$=0.00). Thus this result should be interpreted with caution. Extensive sensitivity and subgroup analysis were conducted among various groups. FOC appeared to be increasing over time. However it is likely that this is due to increased reporting and varied tools used to measure FOC. Even when the twelve studies that used the same definition of FOC (W-DEQ A≥85) were included in a subgroup analysis, there was high heterogeneity in the group 12% (95%CI 0.09-0.14) ($I^2$=95.41, $p$=0.00). I was unable to perform subgroup analysis for maternal age, social support or existing mental health as this data were not available in the included studies. The majority of women in the study were from one population-based study which did not use the W-DEQ A to define FOC but rather used an ICD-10 code which is used to identify women who attended counselling for FOC in Finland. In addition, it must be acknowledged that FOC status could change at any time during pregnancy. Despite these study limitations, the findings from this study are important and add to what is known about tocophobia. In the update of the meta-analysis, a further 7 studies were included, the pooled-prevalence estimate did not change, remaining at 14%.

## 7.4 Findings from the EXPRESS Study data

In the second phase of this doctoral thesis, two studies were conducted. First of all, a cross-sectional prevalence study was performed with the aim of determining the prevalence of FOC in an Irish sample. Secondly, a prospective cohort of women was recruited from this study to investigate pregnancy outcomes for women with FOC.

The main findings of the prevalence study are that FOC is prevalent in Irish women. The prevalence of severe FOC in Ireland is in line with international prevalence at 5.3%, compared to 5 to 21%, and the prevalence of high FOC was slightly higher than international prevalence at 36.7%, compared with 24 to 26% internationally . There was no statistical difference between severe FOC in nulliparous and multiparous women, but nulliparous women were statistically more likely to have high FOC than multiparous women ($p<.005$). Risk factors for FOC were determined and were similar to the findings of previous work. These were single marital status, low perceived informational support, and possible depression. High-quality information and adequate time to answer pregnant women's questions may help to reduce FOC.

In addition to investigating the severity of FOC in the sample, I performed additional analysis using four W-DEQ A subscales which allowed me to delve into the possible nature of the fear. The most common type of fear experienced was in the subscale "Negative emotions" which represents women with low self-efficacy or confidence in the ability to give birth — over half of first-time mothers in the study scored above the cut-off in this subscale. This finding is important as it highlights the need to offer information and positive preparation

for childbirth in order to empower women in the antenatal period. While the subscales were useful in terms of research, more work needs to be done to validate them. In clinical practice, a dialogue between the health care professional and woman may facilitate discussion in relation to these four areas which may be challenging for women. Understanding the nature of fear is important as well as the severity of the fear, to help women self-manage FOC.

In the second part of this study, some women recruited from the original study were followed up so that pregnancy outcomes could be observed. The findings of this study were reassuring as there was no significant association between FOC and gestational age, birthweight, birthweight centile or Apgar score at one minute or five minutes.

## 7.5 Findings from the Meta-Synthesis

The final phase of this doctoral thesis aimed to provide a meaningful new interpretation of how women experience interventions for FOC in the perinatal period, by presenting a novel framework to describe the process of moving beyond the fear to navigating childbirth. This study highlighted the paucity of qualitative research in relation to interventions for FOC despite a growing number of quantitative studies including RCTs and cohort studies. It is important to conduct qualitative research since it is valuable to answer questions and gain deeper understanding than is possible via quantitative research alone. Qualitative research is of particular importance for nurses and midwives since the experience of women, the birth environment and culture of care may be elucidated (255). The WHO has emphasised the need for women to have a positive birth experience rather than simply surviving birth and the

importance of improving women's emotional well-being in the perinatal period is increasingly recognised (14, 21), thus qualitative evidence is vital to support this key issue.

One overarching theme "Ownership of childbirth" and three analytical themes "Facing the fear", "Feeling empowered", and "Managing the fear with a sense of security", were generated through the synthesis. This is a new and novel way of framing the process of moving from fear to "Ownership of Childbirth" which has improved our understanding of women's experiences.

An important finding was that women with FOC find it difficult to express and to acknowledge the fear. Interventions can help women to gain self-awareness and insight into the fear. When women acknowledged and identified the fear, it helped them to own it and understand it better. Once women understood their FOC, they were able to engage in identifying support from health care professionals and their partners. Interventions helped to empower women by imporving internal agency which helped them to grow in self-belief and confidence. While interventions worked on improving women's sense of agency, external factors played an important role in whether a woman developed confidence in her ability to give birth. These external factors included willingness of the staff to provide support or to engage with and acknowledge FOC as an issue, and being treated as an individual with unique individual needs recognised. Being taken seriously by health care professionals was crucial to validate women's feelings and plan for the upcoming birth.

Finally, women felt they could manage FOC when they had a sense of security. Different factors helped women to feel safe. Women learned practical skills and techniques which helped them to cope in times of uncertainty during labour. When women took an active role rather than viewing themselves as passive recipients of labour care, they took ownership of childbirth. A trusting relationship with a known midwife was important for women, but despite this, in the case of one team midwifery intervention, some women experienced birth trauma when they felt disempowered due to inconsistency in staff attitudes and approaches to FOC. When women felt they could "birth on her own terms", this helped move past the fear to manage FOC. In the meta-synthesis, only studies conducted in Scandinavia were located. Thus it is possible that women in other countries have a different experience of interventions since they are in different systems and experience different cultural norms so further research is warranted.

## 7.6 Strengths and limitations of the thesis

### 7.6.1 Strengths

All of the studies in this thesis were novel and made a significant contribution to the existing body of knowledge on FOC. The literature review was conducted using appropriate databases and key search words. A summary was created to gain a valuable understanding of the existing literature to date on the topic. The meta-analysis used rigorous systematic review methods based on a registered protocol and was reported following the PRISMA guidelines. The EXPRESS study was the first study to use the W-DEQ A in an Irish sample of pregnant women. The sample size was large, and the sample was based in a

large Irish maternity unit with a high birth rate. The prospective cohort study which reported pregnancy outcomes was the first, to our knowledge, to look at outcomes of women with FOC as measured by W-DEQ A≥85, the current best measure of FOC. In the previous study, which was population-based (68), FOC was defined using an ICD-10 code which would limit to women who attended a doctor for treatment of FOC. The meta-synthesis used a robust and transparent method to aggregate the findings of primary qualitative research to further our knowledge about how women experience interventions for FOC.

### 7.6.2 Limitations

There were a number of limitations in the work presented in this doctoral thesis. While the literature review is an important piece of work in terms of scoping the existing literature published on the topic, limitations of the literature review must be acknowledged. The published literature review was performed at the outset, therefore the researcher was still a novice and developing critical analysis writing skills. The aim of this invited literature review was mainly educational. Thus, while gaps in the literature were found, the literature review could be more critical of the limitations of previous research.

In the systematic review and meta-analysis, robust methods were used to perform a systematic search of the literature. However, different questionnaires were used to measure FOC and may not have been validated for use in the various languages or countries which may cause possible bias-responder bias, language barrier bias and reporter bias. In addition, many of the included studies were cross sectional and only captured FOC at a certain time point in the study.

The main limitation of the prevalence study was the use of a cross-sectional design at one-time point in pregnancy. Ideally, women in the prevalence study would have been followed up, and FOC would have been measured at another time point in pregnancy, as well as in the second trimester. A further limitation in the prevalence study is the use of a convenience sample from a single site in Ireland. Preferably, a national sample would have been used, but this was not possible due to the lack of external funding for the study. Nonetheless, the site that was used was one of the largest maternity hospitals in Europe with 8,000 births per year. Additionally, since the study was powered for the primary aim, which was to estimate the prevalence of FOC, the sample size was not powered adequately for the risk factor analysis. As a result, some of the results had large RRR but were not statistically significant since numbers of women in the category were small. Similarly, in the prospective cohort study, which reported pregnancy outcomes for women with FOC, the number of women with FOC was small (n=18), thus the study was not sufficiently powered for the analysis.

As regards methodological limitations of the meta-synthesis, there were few. The findings of the meta-synthesis may not be generalisable since only studies from Scandinavia were included.

## 7.7 Clinical and public health implications

The findings of this doctoral thesis are important for clinicians, women, researchers in the field of FOC, and those with a general interest in public health. It is evident from this thesis that FOC is increasing in prevalence over the last thirty years and has significant consequences for women. While this thesis has contributed to the understanding of FOC, the terms “Tocophobia” and “FOC” remain poorly defined and are used as labels encompassing a broad range of emotional challenges related to anxiety and fear in pregnancy. More recent work on tocophobia in the field of psychiatry has proposed that true ‘Tocophobia’ as diagnosed using SCID-5 interview by a psychiatrist is extremely rare (0.03%), with the majority of women who present with FOC actually having a diagnosis of Generalised Anxiety Disorder or a Specific Phobia such as needle-phobia (30). However, there is a distinct lack of perinatal psychiatrists globally. Therefore it is highly unlikely that a majority of women would receive any specific diagnosis. Usually, women with FOC will receive their care from an Obstetric team involving an obstetrician, midwives and primary care doctor. Thus, health care professionals need an awareness and understanding of FOC in pregnancy, to take any FOC expressed by women seriously and be sensitive to individual needs.

The findings presented in this thesis indicate that the prevalence of FOC in Ireland is equivalent and perhaps even higher than international prevalence rates. Yet, at present, there is no specific provision for women with FOC in Ireland. In countries where specific services for women with FOC do exist,

there is a disparity of services, for example in the UK (27) and Sweden (28) with variety in availability of the service and which a health care professional leads the service. Knowing risk factors for FOC is useful for clinicians when discussing FOC with women. Identification of FOC early in pregnancy is crucial to allow time to work with women to identify and reduce fear. Findings of the prospective study provide reassurance in terms of pregnancy outcomes for women with FOC.

The findings of the qualitative study are important for clinicians and women to understand how women can move past FOC during pregnancy, to managing childbirth. “Ownership of Childbirth” was important for women and being facilitated to “Birth on her own terms”. These findings will be of particular interest to anyone who is designing interventions for FOC in the future. Empowering women to take an active role in the birth process was crucial for women to manage their fear with a sense of safety. Providing woman-centred care with a trusted, known midwife can add to this sense of safety. When women felt disempowered or felt a lack of sense of agency, they were likely to feel traumatised. External factors, such as lack of availability of staff or stressed out staff, could lead to negative encounters with staff which could have lasting traumatic impact on women with FOC.

## 7.8 Recommendations for future research

This research has highlighted FOC as an important issue for women in Ireland which deserves increased attention, both in terms of research and in clinical practice. This is the first Irish body of work examining FOC and has thus provided new, significant knowledge in the field. However, this work will continue, and there is potential for more research in the future. In terms of investigating the available interventions for FOC, the meta-synthesis provided an insight into how women experience the interventions, but the question of the effectiveness of the various interventions remains. Thus, there is a need to perform a detailed systematic review of interventions for FOC. I am lead author of a Cochrane Review, which is ongoing, entitled "Interventions for tocophobia (Fear of Childbirth)".

A natural progression of this work would be to perform more high-quality qualitative research to examine women's experience of interventions for FOC. More broadly, women who never became pregnant as a result of tocophobia or FOC are excluded from the majority of research in this field, and this area deserves more attention. During this PhD, I was contacted by some women who were requesting pre-conceptual advice, since they could not consider planning a pregnancy until they could talk about the birth process with a health care professional. This is a further potential area for future research.

## 7.9 Conclusion

This doctoral research provided the first global prevalence estimate of tocophobia which may affect as many as one in six women. This review already stimulated the global discussion on FOC as a significant public health issue. The results of the prevalence study add to the growing number of prevalence studies being conducted in various countries worldwide. Before this study, evidence of FOC in Ireland was purely anecdotal. Using a validated tool to measure FOC has provided useful data to further our knowledge. Moreover, the findings of this doctoral thesis have moved the debate forward by improving our understanding of how women experience interventions for FOC and manage childbirth through empowerment of women and providing a sense of safety through woman-centred care. This study has laid the groundwork for future research into FOC in Ireland. This information can be used to develop interventions for women with FOC in the future, as well as inform policy and clinical practice.

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# APPENDICES

# Appendix 1: Protocol for Systematic Review registered on PROSPERO

PROSPERO
International prospective register of systematic reviews

NHS
National Institute for Health Research

UNIVERSITY of York
Centre for Reviews and Dissemination

## Systematic review

### 1. * Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

Worldwide prevalence of tocophobia: a systematic review and meta-analysis

### 2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

### 3. * Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.

01/04/2015

### 4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

22/04/2016

### 5. * Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.
Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.
This field should be updated when any amendments are made to a published record and on completion and publication of the review. If this field was pre-populated from the initial screening questions then you are not able to edit it until the record is published.

The review has not yet started: No

| Review stage | Started | Completed |
|---|---|---|
| Preliminary searches | Yes | Yes |
| Piloting of the study selection process | Yes | Yes |
| Formal screening of search results against eligibility criteria | Yes | Yes |
| Data extraction | Yes | Yes |
| Risk of bias (quality) assessment | Yes | Yes |
| Data analysis | Yes | Yes |

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

## 6. * Named contact.

The named contact acts as the guarantor for the accuracy of the information presented in the register record.

Miss O'Connell

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

## 7. * Named contact email.

Give the electronic mail address of the named contact.

maeveoconnell@ucc.ie

## 8. Named contact address

Give the full postal address for the named contact.

Irish Centre for Fetal and Neonatal Translational Research (INFANT)

University College Cork,

Cork University Maternity Hospital,

Wilton,

Cork

## 9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

00353214205023

## 10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

University College Cork

Organisation web address:

www.infantcentre.ie

## 11. * Review team members and their organisational affiliations.

Give the title, first name, last name and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong.

Miss Maeve O'Connell. University College Cork
Dr Sinead O'Neill. University College Cork
Professor Louise Kenny. University College Cork
Dr Patricia Leahy Warren. University College Cork
Dr Ali Khashan. University College Cork

## 12. * Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

The Irish Centre for Fetal and Neonatal Translational Research (INFANT Centre), University College Cork,

Ireland which is supported by Science Foundation Ireland (grant no. 12/RC/ 2272)

## 13. * Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

## 14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members.

## 15. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

How is tocophobia defined in current literature?

What is the world-wide pooled prevalence of tocophobia in pregnant women?

## 16. * Searches.

Give details of the sources to be searched, search dates (from and to), and any restrictions (e.g. language or publication period). The full search strategy is not required, but may be supplied as a link or attachment.

CINAHL, MEDLINE, PubMed, PsycINFO, Maternity & Infant Care, Scopus.

An initial limited search will be carried out to identify key words and index terms from the article titles and abstracts.

Secondly, a search using all identified keywords and index terms will be undertaken across all databases included. Thirdly, the reference lists of all identified articles will be searched for additional relevant studies.

## 17. URL to search strategy.

Give a link to a published pdf/word document detailing either the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies), or upload your search strategy.Do NOT provide links to your search results.

http://www.crd.york.ac.uk/PROSPEROFILES/17443_STRATEGY_20160719.pdf

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

## 18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Tocophobia is a severe fear of pregnancy and birth.

This phenomenon has become of more interest to Health Professionals in maternity care in the last twenty years with increasing caesarean section rates since women have begun to request caesarean section due to tocophobia. It has been acknowledged as an area for concern in the National Institute for Clinical Excellence Guidelines (2011) as it has been given as a reason for elective caesarean section at maternal request. Caesarean section rates are currently 31% in UK-double the World Health Organisations (WHO) recommendation of 15%.

Definitions of tocophobia have varied widely therefore the prevalence has been reported at anywhere between 2 and 31% (Raisanen, Lehto, Nielsson, Gissler, Kramer, and Heinonen, 2014; Haines, Pallant, Karlstrom, and Hildingsson, 2011). More accurate reporting of the prevalence of tocophobia is vital to inform maternity caregivers, women, policy and to assess the need for an intervention to address tocophobia. This review will assess the heterogeneity in reported rates.

## 19. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

Pregnant women who have reported high levels of fear of childbirth/ tocophobia will be included in the review.

Non-pregnant women and men with tocophobia will be excluded.

## 20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

Studies examining prevalence of tocophobia will be included in this review.

## 21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details

of both inclusion and exclusion criteria.

Not applicable

## 22. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

Prevalence studies that reported on tocophobia.Case control studies where the prevalence of tocophobia was reported.Population based studies.

## 23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

## 24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

To determine the world-wide pooled prevalence of tocophobia

To define tocophobia in current literature

### Timing and effect measures

## 25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

To determine associated characteristics of pregnant women with tocophobia

### Timing and effect measures

## 26. * Data extraction (selection and coding).

Give the procedure for selecting studies for the review and extracting data, including the number of researchers involved and how discrepancies will be resolved. List the data to be extracted.

All peer-reviewed studies undertaken to present (11th April 2016) in all languages looking at tocophobia will be included in the review to get an insight into definitions used and reported worldwide prevalence of tocophobia.

## 27. * Risk of bias (quality) assessment.

State whether and how risk of bias will be assessed (including the number of researchers involved and how discrepancies will be resolved), how the quality of individual studies will be assessed, and whether and how this will influence the planned synthesis.

Two independent reviewers will assess the methodological quality of all studies retrieved for inclusion in the review using a standardized critical appraisal tool. Where disagreement arises, the reviewers will have a

discussion and if needs be, discuss with a third reviewer. A standardised quality assessment tool will be used for all quantitative papers included, each paper given a score out of eight. Studies with a score of 5 or more out of 8 will be considered high quality.

## 28. * Strategy for data synthesis.

Give the planned general approach to synthesis, e.g. whether aggregate or individual participant data will be used and whether a quantitative or narrative (descriptive) synthesis is planned. It is acceptable to state that a quantitative synthesis will be used if the included studies are sufficiently homogenous.

Meta-analysis: Depending on the study data if a meta-analysis is possible, we will include records that reported the prevalence of fear of childbirth. We will use Stata, version 13.1, statistical software to perform random-effects model meta-analyses, yielding summary prevalence's and 95% CIs. Where a study does not report the standard error (SE) or 95% CI's, we will calculate these estimates using Microsoft Excel.

Heterogeneity: To investigate variability (heterogeneity)we will use the Chi-squared test for heterogeneity and the I-squared statistic. Small study effects and publication bias across studies will be assessed by using funnel plots, which will be reviewed visually, and using Begg's rank correlation and Egger's weighted linear regression tests for formal testing.

## 29. * Analysis of subgroups or subsets.

Give details of any plans for the separate presentation, exploration or analysis of different types of participants (e.g. by age, disease status, ethnicity, socioeconomic status, presence or absence or co-morbidities); different types of intervention (e.g. drug dose, presence or absence of particular components of intervention); different settings (e.g. country, acute or primary care sector, professional or family care); or different types of study (e.g. randomised or non-randomised).

Subgroup analysis will be carried out on prevalence of tocophobia according to study quality (high versus low), by region (Scandinavia v rest of Europe v Australia v America v Asia), by time period (1980s v 1990s v 2000-2009 v 2010 to 2016).

Sensitivity analysis will be carried out by definition using WDEQ A=85, by parity (nulliparous), by parity (multiparous), screening trimester (first v second v third trimester).

## 30. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

### Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
Yes

Individual patient data (IPD) meta-analysis
No

Intervention

No

Meta-analysis
No

Methodology
No

Narrative synthesis
No

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

## Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
No

Complementary therapies
No

Crime and justice
No

Dental
No

Digestive system
No

Ear, nose and throat

No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
No

Musculoskeletal
No

Neurological
No

Nursing
No

Obstetrics and gynaecology
No

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
No

Public health (including social determinants of health)
No

Rehabilitation
No

Respiratory disorders
No

Service delivery
No

Skin disorders
No

Social care
No

Surgery
No

Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

## 31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is an English language summary.

## 32. Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.

Ireland

## 33. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

## 34. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

Give the link to the published protocol.

Alternatively, upload your published protocol to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Yes I give permission for this file to be made publicly available

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

## 35. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

## Do you intend to publish the review on completion?

Yes

## 36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless

these are in wide use.

Tocophobia

Fear of Birth

Perinatal Mental Health

## 37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

## 38. * Current review status.

Review status should be updated when the review is completed and when it is published. For newregistrations the review must be Ongoing.

Please provide anticipated publication date

Review_Completed_published

## 39. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

## 40. Details of final report/publication(s).

This field should be left empty until details of the completed review are available.

O'Connell, M. A., Leahy-Warren, P., Khashan, A. S., Kenny, L. C. and O'Neill, S. M. (2017). Worldwide prevalence of tocophobia in pregnant women: systematic review and meta-analysis. Acta Obstet Gynecol Scand. doi:10.1111/aogs.13138

Give the link to the published review.

http://onlinelibrary.wiley.com/doi/10.1111/aogs.13138/abstract

DOI: 10.1111/aogs.13138

# Appendix 2: Systematic Review Search Strategy and Quality Appraisal

| # | 11th May 2015 | Pubmed results | Cinahl Resul | Psychinfo Results | Maternity & Infant Care Results | Scopus Results (Limit to include Health Sciences) | MEDLINE Results |
|---|---|---|---|---|---|---|---|
| 1 | Tocophobia | 8 | 3 | 1 | 4 | 12 | 8 |
| 2 | To?ophobia | 12900 | 4 | 7 | 174 | 26 | 17 |
| 3 | Parturiphobia | 1 | 0 | 0 | 0 | 1 | 1 |
| 4 | Maieusophobia | 1 | 0 | 0 | 0 | 0 | 0 |
| 5 | Kakorrhaphiophoboia | 0 | 0 | 0 | 0 | 0 | 0 |
| 6 | Maleusiophobia | 0 | 0 | 0 | 0 | 0 | 0 |
| 7 | Lockiophobia | 0 | 0 | 0 | 0 | 0 | 0 |
| 8 | Enfantophobia | 0 | 0 | 0 | 0 | 0 | 0 |
| 9 | "fear of childbirth" | 172 | 106 | 83 | without "" 160 | 203 | 177 |
| 10 | "fear of labour" | 4,086 | 5 | 2 | without "" 10 | 31 | 4 |
| 11 | "fear of labor" | 4,086 | 9 | 7 | without "" 17 | 31 | 27 |
| 12 | "fear of birth" | 36 | 28 | 25 | without "" 45 | 35 | 42 |
| 13 | "childbirth related fear" | 19 | 13 | 8 | without "" 16 | 23 | 19 |
| 14 | "childbirth related anxiety | 175 | 1 | 1 | without "" 1 | 2 | 1 |
| 15 | "fear in pregnancy" | 2,705 | 53 | 54 | without "" 2 | 2 | 2 |
| 16 | #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR # 8 OR #9 OR #10 OR #11 OR # 12 OR #13 OR #14 | 19,078 | 53 | 54 | 292 | 166, then Limited to Medicine, Nursing, Psychology=159 | 256 |
| 17 | Pregnancy | 795,303 | 135879 | 32,571 | 83,838 | 591, 541 | 778,600 |
| 18 | Antenatal | 24,708 | 5809 | 2,296 | 17,087 | 22,677 | 24,863 |
| 19 | Ante natal | 465 | 88 | 48 | 139 | 446 | 472 |
| 20 | Ante-natal | 428 | 83 | 44 | 139 | 412 | 444 |
| 21 | Prenatal | 134,525 | 29059 | 18,055 | 17,698 | 121, 148 | 134,821 |
| 22 | Pre natal | 2,215 | 204 | 358 | 114 | 1, 259 | 1,608 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 23 | Pre-natal | 845 | 162 | 202 | 114 | 774 | 987 |
| 24 | Childbirth | 32,311 | 20842 | 4,460 | 11,871 | 19, 073 | 15,604 |
| 25 | #17 OR #18 OR #19 OR #18 OR #19 OR #20 OR #21 OR #22 | 831,609 | 20,842 | 4,460 | 98,907 | 627, 205 | 813,217 |
| 26 | #16 AND #25 | 3,002 | 43 | 7 | 263 | 157 | 249 |
| 27 | Prevalence Study | 447530 | 9741 | 12,143 | 45 | 274, 972 | 54,262 |
| 28 | #16 AND #25 AND #27 | 279 | 0 | 0 | 1 | 34 | 10 |
| 29 | Limit to humans | 248 | | | | | |
| | Duplicates removed | 222 | 34 | 5 | 224 | 16 | 6 |
| | | | | | | | |
| | All studies | 499 | | | | | |
| | All (excluding duplicates) | 439 | | | | | |
| | | | | | | | |
| | First Search | 20 Articles included | | | | | |
| | Second Search | 5 Articles included | | | | | |
| | Total | 25 Articles | | | | | |
| | Update Search 11th April 2016 | Pubmed | CINAHL | PsycINFO | Mat & Inf Care | Scopus (Limit to Health) | MEDLINE |
| | Additional studies found | 9 | 5 | 1 | 2 | 8 | 1 |
| | Full texts reviewed | 2 | 1 | 1 | 1 | 3 | 1 |
| | | | | | | | |
| | All articles | 525 | | | | | |
| | All (excluding Duplicates) | 468 | | | | | |
| | Total additional articles for review | 9 | | | | | |
| | Full text reviewed | 34 | | | | | |
| | Included articles | 33 | | | | | |

11th May 2015

# Appendix 3 CASP: Critical Appraisal Skills Programme Quality Assessment Tool

Quality Assessment Tool

Articles are assigned one point for each 'yes' received on the following scale for a total score out of 8. If a question is not applicable for the study under review, select 'yes'.

1. Is the target population clearly defined?
   Yes □ No □ Unclear □

   For example, the target population must be defined by shared characteristics assessed and measured accurately. Some of these characteristics include age, sex, ethnicity, and income. Clear inclusion and exclusion criteria.

2. Was either of the following ascertainment methods used? (must be one or the other)
   I. Probability sampling OR
   II. Entire Population Surveyed
   Yes □ No □ Unclear □

   For example, members of the target population were identified through a sampling frame or listing of potential respondents. This listing must provide access to all members or the defined target population, except for exclusions acknowledged by the study's authors.

3. Is the response rate ≥70%
   Yes □ No □ Unclear □
4. Are non-responders clearly described?
   Yes □ No □ Unclear □
5. Is the sample representative of the target population?
   Yes □ No □ Unclear □

   For example, need to ensure that non responders have characteristics similar to those of responders (otherwise may involve selection bias).

6. Were data collection methods standardised?
   Yes □ No □ Unclear □

   For example, identical methods of assessment and data collection were used with all respondents, so that the information for analyses is completely comparable. Standardisation of methods not only refers to eliciting information from respondents but also to interviewing training, supervision, and enlistment of respondents and processing of data.

7. Were validated criteria used to assess for the presence/ absence of disease?
   Yes □ No □ Unclear □
   For example, a validated scale, diagnostic tool or survey.

8. Are the estimates of prevalence and incidence given with confidence intervals and in detail by subgroup (if applicable)?
   Yes □ No □ Unclear □

Total Quality Score: _____/8

Appendix 4 EXPRESS Study Questionnaire Version 1

Infant

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ID no: _____

express

# Exploring Women's Perceptions and Feelings Surrounding Childbirth

UCC

University College Cork, Ireland

Coláiste na hOllscoile Corcaigh

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## Section 1:

This is a questionnaire in which we will ask you about yourself generally, your health and maternity history. We will also be asking you about your sources for pregnancy information and your birth preferences.

1. How many weeks have you been pregnant? _____

2. What is your Estimated Delivery Date (EDD)? _____/_____/_____

3. Your age *(tick one box)*

| Under 20 | 21-25 | 26-30 | 31-35 | 36-40 | Over 40 |
|---|---|---|---|---|---|
| | | | | | |

4. Marital Status *(tick one box)*

| Single (Never Married) | Living with Partner | Married | Divorced | Separated (but still Legally Married) | Widowed |
|---|---|---|---|---|---|
| | | | | | |

5. Your ethnic group *(tick one box)*

| White | Indian | Chinese | Bangladeshi | Black Carribbean | Black-Other | Mixed Ethnic | Other |
|---|---|---|---|---|---|---|---|
| | | | | | | | |

If Other or Mixed, please state:

6. **What is your country of birth?** *(tick one box)*

| Republic of Ireland | Northern Ireland | England | Scotland | Wales | Other |
|---|---|---|---|---|---|
| | | | | | |

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If Other, please state: _____

7. If you were born outside of Ireland, how long have you lived here (tick one box)

| Less than 1 Year | Less than 5 Years | Less than 10 Years | Less than 20 Years | Over 20 Years |
|---|---|---|---|---|
| | | | | |

## YOUR EDUCATION:

8. What qualifications do you have? *(tick all that apply)*

| None | Secondary School (GCSE's or equivalent) | Sixth form/college (A levels/AS levels) | University degree | Postgraduate qualification (e.g. PhD) | Other |
|---|---|---|---|---|---|
| | | | | | |

If Other, please state: _____

## YOUR HEALTH:

9. How is your health in general? *(tick one box)*

1 = Very poor, 5 = Very good

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| | | | | |

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10. Have you experienced any health problems for you or your baby this pregnancy?

| Yes | No |
|---|---|
| | |

*If yes, please describe*: _____

_____

11. Is this the first time that you have been pregnant?

| Yes | No |
|---|---|
| | |

*(If 'Yes', proceed to question 15)*

12. How many previous miscarriages have you experienced? _____

13. How many previous stillbirths have you experienced? _____

**14. How many previous children do you have?** _____

*(If '0', proceed to question 15)*

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14a. Did you experience any health problems for you or your baby in previous pregnancies?

| Yes | No |
|---|---|
| | |

*If Yes, please describe* _____

_____

_____

**15. What type of antenatal care are you booked to have?** *(tick one box)*

| Shared care | Midwifery delivered care | Hospital care | Private antenatal care – consultant led care | Don't know |
|---|---|---|---|---|
| | | | | |

**16. What is Your Weight and Height?**

| | |
|---|---|
| Weight | |
| Height | |

17. Do you smoke? (tick one box)

| Yes | No |
|---|---|
| | |

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If yes, how many cigarettes do you currently smoke?

| Less than 5 per day | Between 5 and 10 per day | Between 10 and 20 per day | More than 20 per day |
|---|---|---|---|
| | | | |

18. Do you watch One Born Every Minute?

| Yes | No |
|---|---|
| | |

If yes, how often do you watch it?

| More than once a Week | Once a Week | Once a Month | Less than once per Month |
|---|---|---|---|
| | | | |

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19. Where do you seek sources of information about pregnancy and childbirth? Please number 1 to 7 in order of importance (1 being most likely to ask, 7 least likely)

| | |
|---|---|
| Family | |
| Friends | |
| GP | |
| Midwife | |
| Internet Sites | |
| Social Media e.g. Facebook | |
| Other sources | |

*If Other, please describe:* _____

_____

20. How would you prefer to give birth?

| Normal Birth | Caesarean Birth |
|---|---|
| | |

21. Have you ever suffered from anxiety?

| Yes | No |
|---|---|
| | |

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If Yes, what treatment did you have? (tick one box)

| I did not seek treatment | Counselling | Cognitive Behavioural Therapy | Medication | Inpatient Admission in Specialised Unit | Alternative Treatment eg Reflexology, Acupuncture, Reiki, etc. | Other Treatment |
|---|---|---|---|---|---|---|
| | | | | | | |

22. Have you ever suffered from depression?

| Yes | No |
|---|---|
| | |

If Yes, what treatment did you have?

| I did not seek treatment | Counselling | Cognitive Behavioural Therapy | Medication | Inpatient Admission in Specialised Unit | Alternative Treatment eg Reflexology, Acupuncture, Reiki, etc. | Other Treatment |
|---|---|---|---|---|---|---|
| | | | | | | |

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23. Have you ever suffered from Postnatal Depression?

| Yes | No |
|---|---|
| | |

If Yes, what treatment did you have?

| I did not seek treatment | Counselling | Cognitive Behavioural Therapy | Medication | Inpatient Admission in Specialised Unit | Alternative Treatment eg Reflexology, Acupuncture, Reiki, etc. | Other Treatment |
|---|---|---|---|---|---|---|
| | | | | | | |

25. What is your employment status?

| Full-time Work | Part-time Work | Unemployed | Student | Homemaker |
|---|---|---|---|---|
| | | | | |

26. Who do you live with?

| Partner | Parents | Friends | Alone | Relatives | Partner and Parents | Partner and Friends |
|---|---|---|---|---|---|---|
| | | | | | | |

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If you are happy for us to access your medical records when your baby is born, please share your medical records number here:_____

(This is written on the sticker on the cover of your green notes just above your name)

**Please go on to complete Section 2: (the W-DEQ Version A questionnaire) next.**

**Thank you for completing Section 1 of this survey.**

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## Section 2: Your thoughts and feelings about your upcoming birth

This questionnaire is about thoughts and feelings women may have at the prospect of labour and birth.

The answers to each question appear as a scale (0 to 5). The outermost answers (0 and 5 respectively) correspond to the opposite extremes of a certain feeling or thought.

Please complete each question by drawing a circle around the number belonging to the answer which most closely corresponds to how you imagine your labour and birth will be.

Please answer how you imagine your labour and delivery will be, *not the way you hope it will be*.

**How do you think your labour and delivery will turn out as a whole?**

1 0 1 2 3 4 5

Extremely fantastic Not at all fantastic

2 0 1 2 3 4 5

Extremely frightful Not at all frightful

**How do you think you will feel in general during the labour and delivery?**

3 0 1 2 3 4 5

Extremely lonely Not at all lonely

4 0 1 2 3 4 5

Extremely strong Not at all strong

5 0 1 2 3 4 5

Extremely confident Not at all confident

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How do you think you will feel in general during the labour and delivery?

6 0 1 2 3 4 5

Extremely afraid Not at all afraid

7 0 1 2 3 4 5

Extremely deserted Not at all deserted

8 0 1 2 3 4 5

Extremely weak Not at all weak

9 0 1 2 3 4 5

Extremely safe Not at all safe

10 0 1 2 3 4 5

Extremely independent Not at all independent

11 0 1 2 3 4 5

Extremely desolate Not at all desolate

12 0 1 2 3 4 5

Extremely tense Not at all tense

13 0 1 2 3 4 5

Extremely glad Not at all glad

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14 0 1 2 3 4 5

Extremely proud Not at all proud

15 0 1 2 3 4 5

Extremely abandoned Not at all abandoned

16 0 1 2 3 4 5

Totally composed Not at all composed

17 0 1 2 3 4 5

Extremely relaxed Not at all relaxed

18 0 1 2 3 4 5

Extremely happy Not at all happy

**What do you think will happen when labour is most intense?**

19 0 1 2 3 4 5

Extreme panic No panic at all

20 0 1 2 3 4 5

Extreme hopelessness No hopelessness at all

21 0 1 2 3 4 5

Extreme longing for the child No longing for the child at all

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22 0 1 2 3 4 5

Extreme self -confidence No self-confidence at all

23 0 1 2 3 4 5

Extreme trust No trust at all

24 0 1 2 3 4 5

Extreme pain No pain at all

25 0 1 2 3 4 5

I will behave extremely badly I will not behave badly at all

26 0 1 2 3 4 5

I will allow my body I will not allow

to take total control my body to take control at all

27 0 1 2 3 4 5

I will totally lose control of myself I will not lose control of myself

**How do you imagine it will feel the very moment you deliver the baby?**

28 0 1 2 3 4 5

Extremely enjoyable Not at all enjoyable

29 0 1 2 3 4 5

Extremely natural Not at all natural

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30 0 1 2 3 4 5

Totally as it should be Not at all dangerous

31 0 1 2 3 4 5

Extremely dangerous Not at all dangerous

**Have you, during the last month, had fantasies about the labour and delivery, for example……**

32 ……fantasies that your child will die during labour/ delivery?

0 1 2 3 4 5

Never Very often

33 ……fantasies that your child will be injured during labour/ delivery?

0 1 2 3 4 5

Never Very often

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**Section 3: Your Social Supports:**

Perinatal Infant Care Social Support (PICSS)

Scale Structural Social Support (Leahy-Warren, 2005, 2007, 2010, 2011)

**From the following list of people, please indicate the persons who you expect to be supportive and helpful to you in caring for your baby**

| Types of support persons (tick more than one as necessary)<br>If any of the names below are not applicable or relevant please leave blank (tick more than one person as necessary | Provide information about caring for your baby in relation to feeding, changing, bathing and settling your baby | Carry out infant care tasks such as feeding, changing, bathing and settling your baby | Show that they care, love and respect you in caring foryour baby | Praise you for doing a good job in caring for your baby |
|---|---|---|---|---|
| Husband/Partner | | | | |
| Mother | | | | |
| Father | | | | |
| Husband/Partners' mother | | | | |
| Husband/Partners' father | | | | |
| Sister(s) | | | | |
| Brother(s) | | | | |
| Friend(s) | | | | |
| Neighbour(s) | | | | |
| Midwife/Nurse(s) | | | | |
| Local Doctor (GP) | | | | |
| Public Health Nurse(s) | | | | |
| Practice Nurse(s) | | | | |
| Others (specify) | | | | |

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**The following statements ask about the support that is available to you once your baby is born. After reading each statement please circle the number that you feel is moist appropriate, there is no right and wrong answer. Please answer each of the 16 questions.**

| | Strongly disagree | Disagree | Agree | Strongly Agree |
|---|---|---|---|---|
| 1. I can get information on | | | | |
| Feeding | 1 | 2 | 3 | 4 |
| Changing/dressing | 1 | 2 | 3 | 4 |
| Comfort/settling | 1 | 2 | 3 | 4 |
| Bathing | 1 | 2 | 3 | 4 |
| 2. I can get information on taking care of my body after child birth | 1 | 2 | 3 | 4 |
| 3. I can learn from other mothers' experiences | 1 | 2 | 3 | 4 |
| 4. I can get consistent information regarding infant care | 1 | 2 | 3 | 4 |
| 5. I can get 'hands on help' with my baby: | | | | |
| Feeding | 1 | 2 | 3 | 4 |
| Changing/dressing | 1 | 2 | 3 | 4 |
| Comfort/settling | 1 | 2 | 3 | 4 |
| Bathing | 1 | 2 | 3 | 4 |
| 6. I have someone to help me with routine housework | 1 | 2 | 3 | 4 |
| 7. I won't be on my own taking care of my baby | 1 | 2 | 3 | 4 |
| 8. I can make time for myself | 1 | 2 | 3 | 4 |
| 9. I have people to count on when things go wrong | 1 | 2 | 3 | 4 |
| 10. I have someone to care and comfort me | 1 | 2 | 3 | 4 |
| 11. I have someone to talk to about how I feel | 1 | 2 | 3 | 4 |
| 12. If I need advice there is someone who will assist me to work out a plan for dealing with the situation | 1 | 2 | 3 | 4 |
| 13. I have people to talk to and share my experiences with | 1 | 2 | 3 | 4 |
| 14. I have people who will show me appreciation for the care I give to my baby | 1 | 2 | 3 | 4 |
| 15. People close to me understand that it is okay for me to | 1 | 2 | 3 | 4 |
| need help | 1 | 2 | 3 | 4 |
| 16. I can get positive feedback from health care professionals about my ability to care for my baby | 1 | 2 | 3 | 4 |

Infant
Irish Centre for Fetal and Neonatal Translational Research

In the past 7 days:

1. I have been able to laugh and see the funny side of things
   - ☐ as much as I always could
   - ☐ not quite so much now
   - ☐ definitely not so much now
   - ☐ not at all

2. I have looked forward with enjoyment to things
   - ☐ as much as I ever did
   - ☐ rather less than I used to
   - ☐ definitely less than I used to
   - ☐ hardly at all

3. I have blamed myself unnecessarily when things went wrong
   - ☐ yes, most of the time
   - ☐ yes, some of the time
   - ☐ not very often
   - ☐ no, never

4. I have been anxious or worried for no good reason
   - ☐ no, not at all
   - ☐ hardly ever
   - ☐ yes, sometimes
   - ☐ yes, very often

5. I have felt scared or panicky for no very good reason
   - ☐ yes, quite a lot
   - ☐ yes, sometimes
   - ☐ no, not so much
   - ☐ no, not at all

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6. Things have been getting on top of me
   - ☐ yes, most of the time I haven't been able to cope at all
   - ☐ yes, sometimes I haven't been coping as well as usual
   - ☐ no, most of the time I have coped quite well
   - ☐ no, I have been coping as well as ever

7. I have been so unhappy that I have had difficulty sleeping
   - ☐ yes, most of the time
   - ☐ yes, sometimes
   - ☐ not very often
   - ☐ no, not at all

8. I have felt sad or miserable
   - ☐ yes, most of the time
   - ☐ yes, quite often
   - ☐ not very often
   - ☐ no, not at all

9. I have been so unhappy that I have been crying
   - ☐ yes, most of the time
   - ☐ yes, quite often
   - ☐ not very often
   - ☐ no, never

10. The thought of harming myself has occurred to me
    - ☐ yes, quite often
    - ☐ sometimes
    - ☐ hardly ever
    - ☐ never

Infant

Irish Centre for Fetal and Neonatal Translational Research

Thank you for taking the time to complete this questionnaire. Your opinions and experiences are valued and will help improve care for women in the future.

Maeve O'Connell, PhD Candidate

maeveoconnell@ucc.ie

0214205026

## Appendix 5 EXPRESS Study Questionnaire Version 2

Infant

Irish Centre for Fetal and Neonatal Translational Research

Study ID no: _____

express

# Exploring Women's Perceptions and Feelings Surrounding Childbirth

UCC

University College Cork, Ireland

Coláiste na hOllscoile Corcaigh

Infant
Irish Centre for Fetal and Neonatal Translational Research

This is a questionnaire in which we will ask you about yourself generally, your health and maternity history. We will also be asking you about your sources for pregnancy information, your birth preferences and about any worries you have about your upcoming birth.

## Section 1:

1. How many weeks have you been pregnant? _____

2. What is your Estimated Delivery Date (EDD)? _____/_____/_____

3. Your age *(tick one box)*

| Under 20 | 21-25 | 26-30 | 31-35 | 36-40 | Over 40 |
|---|---|---|---|---|---|
| | | | | | |

4. Marital Status *(tick one box)*

| Single (Never Married) | Living with Partner | Married | Divorced | Separated (still Legally Married) | Widowed |
|---|---|---|---|---|---|
| | | | | | |

5. Your ethnic group *(tick one box)*

| White | Indian | Chinese | Bangladeshi | Black Carribbean | Black-Other | Mixed Ethnic | Other |
|---|---|---|---|---|---|---|---|
| | | | | | | | |

If Other or Mixed, please state:

6. **What is your country of birth?** *(tick one box)*

| Republic of Ireland | Northern Ireland | England | Scotland | Wales | Other |
|---|---|---|---|---|---|
| | | | | | |

If Other, please state: _____

Infant
Irish Centre for Fetal and Neonatal Translational Research

7. If you were born outside of Ireland, how long have you lived here *(tick one box)*

| Less than 1 Year | Less than 5 Years | Less than 10 Years | Less than 20 Years | Over 20 Years |
|---|---|---|---|---|
| | | | | |

## YOUR EDUCATION:

8. What qualifications do you have? *(tick all that apply)*

| None | Secondary School (GCSE's or equivalent) | Sixth form/college (A levels/AS levels) | University degree | Postgraduate qualification (e.g. PhD) | Other |
|---|---|---|---|---|---|
| | | | | | |

If Other, please state: _____

## YOUR HEALTH:

9. How is your health in general? *(tick one box)*
1 = Very poor, 5 = Very good

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|
| | | | | |

10. Have you experienced any health problems for you or your baby this pregnancy?

| Yes | No |
|---|---|
| | |

*If yes, please describe*: _____

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Irish Centre for Fetal and Neonatal Translational Research

11. Is this the first time that you have been pregnant?

| Yes | No |
|---|---|
| | |

*(If 'Yes', proceed to question 15)*

12. How many previous miscarriages have you experienced? _____

13. How many previous stillbirths have you experienced? _____

**14. How many previous children do you have?** _____

*(If '0', proceed to question 15)*

14a. Did you experience any health problems for you or your baby in previous pregnancies?

| Yes | No |
|---|---|
| | |

*If Yes, please describe* _____

_____

_____

**15. What type of antenatal care are you booked to have?** *(tick one box)*

| Shared care | Midwifery delivered care | Hospital care | Private antenatal care – consultant led care | Don't know |
|---|---|---|---|---|
| | | | | |

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Irish Centre for Fetal and Neonatal Translational Research

16. What is Your Weight and Height?

| | |
|---|---|
| Weight | |
| Height | |

17. Do you smoke? (tick one box)

| Yes | No |
|---|---|
| | |

If yes, how many cigarettes do you currently smoke?

| Less than 5 per day | Between 5 and 10 per day | Between 10 and 20 per day | More than 20 per day |
|---|---|---|---|
| | | | |

18. Do you watch One Born Every Minute?

| Yes | No |
|---|---|
| | |

If yes, how often do you watch it?

| More than once a Week | Once a Week | Once a Month | Less than once per Month |
|---|---|---|---|
| | | | |

Infant
Irish Centre for Fetal and Neonatal Translational Research

19. Where do you seek sources of information about pregnancy and childbirth?

Please number 1 to 7 in order of importance **(1 being most likely to ask, 7 least likely)**

| | |
|---|---|
| Family | |
| Friends | |
| GP | |
| Midwife | |
| Internet Sites | |
| Social Media e.g. Facebook | |
| Other sources | |

*If Other, please describe:* _____

20. How would you prefer to give birth?

| Normal Birth | Caesarean Birth |
|---|---|
| | |

21. Have you attended antenatal education classes?

Yes☐ No ☐ Yes, in a previous pregnancy ☐

22. Do you plan to attend antenatal education classes in this pregnancy? Yes ☐ No ☐

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Irish Centre for Fetal and Neonatal Translational Research

23. Have you ever suffered from anxiety?

| Yes | No |
|---|---|
| | |

If Yes, what treatment did you have? (tick one box)

| I did not seek treatment | Counselling | Cognitive Behavioural Therapy | Medication | Inpatient Admission in Specialised Unit | Alternative Treatment eg Reflexology, Acupuncture, Reiki, etc. | Other Treatment |
|---|---|---|---|---|---|---|
| | | | | | | |

24. Have you ever suffered from depression?

| Yes | No |
|---|---|
| | |

If Yes, what treatment did you have?

| I did not seek treatment | Counselling | Cognitive Behavioural Therapy | Medication | Inpatient Admission in Specialised Unit | Alternative Treatment eg Reflexology, Acupuncture, Reiki, etc. | Other Treatment |
|---|---|---|---|---|---|---|
| | | | | | | |

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Irish Centre for Fetal and Neonatal Translational Research

25. Have you ever suffered from Postnatal Depression?

| Yes | No |
|---|---|
| | |

If Yes, what treatment did you have?

| I did not seek treatment | Counselling | Cognitive Behavioural Therapy | Medication | Inpatient Admission in Specialised Unit | Alternative Treatment eg Reflexology, Acupuncture, Reiki, etc. | Other Treatment |
|---|---|---|---|---|---|---|
| | | | | | | |

26. What is your employment status?

| Full-time Work | Part-time Work | Unemployed | Student | Homemaker |
|---|---|---|---|---|
| | | | | |

27. Who do you live with?

| Partner | Parents | Friends | Alone | Relatives | Partner and Parents | Partner and Friends |
|---|---|---|---|---|---|---|
| | | | | | | |

Infant

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If you are happy for us to access your medical records when your baby is born, please share your medical records number here:_____

(This is written on the sticker on the cover of your green notes just above your name)

**Please go on to complete Section 2: (the W-DEQ Version A questionnaire) next.**

**Thank you for completing Section 1 of this survey.**

Infant
Irish Centre for Fetal and Neonatal Translational Research

## Section 2: Your thoughts and feelings about your upcoming birth

This questionnaire is about thoughts and feelings women may have at the prospect of labour and birth.

The answers to each question appear as a scale (0 to 5). The outermost answers (0 and 5 respectively) correspond to the opposite extremes of a certain feeling or thought.

Please complete each question by drawing a circle around the number belonging to the answer which most closely corresponds to how you imagine your labour and birth will be.

Please answer how you imagine your labour and delivery will be, *not the way you hope it will be.*

**How do you think your labour and delivery will turn out as a whole?**

1 0 1 2 3 4 5

Extremely fantastic Not at all fantastic

2 0 1 2 3 4 5

Extremely frightful Not at all frightful

**How do you think you will feel in general during the labour and delivery?**

3 0 1 2 3 4 5

Extremely lonely Not at all lonely

4 0 1 2 3 4 5

Extremely strong Not at all strong

5 0 1 2 3 4 5

Extremely confident Not at all confident

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**How do you think you will feel in general during the labour and delivery?**

6 0 1 2 3 4 5

Extremely afraid Not at all afraid

7 0 1 2 3 4 5

Extremely deserted Not at all deserted

8 0 1 2 3 4 5

Extremely weak Not at all weak

9 0 1 2 3 4 5

Extremely safe Not at all safe

10 0 1 2 3 4 5

Extremely independent Not at all independent

11 0 1 2 3 4 5

Extremely desolate Not at all desolate

12 0 1 2 3 4 5

Extremely tense Not at all tense

13 0 1 2 3 4 5

Extremely glad Not at all glad

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Irish Centre for Fetal and Neonatal Translational Research

14 0 1 2 3 4 5

Extremely proud Not at all proud

15 0 1 2 3 4 5

Extremely abandoned Not at all abandoned

16 0 1 2 3 4 5

Totally composed Not at all composed

17 0 1 2 3 4 5

Extremely relaxed Not at all relaxed

18 0 1 2 3 4 5

Extremely happy Not at all happy

**What do you think will happen when labour is most intense?**

19 0 1 2 3 4 5

Extreme panic No panic at all

20 0 1 2 3 4 5

Extreme hopelessness No hopelessness at all

21 0 1 2 3 4 5

Extreme longing for the child No longing for the child at all

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22 0 1 2 3 4 5

Extreme self -confidence No self-confidence at all

23 0 1 2 3 4 5

Extreme trust No trust at all

24 0 1 2 3 4 5

Extreme pain No pain at all

25 0 1 2 3 4 5

I will behave extremely badly I will not behave badly at all

26 0 1 2 3 4 5

I will allow my body I will not allow

to take total control my body to take control at all

27 0 1 2 3 4 5

I will totally lose control of myself I will not lose control of myself

**How do you imagine it will feel the very moment you deliver the baby?**

28 0 1 2 3 4 5

Extremely enjoyable Not at all enjoyable

29 0 1 2 3 4 5

Extremely natural Not at all natural

30 0 1 2 3 4 5

Totally as it should be Not at all as it should be

31 0 1 2 3 4 5

Extremely dangerous Not at all dangerous

**Have you, during the last month, had fantasies about the labour and delivery, for example……**

32 ……fantasies that your child will die during labour/ delivery?

0 1 2 3 4 5

Never Very often

33 ……fantasies that your child will be injured during labour/ delivery?

0 1 2 3 4 5

Never Very often

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Irish Centre for Fetal and Neonatal Translational Research

**Section 2:** Your thoughts and feelings about your upcoming birth

34. How do you feel right now about the approaching birth?

Please place a mark on each line below.

0 1 2 3 4 5 6 7 8 9 10

**Calm** **Worried**

0 1 2 3 4 5 6 7 8 9 10

**No Fear** **Strong Fear**

35. What (if any) is your greatest concern about the approaching birth?

_____
_____
_____
_____
_____
_____

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**Section 3: Your Social Supports:**

From the following list of people, please indicate the persons who you expect to be supportive and helpful to you in caring for your baby

| Types of support persons (tick more than one as necessary) If any of the names below are not applicable or relevant please leave blank (tick more than one person as necessary | Provide information about caring for your baby in relation to feeding, changing, bathing and settling your baby | Carry out infant care tasks such as feeding, changing, bathing and settling your baby | Show that they care, love and respect you in caring for your baby | Praise you for doing a good job in caring for your baby |
|---|---|---|---|---|
| Husband/Partner | | | | |
| Mother | | | | |
| Father | | | | |
| Husband/Partners' mother | | | | |
| Husband/Partners' father | | | | |
| Sister(s) | | | | |
| Brother(s) | | | | |
| Friend(s) | | | | |
| Neighbour(s) | | | | |
| Midwife/Nurse(s) | | | | |
| Local Doctor (GP) | | | | |
| Public Health Nurse(s) | | | | |
| Practice Nurse(s) | | | | |
| Others (Specify) | | | | |

Infant

Irish Centre for Fetal and Neonatal Translational Research

The following statements ask about the support that is available to you once your baby is born. After reading each statement please circle the number that you feel is moist appropriate, there is no right and wrong answer. Please answer each of the 16questions

| | | | Strongly disagree | Disagree | Agree | Strongly Agree |
|---|---|---|---|---|---|---|
| 1. | I can get information on | Feeding | | | | |
| | | Changing/dressing | | | | |
| | | Comfort/settling | | | | |
| | | Bathing | | | | |
| 2. | I can get information on taking care of my body after childbirth | | | | | |
| 3. | I can learn from other mothers' experiences | | | | | |
| 4. | I can get consistent information regarding infant care | | | | | |
| 5. | I can get 'hands on' help with my baby | Feeding | | | | |
| | | Changing/dressing | | | | |
| | | Comfort/settling | | | | |
| | | Bathing | | | | |
| 6. | I have someone to help me with routine housework | | | | | |
| 7. | I want to be on my own taking care of my baby | | | | | |
| 8. | I can take time for myself | | | | | |
| 9. | I have people to count on when things go wrong | | | | | |
| 10. | I have someone to care and comfort me | | | | | |
| 11. | I have someone to talk about how I feel | | | | | |
| 12. | If I need advice there is someone who will assist | | | | | |
| 13. | I have people to talk to and share my experiences with | | | | | |
| 14. | I have people who will show me appreciation for the care I give to my baby | | | | | |
| 15. | People close to me understand that it is okay for me to need help | | | | | |
| 16. | I can get positive feedback from healthcare professionals about my ability to care for my baby | | | | | |

Infant
Irish Centre for Fetal and Neonatal Translational Research

**How are you feeling at present?**

As you are pregnant, we would like to know how you are feeling. Please tick the answer that comes closest to how you have felt IN THE PAST 7 DAYS, not just how you feel today.

In the past 7 days:

1. I have been able to laugh and see the funny side of things
   - ☐ as much as I always could
   - ☐ not quite so much now
   - ☐ definitely not so much now
   - ☐ not at all
2. I have looked forward with enjoyment to things
   - ☐ as much as I ever did
   - ☐ rather less than I used to
   - ☐ definitely less than I used to
   - ☐ hardly at all
3. I have blamed myself unnecessarily when things went wrong
   - ☐ yes, most of the time
   - ☐ yes, some of the time
   - ☐ not very often
   - ☐ no, never
4. I have been anxious or worried for no good reason
   - ☐ no, not at all
   - ☐ hardly ever
   - ☐ yes, sometimes
   - ☐ yes, very often
5. I have felt scared or panicky for no very good reason
   - ☐ yes, quite a lot
   - ☐ yes, sometimes
   - ☐ no, not so much
   - ☐ no, not at all

Infant
Irish Centre for Fetal and Neonatal Translational Research

6. Things have been getting on top of me
   - ☐ yes, most of the time I haven't been able to cope at all
   - ☐ yes, sometimes I haven't been coping as well as usual
   - ☐ no, most of the time I have coped quite well
   - ☐ no, I have been coping as well as ever
7. I have been so unhappy that I have had difficulty sleeping
   - ☐ yes, most of the time
   - ☐ yes, sometimes
   - ☐ not very often
   - ☐ no, not at all
8. I have felt sad or miserable
   - ☐ yes, most of the time
   - ☐ yes, quite often
   - ☐ not very often
   - ☐ no, not at all
9. I have been so unhappy that I have been crying
   - ☐ yes, most of the time
   - ☐ yes, quite often
   - ☐ not very often
   - ☐ no, never
10. The thought of harming myself has occurred to me
    - ☐ yes, quite often
    - ☐ sometimes
    - ☐ hardly ever
    - ☐ never

Thank you for taking the time to complete this questionnaire. Your opinions and experiences are valued and will help improve care for women in the future, Maeve O'Connell, PhD Candidate.

maeveoconnell@ucc.ie

# Appendix 6 EXPRESS Study Ethical Approval

UCC
Tel: + 353-21-490 1901
Fax: + 353-21-490 1919

COISTE EITICE UM THAIGHDE CLINICIÚIL
**Clinical Research Ethics Committee**

Lancaster Hall,
6 Little Hanover Street,
Cork,
Ireland.

Coláiste na hOllscoile Corcaigh, Éire
**University College Cork, Ireland**

Our ref: ECM 4 (dd) 06/01/15

17th December 2014

Professor Louise Kenny
Director INFANT
Consultant in Obstetrics and Gynaecology
5th Floor
Cork University Maternity Hospital
Wilton
Cork

**Re: Exploring women's perceptions and feelings surrounding childbirth.**

Dear Professor Kenny

Expedited approval will be granted to carry out the above study at:

- Cork University Maternity Hospital

subject to receipt of the following:

- Post Delivery Data Collection Sheet
- Revised Consent Form – Add sentence "I agree to allow access to my hospital records".

The following documents have been approved:

- Signed Application Form
- CV for Chief Investigator
- Study Protocol
- Information Leaflets
- Questionnaires.



We note that the co-investigators involved in this study will be:

- Dr Rhona O'Connell, Dr Adeline Cooney, Dr Mary Casey and Ms Elizabeth Weathers, Kerry Centre of Nurse and Midwifery Education.

Yours sincerely

Professor Michael G Molloy
Chairman
Clinical Research Ethics Committee
of the Cork Teaching Hospitals

*The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics*

UCC

Tel: + 353-21-490 1901
Fax: + 353-21-490 1919

Coláiste na hOllscoile Corcaigh, Éire
**University College Cork, Ireland**

COISTE EITICE UM THAIGHDE CLINICIÚIL
**Clinical Research Ethics Committee**

Lancaster Hall,
6 Little Hanover Street,
Cork,
Ireland.

Our ref: ECM 4 (dd) 06/01/15 and ECM 3 (ccccc) 03/03/15

27th February 2015

Professor Louise Kenny
Director INFANT
Consultant in Obstetrics and Gynaecology
5th Floor
Cork University Maternity Hospital
Wilton
Cork

**Re: Exploring women's perceptions and feelings surrounding childbirth.**

Dear Professor Kenny

The Chairman approved the following:

- Post Delivery Data Collection Sheet
- Revised Consent Form.

Full approval is now granted to begin this study.

Yours sincerely

Professor Michael G Molloy
Chairman
Clinical Research Ethics Committee
of the Cork Teaching Hospitals

*The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for*

## Appendix 7 EXPRESS Study Postnatal Data Collection Sheet

ID NO: _____ Date of Delivery:_____

**Exploring women's perceptions and feelings surrounding childbirth**

Infant
Irish Centre for Fetal and Neonatal Translational Research

Postnatal Data Collection Sheet

| | | |
|---|---|---|
| Onset of Labour | IOL<br><br>SOL | |
| Duration of Labour | 1st Stage: | |
| | 2nd Stage: | |
| | 3rd Stage: | |
| If induction, reason documented for induction of labour | Post dates<br>PROM<br>PET<br>Diabetes<br>Unknown | |
| Pain relief in labour | No analgesia<br>TENS<br>Entonox<br>Pethidine<br>Epidural | |
| Mode of Delivery | SVD<br>Vacuum<br>Forceps<br>Vacuum and Forceps<br>EMCS<br>ELCS | |
| If C-Section, Category | 1: Immediate threat to life of mother or fetus<br>2: No immediate threat to life of mother or fetus<br>3: Requires early delivery<br>4: Elective | |
| Perineum | Intact<br>1st Degree Tear<br>2nd Degree Tear<br>3rd Degree Tear<br>4th Degree Tear<br>Episiotomy | |
| If C-Section type of analgesia used | Epidural<br>Spinal<br>General Anaesthetic | |
| Cord Blood Gases | Arterial Ph | |
| | Arterial Base Excess | |
| | Venous Ph | |
| | Venous Base Excess | |

ID NO: _____ Date of Delivery:_____

| | |
|---|---|
| Estimated Blood Loss | Unknown<br><500mls<br>≥500mls<br>≥1000mls<br>≥1500mls |
| Maternal Postnatal Hospital Days (Count day of birth as Day 1) | |
| Infant Feeding intention | Breast<br>Bottle<br>Mix feeding<br>Partially breastfeeding (Breast and expressing)<br>Unknown |
| Maternal Outcome<br><br>Note any complications here | Alive and well<br>Alive, long term sequelae<br>Dead<br>Unknown |
| Neonatal Outcome | Live<br>Stillbirth |
| Apgars | @5minutes<br><br>@10minutes |
| Birth weight | |
| Sex | |
| Centile | |
| Gestation at birth | |
| Feeding on Discharge | Breast<br>Bottle<br>Mix<br>Partially Breastfeeding (Breast and Expressing) |
| If Neonatal Unit Admission, reason for admission | |
| Duration of Neonatal Admission (hours) | |
| Pregnancy Complications<br>ie. Medical diagnosis in pregnancy: PET, VTE, PPROM, Obstetric Cholestasis, Hyperemesis, GDM | |

ID NO: _____ Date of Delivery:_____

| | |
|---|---|
| Antenatal admissions | No. of Day Unit Visits<br><br>Antenatal Hospitalisation (in days)<br><br>HDU (in days) |
| Readmissions<br><br>(Reason for readmission) | |

# Appendix 8 Protocol for meta-synthesis

**PROSPERO**
**International prospective register of systematic reviews**

**NHS**
***National Institute for Health Research***

**UNIVERSITY of York**
**Centre for Reviews and Dissemination**

## Systematic review

### 1. * Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

Women's experiences of interventions for fear of childbirth in the perinatal period: a protocol for a meta-synthesis

### 2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

### 3. * Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.

17/11/2017

### 4. * Anticipated completion date.

Give the date by which the review is expected to be completed.

01/06/2018

### 5. * Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.
Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.
This field should be updated when any amendments are made to a published record and on completion and publication of the review. If this field was pre-populated from the initial screening questions then you are not able to edit it until the record is published.

The review has not yet started: No

| Review stage | Started | Completed |
|---|---|---|
| Preliminary searches | Yes | Yes |
| Piloting of the study selection process | Yes | Yes |
| Formal screening of search results against eligibility criteria | Yes | Yes |
| Data extraction | No | No |
| Risk of bias (quality) assessment | No | No |
| Data analysis | No | No |

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

## 6. * Named contact.

The named contact acts as the guarantor for the accuracy of the information presented in the register record.

Maeve O'Connell

## Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Ms

## 7. * Named contact email.

Give the electronic mail address of the named contact.

maeveoconnell@ucc.ie

## 8. Named contact address

Give the full postal address for the named contact.

Irish Centre for Fetal and Neonatal Translational Research, Cork University Maternity Hospital, Wilton, Cork

## 9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

00353876103536

## 10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

Irish Centre for Fetal and Neonatal Translational Research (INFANT Centre), University College Cork

## Organisation web address:

http://www.infantcentre.ie/

## 11. * Review team members and their organisational affiliations.

Give the title, first name, last name and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong.

Ms Maeve O'Connell. University College Cork
Dr Ali Khashan. University College Cork
Professor Louise Kenny. University College Cork
Dr Patricia Leahy-Warren. University College Cork

## 12. * Funding sources/sponsors.

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

The Irish Centre for Fetal and Neonatal Translational Research (INFANT Centre), University College Cork,

Ireland which is supported by Science Foundation Ireland (grant no. 12/RC/ 2272)

## 13. * Conflicts of interest.

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

## 14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members.

## 15. * Review question.

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

What is the experience of the perinatal period (pregnancy, labour, birth and postpartum) for women with fear of childbirth?

Do interventions help women with fear of childbirth?

If so, what interventions helped?

Who supported women to cope with fear of childbirth?

How did women feel about the interventions offered to them for fear of childbirth?

What is perceived as helpful in maternity care by pregnant women with fear of childbirth?

## 16. * Searches.

Give details of the sources to be searched, search dates (from and to), and any restrictions (e.g. language or

publication period). The full search strategy is not required, but may be supplied as a link or attachment.

A systematic search of relevant databases using Boolean terms CINAHL plus, MEDLINE, PsycINFO, PubMed, Maternity and Infant Care, and Scopus will be undertaken. In addition, grey literature will be identified through searches of Google and Google Scholar as well as hand-searching of references for any Studies published in all languages and papers published in any date range will be applied. key words.

## 17. URL to search strategy.

Give a link to a published pdf/word document detailing either the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies), or upload your search strategy.Do NOT provide links to your search results.

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

## 18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Fear of childbirth is thought to affect approximately 20% pregnant women with 6-10% having tocophobia (a severe fear of childbirth). It is a multi-dimensional phenomenon which may be related to many different factors, therefore this group of women have challenging individual maternity care needs in pregnancy. Moreover, it has been argued that women with fear of childbirth often have co-morbid mental health issues and some individuals may be more vulnerable i.e. those with pre-existing mental health issues or low social support. In addition, a recent systematic review concluded that the prevalence of tocophobia appears to be increasing in recent years, thus it is vital that more research is conducted in order to recognise and gain insight into this apparently growing phenomenon. This meta-synthesis will look at women's experiences interventions offered for fear of childbirth, providing an in-depth analysis to enrich our understanding of how women experience interventions for fear of childbirth and ways of coping with this fear. Given the complexity of reasons for tocophobia, this review will provide a meaningful insight into how women experience different interventions for fear of childbirth. In addition, it will draw conclusions which will be the basis of recommendations for future research and policy.

## 19. * Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

Participant criteria: Pregnant women over the age of 18 with fear of childbirth who have used interventions or strategies to cope with fear of childbirth.

The phenomena of interest in this review is pregnant women's experiences of interventions for fear of

childbirth in the perinatal period.

This review will consider qualitative research including the experiences of pregnant women with fear of childbirth and their experiences of interventions as stated in the study. Terms used to define fear of childbirth may include those with "pregnancy-specific anxiety", "high childbirth related fear", "intense fear", "high childbirth fear", "high levels of childbirth fear", "severe childbirth fear" and "severe FOC", "childbirth anxiety", "birth anxiety", "morbid fear" or women who attended an intervention for fear of childbirth.

Exclusion criteria :

Women who were not pregnant

Women who received Assisted Reproductive Therapy

Women with pregnancy loss

Quantitative studies

Studies that used a diagnostic interview technique

Experiences of women as described by:

Partners of women with fear of childbirth

Health Care Professionals

Midwives

Nurses

## 20. * Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

Women's experiences of interventions for fear of childbirth in the perinatal period.

## 21. * Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Not applicable.

## 22. * Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

This review will include qualitative and mixed method studies with clear methodologies which described

women's experiences of interventions for fear of childbirth in the perinatal period.

## 23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

This review will include qualitative research involving the experiences of interventions for fear of childbirth in the perinatal period. This will include both home and hospital environments.

## 24. * Main outcome(s).

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

To determine who supports women to cope with fear of childbirth in the perinatal period.

To investigate how women experience interventions offered to them for fear of childbirth.

To explore how women with fear of childbirth feel about interventions for offered to them.

To evaluate the acceptability of and satisfaction with interventions offered for fear of childbirth.

### Timing and effect measures

## 25. * Additional outcome(s).

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

To identify what pregnant women with fear of childbirth perceive as helpful in maternity care.

### Timing and effect measures

## 26. * Data extraction (selection and coding).

Give the procedure for selecting studies for the review and extracting data, including the number of researchers involved and how discrepancies will be resolved. List the data to be extracted.

All peer-reviewed studies undertaken to present in all languages as identified in the systematic search using the modified PICO criteria (PCO) will be included in the review to get an insight into the experience of women with fear of childbirth in the perinatal period. Where articles in languages other than English are located, Google Translate will be used to translate into English.

Context: Living with fear of childbirth

Outcome: Experiences of interventions for fear of childbirth

• Lead reviewer (MOC) to screen all titles and abstracts initially and a second reviewer (PL-W) will double check. If doubts arise, a third reviewer (ASK) will be available to discuss.

• Where study titles, abstract or key word searches meet the inclusion criteria, the full text document will be obtained for screening.

• The reference list of all identified reports and articles will be hand-searched for additional relevant studies.

Data extraction using a proforma will include:

• Study characteristics- Author, year, country, setting

• Participants characteristics-age/ parity

• Quality -results of the critical appraisal

• First order constructs: participant quotes

• Second order constructs: Main themes identified by study authors and conclusions of study authors.

## 27. * Risk of bias (quality) assessment.

State whether and how risk of bias will be assessed (including the number of researchers involved and how discrepancies will be resolved), how the quality of individual studies will be assessed, and whether and how this will influence the planned synthesis.

Two reviewers (MOC and PL-W) will independently review the methodological quality of the research using a Walsh and Downe (2006) quality checklist. Study quality will be graded A-D as determined by the assessment. This has been widely used to assess the quality of qualitative research studies therefore this is deemed appropriate to assess the methodological quality of studies included in this meta-synthesis. Where doubts arise, a third reviewer (ASK) will be contacted to reach a consensus. The results of the quality assessment will inform the inclusion of studies in the review and studies will be included if graded A-C and deemed useful to the review.

## 28. * Strategy for data synthesis.

Give the planned general approach to synthesis, e.g. whether aggregate or individual participant data will be used and whether a quantitative or narrative (descriptive) synthesis is planned. It is acceptable to state that a quantitative synthesis will be used if the included studies are sufficiently homogenous.

This synthesis will be undertaken using the meta-ethnographic framework in 7 phases as outlined by Noblit and Hare (1988):

1. Getting started" (the topic focus)

2. Deciding what is relevant to the initial interest

3. Reading the studies

4. Determining how the studies are related

5. Translating the studies into one another

6. Synthesising translations

7. Expressing the synthesis

Furthermore it employs a three stage approach. Firstly determining first-order constructs (key concepts in the article), secondly determining and creating second order constructs to finally produce overarching third-order constructs pertaining to the review question.

The author's original findings will be summarised by one author and first author constructs reached by consensus. Microsoft Excel will be used to develop a grid of first order constructs from each study. Further meetings will result in second order constructs being developed. Using these second order constructs, third order constructs will be created to represent an overarching theoretical framework. This will be achieved through discussions and meetings of the team. Following on from this, as recommended by Noblit and Hare (1988) [35] we will investigate the relationship between studies as either 1) Reciprocal (directly comparable) or 2) Refutational (in opposition). This review will employ an interpretive approach rather than integrative approach to synthesise the data, concepts will evolve following analysis of primary data. Finally, we will create a theoretical model to describe our findings. N-VIVO 11 Software may be used in the data synthesis and analysis process.

## 29. * Analysis of subgroups or subsets.

Give details of any plans for the separate presentation, exploration or analysis of different types of participants (e.g. by age, disease status, ethnicity, socioeconomic status, presence or absence or co-morbidities); different types of intervention (e.g. drug dose, presence or absence of particular components of intervention); different settings (e.g. country, acute or primary care sector, professional or family care); or different types of study (e.g. randomised or non-randomised).

If type of qualitative methods used (interviews, focus groups) the following study characteristics:

• Study context (by Country)

Investigating differences in findings from methods used may inform future researchers in the design of research studies. Comparing findings across contexts and countries is useful in terms of improving our understanding of fear of childbirth in different cultures. Evidence from this analysis may inform evidence-informed policymaking. In addition, there may be hypotheses generated which may stimulate context-specific further quantitative research in the area.

## 30. * Type and method of review.

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

### Type of review

Cost effectiveness
No

Diagnostic
No

Epidemiologic
No

Individual patient data (IPD) meta-analysis

No

Intervention
No

Meta-analysis
No

Methodology
No

Narrative synthesis
No

Network meta-analysis
No

Pre-clinical
No

Prevention
No

Prognostic
No

Prospective meta-analysis (PMA)
No

Review of reviews
No

Service delivery
No

Synthesis of qualitative studies
No

Systematic review
Yes

Other
No

## Health area of the review

Alcohol/substance misuse/abuse
No

Blood and immune system
No

Cancer
No

Cardiovascular
No

Care of the elderly
No

Child health
No

Complementary therapies
No

Crime and justice
No

Dental
No

Digestive system

No

Ear, nose and throat
No

Education
No

Endocrine and metabolic disorders
No

Eye disorders
No

General interest
No

Genetics
No

Health inequalities/health equity
No

Infections and infestations
No

International development
No

Mental health and behavioural conditions
Yes

Musculoskeletal
No

Neurological
No

Nursing
Yes

Obstetrics and gynaecology
Yes

Oral health
No

Palliative care
No

Perioperative care
No

Physiotherapy
No

Pregnancy and childbirth
Yes

Public health (including social determinants of health)
No

Rehabilitation
No

Respiratory disorders
No

Service delivery
No

Skin disorders
No

Social care
No

Surgery
No

Tropical Medicine
No

Urological
No

Wounds, injuries and accidents
No

Violence and abuse
No

## 31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.
English

There is not an English language summary

## 32. Country.

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.

Ireland

## 33. Other registration details.

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

## 34. Reference and/or URL for published protocol.

Give the citation and link for the published protocol, if there is one

Give the link to the published protocol.

Alternatively, upload your published protocol to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Yes I give permission for this file to be made publicly available

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

## 35. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

Systematic review and meta-ethnography to be reported following the Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ Statement and published in high impact peer-reviewed journal.

## Do you intend to publish the review on completion?

Yes

## 36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Systematic Review; Meta-ethnography; Meta-Synthesis; fear of birth; childbirth fear; tocophobia; perinatal mental health

## 37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

## 38. * Current review status.

Review status should be updated when the review is completed and when it is published. For newregistrations the review must be Ongoing.
Please provide anticipated publication date

Review_Ongoing

## 39. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

## 40. Details of final report/publication(s).

This field should be left empty until details of the completed review are available.

Give the link to the published review.

## Appendix 9: Fieldnotes related to Meta-Synthesis

Notes following the initial reading August 2018

Poor connection with baby
Difficult to imagine a babe in arms
Avoid planning the birth
Women should feel safe/ secure
[From avoidance to active participants in the birth process]
Detached>>> confidence
Low self-confidence
Alone>>>> supported by staff
Desire to be taken seriously and listened to
Difficulty picturing themselves as a mother and bonding with the baby
Finally verbalising emotions
From fear of unknown to coping and participating in birth
Focussing on the baby helps the mother to cope in labour
Concerns to be taken seriously and listened to
Isolated in their fear
Unable to communicate to others
Releasing the fear

ART IX
1CST

Focus on
- fear
- Confidence
- self Capability.

MW
counselling
+ Teamwork

Focus on
- birth process
- experts / systems
- birth plans.

Change in Perspective / Opinion
Hopelessness to Positive attitude

Ramni - ???

Individual situations
- Concerns

Information

**Meta-Synthesis Notes**

**Overarching Theme 31082018**

Helping women with fear of childbirth reclaim emotional control over the birth process

**Subthemes**

1. Re-framing the emotions about birth
2. Practical techniques for managing fear
3. Importance of communication
4. Importance of social support
5. Strengthening bonds with partner and baby
6. Perceived barriers
7. Need for diverse options for interventions for fear of childbirth

| Concept | Theme | Descriptive Code | Code |
|---|---|---|---|
| Developing emotional strength | Re-framing the emotions about birth | Belief in the competence of their caregiver in labour | 1, 2, 6 |
| | | Coping when things didn't go as expected | 6 |
| | | Developing confidence in ability to birth | 5 |
| | | Feeling calm | 2, 4, 5, 6 |
| | | Feeling safe | 2, 4, 5, 6 |
| | | Gaining hope | 5 |
| | | Separating emotions from reality | 6 |
| | | Understanding the cause of the fear | 5, 6 |
| | | Reflecting on the fear | 3, 6 |
| | | Imagining a supportive birth environment | 1, 5, 6 |
| | | Imagining supportive staff | 1, 5, 6 |
| | | Perceiving pain as serving a purpose during birth process | 6 |
| | | Positive anticipation of the baby | 4, 5 |
| | | Reflecting on the fear | 5 |
| | | Re-framing their feelings about birth from negative to positive | 4 |
| | | Sense of control over decisions and choices during birth - autonomy | 6 |
| | | Understanding the cause of the fear | 5, 6 |
| | | Improved self-confidence in other areas of life | 6 |
| Gaining Knowledge | Practical techniques for managing fear | Active role in birth process | 6 |
| | | Developed techniques and tools for coping | 6 |
| | | Gaining a sense of control over decisions and choices during birth-autonomy | 1, 6 |
| | | Gaining control of the birth process | 6 |
| | | Gaining knowledge | 1, 4, 6 |
| | | Learned to manage the fear (it didn't disappear) | 6 |
| | | Listen to your body in labour | 6 |

| | | | |
|---|---|---|---|
| | | Prepared for birth-knowing what to expect | 1, 4, 6 |
| | | Team midwife gave information r/t pregnancy & birth | 1, 6 |
| | | Understanding the previous birth | 6 |
| | | Verbalising the fear helps letting go | 6 |
| | | Visiting labour ward | 6 |
| Importance of Communication | Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Abusive encounters with maternity staff was traumatic | 5 |
| | | Allow a real mutual dialogue with the women and caregivers | 3, 6 |
| | | Fear acknowledged by staff | 1, 2, 6 |
| | | Feeling understood | 1, 6 |
| | | Felt could not speak up | 3 |
| | | Felt the gynae did not listen | 3 |
| | | Having an advocate to verbalise wishes during labour | 1 |
| | | Midwife knew the woman's individual fears | 2, 6 |
| | | Midwife listens and understands | 2, 6 |
| | | Midwife reassured me | 3 |
| | | Midwife validated the emotion of fear | 2, 6 |
| | | Perceived that caregiver did not care about their opinion r/t their birth | 3, 6 |
| | | Building a trusting relationship with the midwife | 6 |
| | | Wanted to be treated humanely | 3 |
| | Expressing the emotion of fear with others helped | Verbalising the fear helps letting go | 1, 2, 6 |
| | | Expressing the emotion of fear | 2, 3, 6 |
| | | Working with other women helped to process the fear | 5 |
| Importance of Social Support | Formal and informal social supports help to meet the psychological needs of women | Building a trusting relationship with the midwife | 1, 2, 6 |
| | | Communicating the fear with their partner | 5, 6 |
| | | Could not have managed without midwife support | 1 |
| | | Group therapy helpful when women similar gestation/ parity | 5 |
| | | Midwife provided emotional support | 2 |
| | | Midwife went beyond expectations | 2 |
| | | Midwifes practical support crucial when partner not involved | 6 |
| | | Negligent encounters with maternity staff was traumatic | 5 |

| | | | |
|---|---|---|---|
| | | Partners provide active support | 4, 5, 6 |
| | | Peer support- women of the same gestation and parity | 5 |
| | | Stressed staff led to perceived lower support | 6 |
| | | Team midwife provided additional support, gave extra time | 1 |
| | Strengthening bonds with partner and baby | Visualising the baby | 4, 5 |
| | | Facilitated dialogue with partner | 5 |
| | | Had positive birth experience but poor bond with baby, felt was not listened to in the antenatal period | 3 (Marie) |
| | | Poor communication in the antenatal period affected her partner relationship | 3 (Marie) |
| Barriers to accessing interventions for FOC | Interventions not meeting the needs of the women | Prefer to meet a separate person as felt it was too private to share (1 woman) | 6 |
| | | Midwife counselling described as superficial (2 women) | 6 |
| | | Drop out for unknown reasons (7 women) | 4 |
| | | Wanted to feel like she had a choice, to birth on her terms | 3 (Kristine) |
| | | Drop out of icbt due to 'lack of time' (2 women) | 4 |
| | | Intervention did not help with other fears like fear of blood or hospitals | 4 |
| | | Initially felt negative about the intervention (Team Midwifery) | 3 (Kristine) |
| | | Limited contact with therapist as via the internet (icbt) | 4 |
| | | 3 women voiced adverse feelings about the midwife helping with the fear | 6 |
| | | Was not considered expert despite giving birth 3 times before | 2 |
| | | Woman with previous sexual abuse did not feel benefit of intervention as previous traumatic events were not addressed | 4 |
| | Need for diverse options for interventions for FOC | Art therapy was well accepted | 5 |
| | | Women may like to be offered the option of other interventions if co-morbid mental health | 6 |
| | | No negative effects of art therapy | 5 |

| | | | |
|---|---|---|---|
| | | Women agreed to participate but no information on those who didn't (Team Midwifery/ Midwife Counselling for FOC) | 1, 3, 6 |
| | | Satisfied with midwife counselling, would have it again in a future pregnancy | 6 |
| | | Women need individualised care | 1, 4, 6 |

**Meta-synthesis Notes 05092018**

**Overarching Theme**

Helping women with fear of childbirth reclaim emotional control over the birth process

| **Concept** | **Theme** |
|---|---|
| *Developing emotional strength* | Re-framing the emotions about birth |
| *Gaining knowledge* | Practical techniques for managing fear |
| *Importance of communication* | Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women |
| | Expressing the emotion of fear with others helped |
| *Importance of social support* | Formal and informal social supports help to meet the psychological needs of women |
| | Strengthening bonds with partner and baby |
| *Barriers to accessing interventions for FOC* | Interventions not meeting the needs of the women |
| | Need for diverse options for interventions for FOC |

**Meta-Synthesis Notes 06092018**

**Overarching Theme**

Helping women with fear of childbirth reclaim emotional control over the birth process

| **Concept** | **Theme** |
|---|---|
| *Developing emotional strength* | Re-framing the emotions about birth |
| *Gaining knowledge* | Practical techniques for managing fear |
| *Importance of communication* | Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women |
| | Expressing the emotion of fear with others helped |
| *Importance of social support* | Formal and informal social supports help to meet the psychological needs of women |
| | Strengthening bonds with partner and baby |
| *Barriers to satisfaction with interventions for FOC* | Interventions not meeting the needs of the women |
| | Need for diverse options for interventions for FOC |

Limited data.

Ramu
- Only 5 of 8 agreed to participate.
- Was it unacceptable to 3 women?

Lyberg A TS.

25 women invited, 13 agreed
we dont know about the non-participants.

Nicaragua.
30 nulliparous women
2 dropped out in the first week
15/28 completed the 8 weeks.

10/10/2018 (looking at the Themes in the Papers)

Emotional Preparation for birth.
Gaining Control
Practical Support
Sharing The Problem *
Coping
Listen To Women *
Accept the fear
Trusting relationship with the clinician
Willing to Provide Support *
Gaining self insight into the reasons for fear
Being treated with dignity.
A Real Dialogue between women and clinician.
Sensitivity to individual needs
Clinicians to be non-judgemental (1,2,3) about fear of childbirth. 4

formal/informal Social Support.

Ramu Field Notes 11/10/18

Amalie Case:-

FOC intergenerational

- passed from granny - highlighted lack of social support
- Had traumatic births
- Did not feel listened to.
- Request for CS ignored
- FOC r/t longer labour
- Amalie made slow progress
- Slow dilatation
- Forceps after failed vacuum x4
- Terrified
- Traumatised.
- No social support
- Difficult PostPartum Period

Nieuwenhuis Field Notes 11/10/18

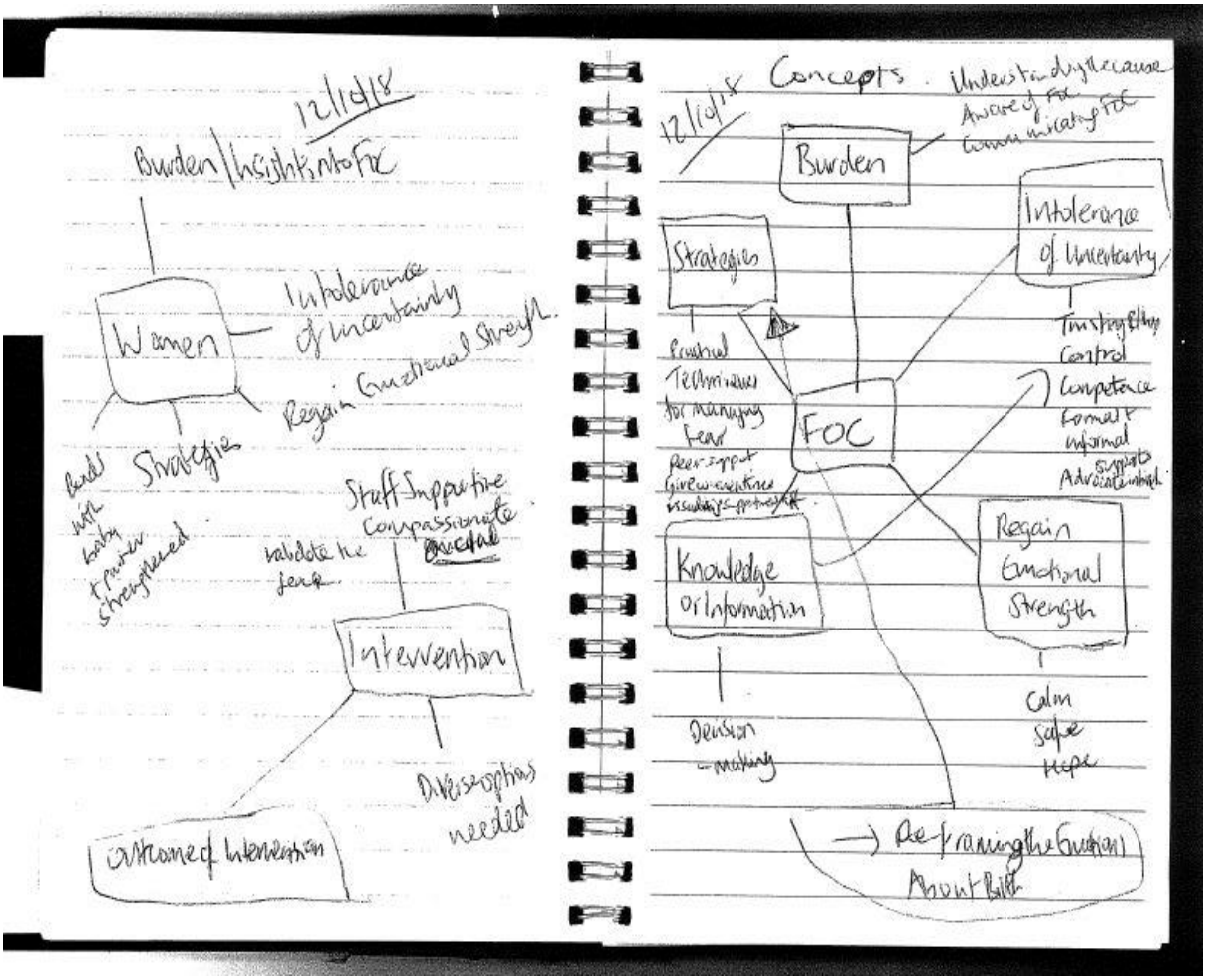
Health professionals need to be open to FOC.
Women do not need to legitimise their fear to have a respectful dialogue about a CS request

Understanding or going behind the fear can be important.
Herm (2006) – becoming aware of and working through the fear can be helpful.

Women to be taken seriously

NB: Moving from uncertainty to certainty after Tx
(Shen et al identified IU as key aspect in their meta-synthesis)
NB for Discussion.

Developing a trusting R/ship with partner as well as midwife.
Believing in the partner's ability to support.


12/10/18
Burden/Insights into FOC
Women
Intolerance of Uncertainty
Regain Emotional Strength
Strategies
Staff Supportive
Compassionate
Intervention
Outcome of Intervention
Decision options needed
12/10/18 Concepts
Burden
Strategies
Intolerance of Uncertainty
FOC
Knowledge or Information
Regain Emotional Strength
Decision-making
Calm
Safe
Hope
Re-framing the Situation About Birth

Intervention
uses strategies to help
women with FOC
- Understand the cause of fear
- Express the fear
- Share FOC with others
- Reduce FOC
- Gain certainty
- Prepare for birth
Needs of women with FOC
External
factors which
cannot be
controlled
or which
may vary
Outcomes


Concept:
Wishes: to express a strong
desire or hope for something
that cannot or probably will not
happen
: want something to be done
: an expression of a desire,
typically in the form of a
request or instruction
Outcome: The way a thing turns out
A consequence
Strategy: A plan of action designed
to achieve an overall aim

24/10/2018

"Handling" the fear

"On your own terms"

Elements of the intervention were a different element of the ~~[illegible]~~.

Self - Agency.

Ownership.

Autonomy.

NVivo work 25/10/2018

New descriptive code

Indep.

'Agency' - self — capacity to make free choices.

'Power' - empowered — act independently

— disempowered

30/10/2018 Metasynthesis

Analytical Themes.

(1)

Before

Self

| | |
|---|---|
| Fear | Fear |
| Handling the fear | Agency |
| Agency | Self-Efficacy |
| Expressing foc | Handling the fear |
| Self-Efficacy | Expressing foc |

Field notes13/10/2018

***Interventions:***

**Strategies** to help women with fear of childbirth:

Gain insight into the fear

Understand the cause of the fear

Express the fear

Share fear (the problem) with others

Reduce fear of childbirth

Gain certainty and or control

Prepare for birth

Knowledge or information

Regain emotional strength

Connect with and visualise baby

Peer support (speak to others)

**Wishes** of women with fear of childbirth:

Reassurance

Validate the fear

Clear information

**External factors** which cannot be controlled or which may vary:

Attitudes of staff/ Supportive staff

Willingness to listen

Trusting relationship with health care professional

Negligent encounter with staff

Judgemental staff

**Outcomes** of women with fear of childbirth after the intervention:

Calm, safe, hope

Self-awareness

**External Factors** which can be controlled:

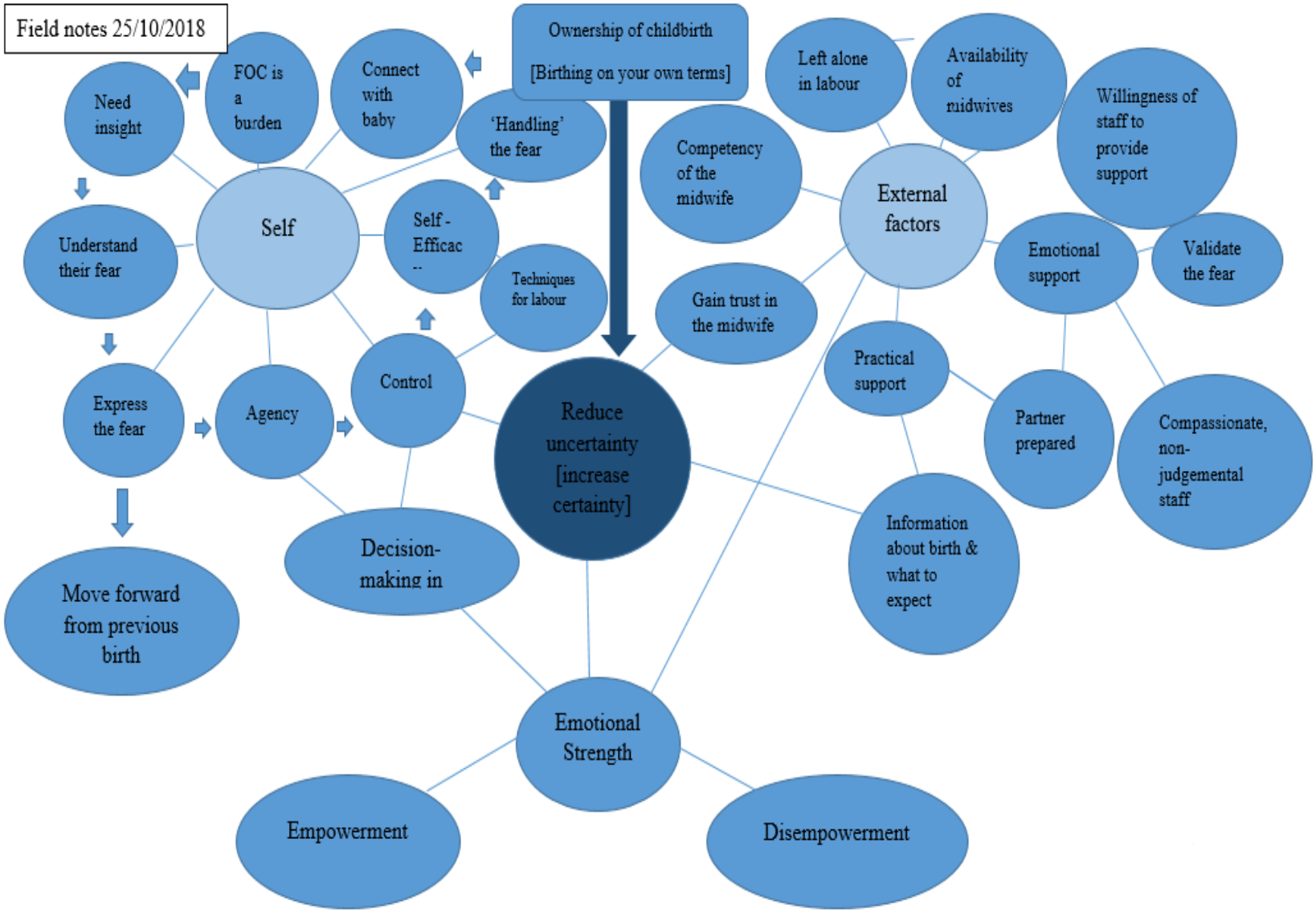
Partner prepared and supportive

Known midwife

Trusting relationship with health care professional

Validate the fear

Involve in decision-making


Field notes 25/10/2018
Ownership of childbirth
[Birthing on your own terms]
Need insight
FOC is a burden
Connect with baby
'Handling' the fear
Self
Understand their fear
Self - Efficac --
Techniques for labour
Express the fear
Agency
Control
Move forward from previous birth
Decision-making in
Reduce uncertainty [increase certainty]
Competency of the midwife
Gain trust in the midwife
Left alone in labour
Availability of midwives
Willingness of staff to provide support
External factors
Emotional support
Validate the fear
Practical support
Partner prepared
Compassionate, non-judgemental staff
Information about birth & what to expect
Emotional Strength
Empowerment
Disempowerment

Meta-synthesis analysis notes 28/10/2018

| Analytical Theme | Descriptive Themes | Categorical Codes |
|---|---|---|
| | At the mercy of someone unknown (LYA10, RA11) | Before the intervention |
| | Avoidance (NI15) | |
| | Birth as a private and intimate situation (LYA10) | |
| | Birth process viewed with uncertainty (LYA10, RA11, NI15, LA18) | |
| | Caesarean perceived as a solution by the woman (LYA10, RA11) | |
| | Communicating the fear was difficult (LYB10, RA11, LA18, WA17) | |
| | Fear injury of infant (WA17) | |
| | Fear of loss of control (LYA10, RA11, NI15, WA17, LA18) | |
| | Feeling trapped during the birth (LYA10, RA11) | |
| | Feeling vulnerable (LYA10, RA11) | |
| Tolerance of Uncertainty | FOC is a burden for women (LYB10) | |
| Developing emotional strength and Self-efficacy | Had negative self-image (WA17) | |
| | Left alone in labour (NI15) | |
| | Lack of agency (LYA10, LYB10, NI15) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Not being treated with dignity (RA11, NI15) | |
| | Disempowerment (LYA10, NI15) | |
| | Sharing the problem (LYB10, NI15, WA17, LA18) | |
| Strengthening bonds with partner and baby | Unable to picture parenthood (WA17) | |
| | Woman felt she lacked emotional capacity (LYA10) | |
| | A real dialogue between clinician and woman about FOC (LYB10, RA11, LA18) | During the intervention |
| | Birth discussion was an opportunity to reconcile (LA18) | |
| | Birth on own terms (LYB10, RA11, LA18) | |
| | Communicating the fear was difficult (LYB10, RA11, WA17, LA18) | |
| | Confirmed my emotional dimension (LYB10) | |
| | Coping at times of uncertainty during labour (LYA10, LA18) | |
| | Could answer my questions (LA18) | |
| | Developing a trusting relationship led to a feeling of security (LYA10, LYB10, RA11, LA18) | |

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| | Developing self-confidence or self-efficacy (LYB10, RA11, NI15, WA17, LA18) | |
| | Emotional preparation for birth (RA11, NI15) | |
| | Empowerment | |
| | Facilitated bonding (NI15, WA17) | |
| | Feeling trapped during the birth (LYA10, RA11) | |
| | Felt listened to (LYA10, LYB10, RA11, LA18) | |
| | Gaining control over decisions and choices during birth | |
| | Gaining insight into reasons for the fear | |
| | Gaining more certainty | |
| | Helping others to understand FOC | |
| | Intervention as an emotional process | |
| | Intervention did not improve birth experience | |
| | Learned to manage the fear (it did not disappear) | |
| | Letting the fear go | |
| | Midwife was understanding | |
| | Moving forward from the previous birth experience | |
| | Normalised the emotion of FOC | |
| | Partners provide active support in birth process | |
| | Practical support | |
| | Prepare for the birth | |
| | Processing the previous birth experience | |
| | Sensitivity to individual needs (LYB10, RA11) | |
| | Sharing feelings (LYB10, RA11, WA17) | |
| | Sharing the problem (LYB10, NI15, WA17, LA18) | |
| | Speaking to other women with FOC (WA17) | |
| | Supported partner as well (LYA10, NI15) | |
| | Take fear seriously (LA18) | |
| | Team midwife gave information about pregnancy and birth (LYA10, LA18) | |
| | Thought process between sessions helped get feelings in order (LA18) | |
| | Treated as an individual (LYA10, LA18) | |
| | Turning negative thoughts around (NI15, WA17, LA18) | |
| | Understanding the previous birth (RA11, LA18) | |
| | Visiting the labour ward made the upcoming birth real (LA18) | |

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| | Visualising the baby (RA11, NI15, WA17) | |
| | Women learned techniques to cope (NI15, WA17, LA18) | |
| | Women perceived that the midwife was in control (LYB10, RA11, LA18) | |
| | Working with other women helped to process the fear (WA17) | |
| Developing emotional strength and self-efficacy | Taking an active role in birth process (LYA10, LYB10, RA11, NI15, LA18) | Elements of interventions perceived as helpful by women with FOC |
| Developing emotional strength and self-efficacy | Able to gain a sense of control using techniques learned (NI15, LA18) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | A real dialogue between clinician and woman about FOC (LYB10, RA11, LA18) | |
| Expressing the emotion of fear with others helped | Belief in the staffs competence of skills (LYA10, LYB10, RA11, NI15, LA18) | |
| | Benefits of group therapy (WA17) | |
| | Birth discussion was an opportunity to reconcile (LA18) | |
| | Could answer my questions (LA18) | |
| Tolerance of Uncertainty | Coping at times of uncertainty in labour (LYA10, LA18) | |
| Developing emotional strength and self-efficacy | Developing self-confidence or self-efficacy (LYB10, RA11, NI15,WA17, LA18) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Developing a trusting relationship with the midwife (LYA10, LYB10, RA11, LA18) | |
| | Emotional preparation for the birth (RA11, NI15) | |
| | Facilitated bonding ( NI15, WA17) | |
| | Felt listened to (LYA10, LYB10, RA11, LA18) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Fear acknowledged by staff (LYA10, LYB10, LA18) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Feeling understood (LYA10, LA18) | |
| Tolerance of Uncertainty | Gaining a sense of control over decisions and choices during birth-autonomy (LYB10, RA11, NI15, LA18) | |
| | Gaining more certainty (NI15) | |

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| Expressing the emotion of fear with others helped | Group therapy helpful when women similar gestation/ parity (WA17) | |
| | Help partner to understand FOC (WA18) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Having an advocate to verbalise wishes during labour (LYA10) | |
| Re-framing the emotions about the birth process | Helped to feel calm and safe (LYB10, NI15, WA17, LA18) | |
| Re-framing the emotions about the birth process | Imagining a supportive birth environment (LYA10, WA17, LA18) | |
| Re-framing the emotions about the birth process | Imagining supportive staff (LYA10, WA17, LA18) | |
| | Intervention helped women to open up or express the fear (RA11, WA17, LA18) | |
| | Learned to manage or handle the fear (it didn't disappear) (LA18, WA17) | |
| | Letting the fear go (WA17, LA18) | |
| Gaining Knowledge | Making the birth real (NI15, WA17) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Midwife knew the woman's individual fears (LYB10, LA18) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Midwife was understanding (LYA10, LYB10, RA11, WA17, LA18) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Midwife reassured me (RA11) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Midwife validated the emotion of fear (LYB10, LA18) | |
| | Moving forward from the previous birth experience (LA18) | |
| | Partners perceived as providing active support in the birth (NI15) | |
| | Practical support (LYB10, NI15) | |
| Strengthening bonds with partner and baby | Positive anticipation of the baby (NI15, WA17) | |
| Need for diverse intervention options for women with FOC | Sensitive to individual needs (LYA10, LYB10, RA11, NI15, LA18) | |

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| Re-framing the emotions about birth | Separating emotions from reality (LA18) | |
| | Sharing feelings (LYB10, RA11, WA17) | |
| | Speaking to other women with FOC (WA17) | |
| Need for diverse intervention options for women with FOC | Taking an active role in decision making (LYA10, LYB10, RA11, NI15, LA18) | |
| | Team midwife gave information about pregnancy and birth (LYA10, LA18) | |
| | Thought process between sessions helped get feelings in order (WA17) | |
| | Treated as an individual (LYB10, LA18) | |
| | Turning negative thoughts around (NI15, WA17, LA18) | |
| Re-framing the emotions about the birth process | Viewing labour pain as serving a purpose during birth process (NI15, LA18) | |
| Strengthening bonds with partner and baby | Visualising the baby (RA11, NI15, WA17) | |
| Interventions meeting or not meeting the wishes of women with FOC | Wanted to feel like she had a choice, to birth on her terms (RA11) | |
| | Women learned techniques to cope (NI15, WA17, LA18) | |
| Need for diverse intervention options for women with FOC | Did not feel listened to (RA11, LA18) | Women's feelings about the interventions for FOC |
| Interventions meeting or not meeting the wishes of women with FOC | Initially felt negative about the intervention (Team Midwifery) (RA11) | |
| Interventions meeting or not meeting the wishes of women with FOC | Women agreed to participate but no information on those who didn't (Team Midwifery/ Midwife Counselling for FOC) (LYA10, RA11, LA18) | |
| Interventions meeting or not meeting the wishes of women with FOC | Art therapy was well accepted (WA17) | Acceptability of the intervention for FOC |
| Interventions meeting or not meeting the wishes of women with FOC | No negative effects of art therapy (WA17) | |
| Need for diverse intervention options for women with FOC | Prefer to meet a separate person as felt it was too private to share (1 woman) LA18 | Satisfaction with the intervention for FOC |
| Interventions meeting or not meeting the wishes of women with FOC | 3 women voiced adverse feelings about the midwife helping with the fear (LA18) | |
| Interventions meeting or not meeting the wishes of women with FOC | Satisfied with midwife counselling, would have it again in a future pregnancy (LA18) | |
| Formal and informal social supports help to meet the psychological needs of women | Could not have managed without midwife support (LYA10) | Sources of support for women with FOC |
| Formal and informal social supports help to meet the psychological needs of women | Midwife provided emotional support (LYB10) | |

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| Formal and informal social supports help to meet the psychological needs of women | Midwife went beyond expectations (LYB10) | |
| Formal and informal social supports help to meet the psychological needs of women | Midwifes practical support crucial when partner not involved (LA18) | |
| Formal and informal social supports help to meet the psychological needs of women | Partners provide active support in birth process (NI15, WA17, LA18) | |
| Formal and informal social supports help to meet the psychological needs of women | Peer support- women of the same gestation and parity (WA17) | |
| Formal and informal social supports help to meet the psychological needs of women | Practical Support (LYA10, NI15) | |
| Formal and informal social supports help to meet the psychological needs of women | Speaking to other women with FOC (WA17) | |
| Formal and informal social supports help to meet the psychological needs of women | Working with other women helped to process the fear (WA17) | |
| Re-framing the emotions about the birth process | Belief in the staffs competence or skills (LYA10, LYB10, RA11, NI15, LA18) | Perceived benefits of the intervention |
| Expressing the emotion of fear with others helped | Benefits of group therapy (WA17) | |
| Tolerance of Uncertainty | Coping at times of uncertainty or when things didn't go as expected (LYA10, LA18) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Clinicians need to be non-judgemental about FOC (LYB10, RA11) | |
| Expressing the emotion of fear with others helped | Communicating the fear (LYB10, RA11, WA17, LA18) | |
| Expressing the emotion of fear with others helped | Communicating the fear with their partner (WA17, LA18) | |
| Developing emotional strength and self-efficacy | Developing power and pride (NI15, WA17) | |
| Developing emotional strength and self-efficacy | Developing self-confidence or self-efficacy (RA11, NI15, WA17, LA18) | |
| Developing emotional strength and self-efficacy | Emotional preparation for birth (RA11, NI15) | |
| Strengthening bonds with partner and baby | Facilitated bonding with baby (NI15, LA18) | |
| Strengthening bonds with partner and baby | Facilitated dialogue with partner (WA17) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Felt listened to (LYA10, LYB10, RA11, LA18) | |
| Re-framing the emotions about the birth process | Gained hope (LYB10, NI15, WA17) | |
| Developing emotional strength and self-efficacy | Gaining control of the birth process (LA18) | |

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| Gaining Knowledge | Gaining insight into reasons for the fear (LYB10, RA11, LA18) | |
| Tolerance of Uncertainty | Gaining more certainty (NI15) | |
| Gaining Knowledge | Gaining knowledge (LYA10, NI15, LA18) | |
| Developing emotional strength and self-efficacy | Getting through the birth (RA11, LA18) | |
| Strengthening bonds with partner and baby | Help partner to understand FOC (WA17) | |
| Expressing the emotion of fear with others helped | Helping others to understand FOC (RA11, WA17) | |
| Expressing the emotion of fear with others helped | Intervention helped the woman to open up (RA11, WA17, LA18) | |
| Developing emotional strength and self-efficacy | Intervention as an emotional process (LYB10, RA11, WA17) | |
| Developing emotional strength and self-efficacy | Improved self-confidence in other areas of life (LA18) | |
| Re-framing the emotions about the birth process | Letting the fear go (WA17, LA18) | |
| Developing emotional strength and self-efficacy | Learned to manage the fear (it didn't disappear) (LA18) | |
| Developing emotional strength and self-efficacy | Managing the emotion (RA11, LA18) | |
| Gaining Knowledge | Making the birth real (NI15, WA17) | |
| Gaining Knowledge | Moving forward from the previous birth experience (LA18) | |
| Re-framing the emotions about the birth process | No worries or fears after the intervention (LA18) | |
| Expressing the emotion of fear with others helped | Normalised the emotion of fear (LA18) | |
| Gaining Knowledge | Prepared for birth-knowing what to expect (LYA10, NI15, LA18) | |
| Gaining Knowledge | Prepare for the birth (LYA10, LYB10, NI15, LA18) | |
| Formal and informal social supports help to meet the psychological needs of women | Present during the birth (LYB10, RA11, NI15) | |
| Gaining Knowledge | Processing the previous birth experience (LYA10, LYB10, LA18) | |
| Re-framing the emotions about the birth process | Reflecting on the fear (RA11, LA18) | |
| Re-framing the emotions about the birth process | Re-framing their feelings about birth from negative to positive (NI15) | |
| Developing emotional strength and self-efficacy | Sense of control over decisions and choices during birth autonomy (LA18) | |
| Expressing the emotion of fear with others helped | Sharing feelings/ Sharing the problem (LYB10, RA11, NI15, WA17, LA18) | |
| Formal and informal social supports help to meet the psychological needs of women | Speaking to other women with FOC (WA17) | |
| Strengthening bonds with partner and baby | Supported partner as well (LYB10, NI15) | |
| Re-framing the emotions about the birth process | Turning negative thoughts around (NI15, WA17, LA18) | |

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| Gaining Knowledge | Team midwife gave information r/t pregnancy & birth (LYA10, LA18) | |
| Developing emotional strength and self-efficacy | Thought process between sessions (WA17) | |
| Formal and informal social supports help to meet the psychological needs of women | Team midwife provided additional support, gave extra time (LYA10) | |
| Re-framing the emotions about the birth process | Understanding the cause of the fear (WA17, LA18) | |
| Gaining Knowledge | Understanding the previous birth (RA11, LA18) | |
| Gaining Knowledge | Understanding the birth process (LA18) | |
| Developing emotional strength and self-efficacy | Verbalising the fear helps letting go (LA18) | |
| Expressing the emotion of fear with others helped | Verbalising the fear helped the partner to understand (WA17) | |
| Gaining Knowledge | Visiting labour ward made the upcoming birth real (LA18) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Felt could not speak up (RA11) | Women's suggestions for the improvement of interventions for FOC/ Perceived barriers to the effectiveness of interventions |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Felt the gynae did not listen (RA11) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Listen to women (LYB10) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Abusive encounters with maternity staff was traumatic (WA17) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women | Perceived that caregiver did not care about their opinion r/t their birth (RA11, LA18) | |
| Developing emotional strength and self-efficacy | Positive birth experience reduced FOC (LA18) | |
| Interventions meeting or not meeting the wishes of women with FOC | Stressed staff led to perceived lower support (LA18) | |
| Interventions meeting or not meeting the wishes of women with FOC | Traumatic hospital experiences left deep emotional impressions (RA11, WA17) | |
| Need for compassionate, non-judgmental support from maternity staff in order to meet the psychological and emotional needs of women/ Interventions meeting or not meeting the wishes of women with FOC | Wanted to be treated humanely (RA11) | |

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| Interventions meeting or not meeting the wishes of women with FOC | Women may like to be offered the option of other interventions if co-morbid mental health (LA18) | |
| Strengthening bonds with partner and baby | Had positive birth experience but poor bond with baby, felt was not listened to in the antenatal period (RA11) | |
| Strengthening bonds with partner and baby | Poor communication in the antenatal period affected her partner relationship (RA11) | |
| Interventions meeting or not meeting the wishes of women with FOC | Clinicians need to be willing to provide support (LYB10, RA11) | |
| Interventions meeting or not meeting the wishes of women with FOC | Loss of control (LYA10, RA11) | |
| Interventions meeting or not meeting the wishes of women with FOC | Midwife counselling described as superficial (2 women) (LA18) | |
| Interventions meeting or not meeting the wishes of women with FOC | Drop out for unknown reasons (7 women) (NI15) | |
| Interventions meeting or not meeting the wishes of women with FOC | Drop out of icbt due to 'lack of time' (2 women) (NI15) | |
| Need for diverse intervention options for women with FOC | Intervention did not help with other fears like fear of blood or hospitals (NI15) | |
| Interventions meeting or not meeting the wishes of women with FOC | Limited contact with therapist as via the internet (icbt) (NI15) | |
| Interventions meeting or not meeting the wishes of women with FOC | Was not considered expert despite giving birth 3 times before (LYB10) | |
| Interventions meeting or not meeting the wishes of women with FOC | Woman with previous sexual abuse did not feel benefit of intervention as previous traumatic events were not addressed (NI15) | |
| Interventions meeting or not meeting the wishes of women with FOC | Intervention did not improve birth experience (LA18) | |

KEY: Articles coded, LYA10= Lyberg (a) (2010), LYB10= Lyberg (b) (2010), RA11= Ramvi (2011), NI15= Nieminen (2015), WA17= Wahlbeck (2017), LA18= Larsson (2018)

Questions asked of the data

1. *How did women feel before experiencing the intervention for fear of childbirth?*
2. *What interventions are perceived as helpful in maternity care by pregnant women with fear of childbirth?*
3. *How did women feel about the interventions offered to them for fear of childbirth?*
4. *Was the intervention acceptable to women?*
5. *Were women satisfied with the intervention for fear of childbirth?*
6. *Who supported women to cope with fear of childbirth?*
7. *What was good about the intervention?*
8. *How could the intervention be improved? Limitations or barriers of the intervention effectiveness*

Meta-synthesis analysis notes 30/10/2018

| Before the intervention | | During the intervention | | Helpful elements of the intervention | | External factors | | After the intervention | | Women's suggestions for improvement of interventions | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Descriptive theme | Analytical theme | Descriptive theme | Analytical theme | Descriptive theme | Analytical theme | Descriptive theme | Analytical theme | Descriptive theme | Analytical theme | Descriptive theme | Analytical theme |
| At the mercy of someone unknown | Fear | Understanding the previous birth | Reconciling the previous birth | Birth discussion was an opportunity to reconcile | Reconciling the previous birth | Left alone in labour | Lacking the emotional dimension of birth | No worries or fears after the intervention | Reduced FOC | Clinicians need to be non-judgmental about FOC | Non-judgemental care |
| Birth as a private and intimate situation | Fear | Moving forward from the previous birth experience | Reconciling the previous birth | Moving forward from the previous birth experience | Reconciling the previous birth | Not being treated with dignity | Lacking the emotional dimension of birth | Understanding the birth process | Sense of Agency | Clinicians need to be willing to provide support | Willing to provide support |
| Fear of injury of infant | Fear | Birth discussion was opportunity to reconcile | Reconciling the previous birth | Midwife was understanding | Confirming the emotional dimension of birth | Feeling unheard | Lacking the emotional dimension of birth | Coping at times of uncertainty in labour | Sense of Agency | Did not feel listened to | Confirm the emotional dimension of birth |
| Fear of loss of control | Fear | Processing the previous birth experience | Reconciling the previous birth | Emotional preparation for birth | Confirming the emotional dimension of birth | Traumatic hospital experiences left deep emotional impressions | Lacking the emotional dimension of birth | Empowerment | Sense of Agency | Listen to women | Confirm the emotional dimension of birth |
| Feeling trapped during the birth | Fear | A real dialogue between clinician & woman about FOC & birth plan | Sense of Agency | Felt listened to | Confirming the emotional dimension of birth | The importance of how labour ward staff treated them | Lacking the emotional dimension of birth | Taking an active role in decision-making | Sense of Agency | Stress of staff affected support received in labour | Confirm the emotional dimension of birth |
| Feeling vulnerable | Fear | Gaining control over decisions and choices during birth | Sense of Agency | Help partner to understand FOC | Confirming the emotional dimension of birth | Women perceived that the midwife was in control | Lack of Agency | Developing power, pride | Sense of Agency | Positive birth experiences reduced FOC | Aim for positive birth experience |
| Left alone in labour | Fear | Prepare for the birth | Sense of Agency | Intervention helped women to open up | Confirming the emotional dimension of birth | Disempowerment | Lack of Agency | Able to gain a sense of control using techniques learned | Sense of Agency | Helpful to group women in the same gestational | Peer support useful |

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| | | | | | | | | | | week if group session | |
| Not being treated with dignity | Fear | Empowerment | Sense of Agency | Gaining control over decisions and choices during birth | Sense of Agency | Women had other mental health concerns | Intervention did not meet needs of the woman | Normalised the emotion of FOC | Reduced stigma of FOC | | |
| Birth process viewed with uncertainty | Sense of Agency | Loss of control | Sense of Agency | Gaining more certainty | Sense of Agency | Willingness of staff to provide support | Staff willing | Gained hope | Re-framed negative emotions | | |
| Disempowerment | Sense of Agency | Treated as an individual | Sense of Agency | Learned to manage the fear (it didn't disappear) | Sense of Agency | Competency of the midwife | Staff competent | Belief in the staffs competence or skills | Trust staff | | |
| Lack of Agency | Sense of Agency | Women learned techniques to cope | Sense of Agency | Listening to their bodies | Sense of Agency | Availability of midwives | Staff available | Viewing labour pain as having a purpose | Understanding the birth process | | |
| Had negative self-image | Low Self-efficacy | Women perceived that the midwife was in control | Sense of Agency | Prepare for the birth | Sense of Agency | Intervention did not improve birth experience | Birth experience not improved | Turning negative thoughts around | Re-framed negative emotions | | |
| Woman felt she lacked emotional capacity | Low Self-efficacy | Feeling trapped during the birth | Sense of Agency | Taking an active role in decision making | Sense of Agency | | | Coping when things don't go as expected | Safe in the uncertainty | | |
| Caesarean perceived as the solution by women | 'Handling the fear' | Birth on own terms | Sense of Agency | Women learned techniques to cope | Sense of Agency | | | Developing a trusting relationship led to a feeling of security | Safe in the uncertainty | | |
| Unable to picture parenthood | 'Handling the fear' | Developing self-confidence or self-efficacy | Sense of Agency | Developing self-confidence or self-efficacy | Sense of Agency | | | Helped to feel calm, safe | Safe in the uncertainty | | |
| Avoidance | 'Handling the fear' | Take fear seriously | Confirming the emotional dimension of birth | Making the birth real | Understanding the birth process | | | Sensitivity to individual needs | Individualised care | | |
| Communicating the fear was difficult | Expressing FOC | Confirmed my emotional dimension | Confirming the emotional dimension of birth | Could answer my questions | Understanding the birth process | | | Visiting the labour ward made the upcoming birth real | Re-framed negative emotions | | |

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| FOC is a burden for women | Expressin g FOC | Emotional preparation for the birth | Confirming the emotional dimension of birth | Team midwife gave information about pregnancy and birth | Understandin g the birth process | | | Visualising the baby | Connecting with the baby | | |
| Sharing the problem | Expressin g FOC | Midwife was understanding | Confirming the emotional dimension of birth | Sharing feelings | Expressing FOC | | | Partners provided active support in the birth process | Empowered partners | | |
| | | Felt listened to | Confirming the emotional dimension of birth | Sharing the problem | Expressing FOC | | | Satisfied with the intervention | Satisfaction with the intervention | | |
| | | Sensitivity to individual needs | Confirming the emotional dimension of birth | Letting the fear go | Processing the fear | | | | | | |
| | | Developing a trusting relationship led to a feeling of security | Confirming the emotional dimension of birth | Speaking to other women with FOC | Processing the fear | | | | | | |
| | | Communicatin g the fear was difficult | Expressing FOC | Managing the emotion | Processing the fear | | | | | | |
| | | Normalised the emotion of FOC | Expressing FOC | Thought process between sessions helped get feelings in order | Processing the fear | | | | | | |
| | | Helping others to understand FOC | Expressing FOC | Turning negative thoughts around | Processing the fear | | | | | | |
| | | Sharing the problem | Expressing FOC | Painting promoted inner healing processes | Processing the fear | | | | | | |
| | | Speaking to other women with FOC | Expressing FOC | Feel safe in the uncertainty | Safe in the uncertainty | | | | | | |

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|---|---|---|---|---|---|---|---|---|---|---|
| | Sharing feelings | Expressing FOC | Viewing labour pain as having a purpose | Understanding the birth process | | | | | | |
| | Letting the fear go | Expressing FOC | Treated as an individual | Individualised care | | | | | | |
| | Gaining more certainty | Safe in the uncertainty | Partners provide active support in birth process | Empower partners | | | | | | |
| | Coping at times of uncertainty in labour | Safe in the uncertainty | Facilitated bonding | Connecting with baby | | | | | | |
| | Feel safe in the uncertainty | Safe in the uncertainty | Practical support | | | | | | | |
| | Practical Support | Safe in the uncertainty | | | | | | | | |
| | Partners provide active support in the birth process | Empower partners | | | | | | | | |
| | Supported partner as well | Empower partners | | | | | | | | |
| | Team midwife gave information about pregnancy and birth | Information support | | | | | | | | |
| | Could answer my questions | Information support | | | | | | | | |
| | Intervention as emotional process | Processing the fear | | | | | | | | |
| | Gaining insight into reasons for the fear | Processing the fear | | | | | | | | |
| | Turning negative thoughts around | Processing the fear | | | | | | | | |
| | Thought process between sessions- | Processing the fear | | | | | | | | |

| | | | |
|---|---|---|---|
| | getting feelings in order | | |
| | Visiting the labour ward made the upcoming birth real | Processing the fear | |
| | Working with other women helped to process the fear | Processing the fear | |
| | Learned to manage the fear (it didn't disappear) | Processing the fear | |
| | Facilitated bonding | Connect with baby | |
| | Visualising the baby | Connect with baby | |

Meta-synthesis analysis notes 30/10/2018

| Categorical code | Before the intervention | During the intervention | After the intervention | Helpful elements of the intervention | External factors | Women's suggestions for improvement of interventions |
|---|---|---|---|---|---|---|
| Analytical Theme | Fear | Reconciling the previous birth | Reduced FOC | Reconciling the previous birth | Availability of midwives | Non-judgemental care |
| Analytical Theme | Lack of Agency | Sense of Agency | Sense of Agency | Sense of Agency | Lack of Agency | |
| Analytical Theme | Low Self-efficacy | Confirming the emotional dimension of birth | Reduced stigma of FOC | Confirming the emotional dimension of birth | Lacking the emotional dimension of birth | Confirming the emotional dimension of birth |
| Analytical Theme | Expressing the FOC | Expressing the FOC | Trust staff | Expressing FOC | Staff willing to provide support | Staff willing to provide support |
| Analytical Theme | | Information support | Understanding the birth process | Understanding the birth process | Staff competent | |
| Analytical Theme | 'Handling the fear' | Processing the fear | Re-framed negative emotions | Processing the fear | Birth experience not improved | Aim for positive birth experience |
| Analytical Theme | | Safe in the uncertainty | Safe in the uncertainty | Safe in the uncertainty | Intervention did not meet the needs of the woman | Peer support useful |
| Analytical Theme | | | Individualised care | Individualised care | | |
| Analytical Theme | | Empower partners | Empowered partners | Empower partners | | |
| Analytical Theme | | Connecting with baby | Connecting with baby | | | |
| Analytical Theme | | | Satisfaction with the intervention | | | |

Meta-synthesis analysis 06/11/2018

| **Theme 1-**<br>The process of owning the fear | | **Theme 2 :**<br>Growing in self-belief | | **Theme 3:**<br>Managing the fear with a sense of safety | |
|---|---|---|---|---|---|
| ***Subtheme*** | ***Subtheme*** | ***Subtheme*** | ***Subtheme*** | ***Subtheme*** | ***Subtheme*** |
| *Acknowledging the fear* | *Identifying the fear* | *Internal Agency* | *External factors –*<br><br>*engaged clinicians & partners* | *Coping in times of uncertainty* | *Feeling empowered* |
| Communicating the fear was difficult | Fear of injury of infant | Developing self-confidence and self-efficacy | A real dialogue between clinician & woman | Viewing labour pain as having a purpose | Taking an active role in decision-making |
| Birth process viewed with uncertainty | Fear of loss of control | Gaining control over decisions and choices during birth | Birth discussion was opportunity to reconcile | Belief in the staffs competence and skills | Helped to feel calm, safe |
| Unable to picture parenthood | Feeling trapped during the birth | Gaining insight into reasons for the fear | Developing a trusting relationship | Able to gain a sense of control using techniques learned | Gained hope |
| Not being treated with dignity | Feeling vulnerable | Gaining more certainty | Felt listened to | Willingness of staff to provide support | Developing a trusting relationship led to a feeling of security |
| Lack of Agency | Being Left alone in labour | Thought process between sessions-getting feelings in order | Midwife was understanding | Emotional preparation | No worries or fears after the intervention |
| Negative self-image | Lacking emotional capacity | Turning negative thoughts around | Take fear seriously (is this midwives/clinicians?) | Feel safe in the uncertainty | Turning negative thoughts around |
| Midwife in control | Feeling unheard | Understanding the previous birth | Treated as an individual | | Helped women to open up |

| | | | | | |
|---|---|---|---|---|---|
| Competency and availability of the midwife | Not being treated with dignity | learned techniques to cope | Working with other women helped to process the fear, sharing feelings, share problem | | |
| Previous Traumatic experiences left deep emotional impressions | | Visualising the baby | Supportive partner | | |
| Feeling trapped during the birth | | Painting promoted inner healing processes | Sensitivity to individual needs | | |
| | | Normalising the emotions of the fear | Visiting the labour ward | | |
| | | Managing the fear is emotional process | | | |
| | | Developing power, pride | | | |
| | | Learning to trust in others and self | | | |

# Appendix 10 Dissemination of Work

## Appendix 10.1. Peer-reviewed PhD-related publications

**Portable Document Formats (PDFs) available at the following DOIs:**

**O'Connell M.,** Leahy-Warren P., Khashan A.S., Kenny L.C. Tocophobia–the new hysteria? (2015) *Obstetrics, Gynaecology & Reproductive Medicine* 25 (6):175-7. doi.org/10.1016/j.ogrm.2015.03.002

**O'Connell M.A.**, Leahy-Warren, P., Khashan, A.S., Kenny, L.C. and O'Neill, S.M. Worldwide prevalence of tocophobia in pregnant women: systematic review and meta-analysis. (2017) *Acta Obstetrica Gynecologica Scandinavica.* (96) 907-20. doi:10.1111/aogs.13138

**O'Connell M.** Collaboration on fear of childbirth. (2017) *British Journal of Midwifery.* Dec 2; 25 (12):808-9. doi:10.12968/bjom.2017.25.12.808

**O'Connell M.A.** Repealed the Eighth. (2018) *British Journal of Midwifery.* July; 26 (7): 428-33. doi.org/10.12968/bjom.2018.26.7.428

**O'Connell M.** Repealing the Eighth. (2018) *British Journal of Healthcare Assistants.* Aug 2; 12(8):405-11.

**O’Connell M.,** Leahy-Warren, P., Khashan, A.S., Kenny, L.C., and O’Neill, S.M.) Fear of childbirth in Focus (Re: Sixty Seconds on...tokophobia) (2018) *The BMJ* September; 362: k933. doi.org/10.1136/bmj.k3933

**O’Connell M.A.,** Leahy-Warren, P., Kenny, L.C., O’Neill, S.M., Khashan, A.S. The prevalence and risk factors of fear of childbirth among pregnant women: A cross sectional study in Ireland. (2019) *Acta Obstetrica Gynecologica Scandinavica*. doi:10.1111/aogs.13599

**O’Connell M.A.,** Leahy-Warren, P., Kenny, L.C., Khashan, A.S. Pregnancy outcomes in women with severe fear of childbirth. (2019) *Journal of Psychosomatic Research*. 120 , 105-109. doi.org/10.1016/j.psychores.2019.03.013

**O'Connell, M.A.,** O'Neill, S.M., Dempsey, E., Khashan, A.S., Leahy-Warren, P., Smyth, R.M. and Kenny, L.C. Interventions for fear of childbirth (tocophobia). (2019) *Cochrane Database of Systematic Reviews*, May 2, (5). doi.org/10.1002/14651858.CD013321

**O'Connell M.A.,** Preventing, recognising, and responding to fear of childbirth and birth trauma. (2019) *The BMJ.* May 24; 365:l2279. doi.org/10.1136/bmj.l2279

**Appendix 10.2. Conference presentations**

**O'Connell M.A.** Fear of Childbirth. Invited Speaker at The International Forum for Well-Being in Pregnancy (IFWIP) HOPE December 10 event to raise awareness of Perinatal Mental Health in the UK Parliament, House of Commons. *London, United Kingdom. 2018.*

**O'Connell, M.A.** Three key things you should know about Tocophobia. Invited presentation at Grand Rounds for all health care professionals at Cork University Maternity Hospital. *Cork, Ireland. 2018.*

**O'Connell, M.A.** Three key things you should know about Tocophobia. Invited presentation at a Birth Trauma Study Day for all health care professionals at Guy's and St. Thomas' Hospital. *London, United Kingdom. 2018.*

**O'Connell, M.A.** An exploration of tocophobia in an Irish maternity setting. Invited speaker at INFANT Centre Research Seminar. *Cork, Ireland. 2018.*

**O'Connell, M.A.**, Leahy-Warren, P., O'Neill, S.M., Khashan, A.S. and Kenny, L.C. The prevalence of tocophobia and associated risk factors: Findings from an Irish Cross-Sectional Study Shortlisted for Jacqueline Horgan Bronze Medal at the Royal Academy of Medicine Ireland. *Dublin, Ireland. 2017.*

**O'Connell, M.A.**, Leahy-Warren, P., Kenny, L.C, O'Neill, S.M., and Khashan, A.S. Prevalence and associated risk factors of tocophobia in an Irish population INFANT Research Day *Cork, Ireland. 2017.*

**O'Connell, M.A.**, Leahy-Warren, P., O'Neill, S.M., Kenny, L.C. and Khashan, A.S. What is the prevalence of tocophobia in an Irish cohort of pregnant women? World Congress for Women's Mental Health *Dublin, Ireland. 2017.*

**O'Connell M.A.** Tocophobia: A contemporary perinatal mental health issue. Women's Health at King's College London Maternal Health Research Group *London, United Kingdom. 2016.*

**O'Connell, M.A.**, Leahy-Warren, P., Kenny, L.C., Khashan, A.S., and O'Neill, S.M., A systematic review of the global prevalence of tocophobia. Society for Reproductive Investigation (SRI) *Montreal, Canada. 2016* [Poster Presentation].

**O'Connell, M.A.**, O'Neill, S.M., Leahy-Warren, P., Khashan, A.S. and Kenny, L.C. The global prevalence of tocophobia: A Systematic Review and Meta-Analysis. Shortlisted for the Jacqueline Horgan Bronze Medal at the Royal Academy of Medicine Ireland. *Dublin, Ireland. 2015.*

**O'Connell, M.A.** Tocophobia in an Irish Context: establishing an evidence-base for tocophobia care in pregnant women. Health Research Board. *Dublin, Ireland. 2016* [Shortlisted for a HRB Research Training Fellowship for Health Professionals]

## Appendix 10.3 Other Achievements

### Funding & awards

2017 Shortlisted for the Jacqueline Horgan Bronze Medal Award at the Royal Academy of Medicine Ireland

2017 COST Birth Action IS1405 Short Term Scientific Mission Award to visit Uppsala University, Sweden €1,200

2016 Health Research Board Cochrane Training Fellowship €66,478

2015 College of Medicine & Health University College Cork Travel Bursary €1,000

2015 Shortlisted for the Jacqueline Horgan Bronze Medal Award at the Royal Academy of Medicine Ireland

2014 Finalist Doctoral Showcase, University College Cork

### Student mentorship

2015 Michelle McCarthy (Medicine)

2015 Kristina Mendelis (Public Health)

2015 Nicola Kelleher (Public Health)

2016 Eimear Carr (Public Health)

### Online blog web publications

#wearedelivering Academic Midwives

[http://humansofirishmaternity.simplesite.com/434027122]

The Irish Examiner Readers Blog: Bar must be raised for expectations of birth

[https://www.irishexaminer.com/breakingnews/views/yourview/readers-blog-bar-mustbe-raised-for-expectations-of-birth-846058.html]

Tocophobia (Tokophobia) Co-authored blog with Dr Raja Gangopadhyay https://www.ifwip.org/tocophobia-tokophobia/

## Other contributions

2018 Top 10 UK Nurses and Midwives (Number 8). Tweet about nursing & midwifery.

2018 Peer Reviewer 'Midwifery' and 'Journal of Psychosomatic Research'.

2018 Founder member of the Irish Maternity Experience #IrishMatExp in Galway

The Irish Maternity Experience is a grassroots campaign which started in the UK.

It aims to:

- Encourage and empower users of maternity services to join conversations about their experiences of maternity care, and what really makes a difference to that experience.
- Get health care professionals (in and beyond the NHS) and local communities to listen and work in partnership with women and families to improve maternity experiences.
- To enable anyone to take action to improve maternity experience, however big or small, whoever you are: user, partner, community group or hospital staff.

I designed a poem for The Maternity Experience with the aim of starting discussions on tocophobia in co-production/ co-design groups which aim to improve maternity services in the UK and Ireland. The poem has been distributed as part of a package of perinatal mental health resources in over 50 maternity units.

2017 Board of Advisors IFWIP (International Forum for Well-being in Pregnancy) www.ifwip.org

2017 Co-host live Twitter chat on #IrishMed 'The Demographic Timebomb

Various outreach events as part of working with INFANT Centre 2014-2018

[including two Smart Futures #scicomm schools visits]

2015 to 2018 Member of the Postgraduate Society of UCC College of Medicine and Health

Founder member of the "SPEAK" Public Speaking group as part of the Postgraduate Society of UCC College of Medicine and Health

## Modules and Other training

***University College Cork Postgraduate Modules***

PG 7016 Systematic Reviews for the Health Sciences

PG 6001 STEPS Scientific Training for Postgraduate Research Students

ST 6013 Statistics and Data Analysis for Postgraduate Research Students

PG 6003 Teaching and Learning Module for Graduate Studies (Result: Well Achieved)

PG 6012 Scholarly approaches to Teaching & Learning

(Result: Well Achieved)

***Other Training***

2018: Cochrane Review training RA3 and RA4

2017: Infant Mental Health Master-class Cork University Maternity Hospital (2 day)

2017: Kingston University Qualitative Research Summer School (1 week)

2017: Cochrane Review training RA 1 and RA 2

2017: K2MS Perinatal Training Programme (online) [CPD] Intra-partum CTG, Acid base and fetal physiology, antepartum haemorrhage, postpartum haemorrhage, breech [CPD]

2017: Carr Communications: Leadership Workshop

2016: Cochrane 2 day short course at University College Cork

2016: Fistral Training and Consultancy: Prince 2 Project Management in the real world

2016: GCP E6 Refresher course (HRB-CRF) [15/12/2016]

2016: University College Cork: SPSS Software 2 day workshop

2016: Training in MNCMS maternal e-health notes

2014: GCP Training (HRB-CRF/ ICRIN)

**Appendix 10.4 RCM Twitter Chat 2016 Analytics and Wordcloud**


Total contributers: 48 Total tweets: 769 Total reach: 3,593,503

**Appendix 10.5 Perinatal Mental Health Resource poem distributed to over 50 NHS units in the UK and Ireland via The Maternity Experience #MatExp (Co-author Gill Phillips)**

# INDESCRIBABLE FEAR

I see the other mums, the bumps, the smiles.
Everyone chatting and laughing.
The NCT class, learning about the ins and outs of birth.
I close my ears.

I lie awake at night. Indescribable fears.
Something awful is going to happen
To me or my baby during childbirth.
The voice plays over and over.
I just know it.
I turn up at appointments, numb, terrified. I try not to show it.

I'm given IV fluids as I cannot eat or drink.
My friends want to throw a baby shower party.
I get angry.
We need to wait and not tempt fate.
There is nothing yet to celebrate.

I ask for a c-section.
The midwife scoffs and just can't understand what I'm afraid of.
My thoughts race but I can't speak.

I look to the future.
The three of us paddling in the sea, playing with his cousins.
But I just can't see it.
This crippling fear of birth which I've always had.
It's driving me mad.

*Inspired by Maeve O'Connell @thelovelymaeve*

**Appendix 10.6 Collaboration on Fear of Childbirth**

Report

# Collaboration on fear of childbirth

*In Ireland, as in many other countries, perinatal tocophobia is an under-explored condition. With EU funding, Maeve O'Connell travelled to Sweden to meet the midwives helping expectant mothers*

Last year, at a conference held in Trinity College Dublin, I attended a presentation by a Swedish midwifery researcher, Professor Ingegerd Hildingsson. She presented her research findings on fear of childbirth, an area she has been researching for over 15 years, and spoke about well-established clinics for women with fear of childbirth in Sweden. Although the clinics were not preceded by an randomised controlled trial, they were set up in the 1990s by the Aurora Midwives—a team of midwifery professionals who saw a need for them. They meet women and talk through their fears, creating birth plans with them and providing reassurance. Women have evaluated their care positively, and have had good birth experiences and fewer caesarean births.

I was intrigued; I had read about these midwives in the literature and was keen to learn more, as my PhD is on tocophobia (severe fear of childbirth) in Ireland.

After the presentation, I introduced myself and we talked about the research that I have carried out to date. I am the first person to research tocophobia in Ireland, where we have no dedicated service. Much of the research focus has been related to the fact that women with tocophobia may often request a caesarean section. But in addition, I see tocophobia as a perinatal mental health issue, because evidence suggests women with tocophobia are more likely to have pre-existing mental health issues, such as anxiety and depression, and are more likely to have postnatal depression and post-traumatic stress disorder (PTSD) after the birth. We know that women with low social supports are more likely to experience tocophobia, making already vulnerable women even more so.

Maeve O'Connell
Research midwife, PhD student and Health Research Board Cochrane Fellow, Irish Centre for Fetal and Neonatal Translational Research (INFANT Centre), University College Cork

Professor Christina Rubertsson, Professor Ingegerd Hildingsson, Maeve O'Connell, Ingela Tegman, Marianne Kordel and Dr. Elin Ternstrom at Uppsala University

Public perinatal mental health services are greatly lacking and under-resourced globally. In fact, in Cork, where I am based, there no specific perinatal psychiatrist in a hospital with approximately 8000 births per year. In Ireland, the three (part-time) perinatal psychiatrists are based in Dublin, so services are considerably over-stretched. The 2016 National Maternity Strategy has called for additional awareness, screening and support for perinatal mental health in Ireland.

Tocophobia may have an impact on women's psychological and physical health. Women may have panic attacks, insomnia and nightmares; catastrophise pain and birth outcomes; or may fear for their infant's life, among other things. Fear of childbirth has been recognised as a psychological domain in its own right and it may have a similar action as stress in pregnancy. There is good evidence from a large epidemiological population-based study in Finland that, in women without a history of depression, women with fear of childbirth are almost three times as likely to develop postpartum depression. Moreover, fear of childbirth has been associated with longer labours, caesarean births, and greater use of epidural; and may influence infant bonding, attachment and partner relationships. I led a team of researchers who carried out a systematic review and meta-analysis which looked at the global prevalence of tocophobia and we found that it may affect up to 14% of women. It also appears to have become more prevalent since 2000. However, we found that prealence rates reported varied widely, from 3.7-43%, which may be attributed to a lack of an agreed definition.

I heard about the European Cooperation in Science and Technology (COST) programme, an EU-funded scheme that facilitates researchers to set up interdisciplinary research networks abroad, and I felt that collaboration with Professor Hildingsson would be a fantastic opportunity, both for my research and to progress the body of knowledge on fear of childbirth. I put together an application with the support of Professor Hildingsson in March, and was delighted when I was awarded the travel bursary in April this year.

Uppsala is a beautiful university city in Sweden. It has a population of about 200 000 people, with approximately 2500 births per year. Professor Hildingsson gave me a warm welcome, which included the Swedish tradition of *fika* (coffee and cake). During my trip, I had the opporunity to meet with the women's health team at Uppsala University, and took a trip to Sundsvall, a city north of Uppsala, to visit the Aurora midwives.

On Monday afternoon, I presented my PhD work to a group of researchers and two Aurora midwives, Ingela Tegman and Marianne Kordel. Meeting them face-to-face was a wonderful experience, and we had great discussions about our research and our experiences of working with women with fear of childbirth. It was amazing to feel such passion and dedication to women's health in one room. This was a crucial part of the research process: hearing about their research first-hand and discussing the challenges met throughout. It became obvious to me that although we are working in completely different parts of the world, the women are the same—and many of the issues are, too.

> We are a group of researchers with a common goal, to improve women's health and well-being and to deliver a positive birth experience for women so that families have the best start in life

I then met with Dr Annika Karlstrom and Dr Birgitta Larsson in Sundsvall, a picturesque coastal town 395 km north of Stockholm, which is home to the Aurora midwives. The unit has approximately 1700 births per year, and the midwives here offer midwife-led counselling for women with fear of childbirth. Birgitta was one of the founding Aurora midwives and recently defended her thesis, entitled: "Treatment for childbirth fear with a focus on midwife-led counselling". She explained that the midwives have no formal counselling education, and they are usually midwives from the labour ward who express an interest in working with women with fear of childbirth.

These counselling sessions normally happen from about 25 weeks, and last 1 hour. The partner may or may not be present, and there can be two or three sessions, depending on the woman's needs. At times, if the fear is very severe, or the woman has other mental health issues, a referral may be made to a perinatal psychiatrist for additional support. The counselling focuses on describing the birth process, delivering antenatal education, and ensuring that women's fears and stories are listened to. The women are given resources, such as breathing techniques and other relevant antenatal information. Ensuring that women have a good understanding of the normal birth process is very important.

The trip reminded me of the saying, 'If you want to go fast, go alone; if you want to go far, go together.' We are a group of researchers with a common goal: to improve women's health and wellbeing and to deliver a positive birth experience for women, so that families can have the best possible start in life. ■