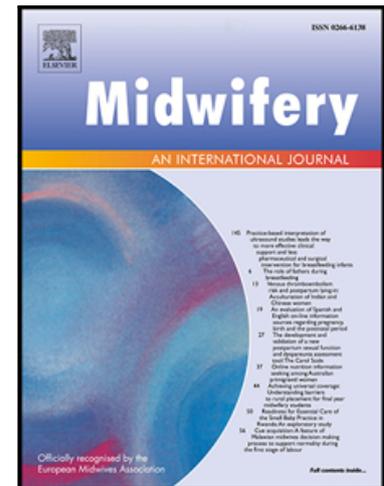


RECONSIDERING FEAR OF BIRTH: LANGUAGE MATTERS

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To the Editor of Midwifery Journal

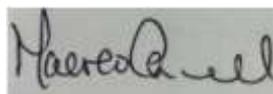
Re: RECONSIDERING FEAR OF BIRTH: LANGUAGE MATTERS

Dear Deb,

We have pleasure in submitting this paper for consideration in your journal. We confirm that this work is original and has not been submitted for publication elsewhere. In this paper we urge clinicians to reconsider the widespread use of the term 'tocophobia' and consider the use of specific screening for fear of birth. We believe this paper will be of interest to your readership with its woman-centred focus and implications for midwifery and obstetric practice.

Kind regards, Maeve

Maeve O'Connell



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**Title Page** RECONSIDERING FEAR OF BIRTH: LANGUAGE MATTERS

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## Introduction

Childbirth is an important, meaningful and life changing experience. A joyful and positive experience is hoped for, but it may be considered normal to have some childbirth-related fears during pregnancy since the nature of childbirth is uncertain. Fear can fluctuate during pregnancy and up to 80% of pregnant women experience childbirth-related fear at some point, with fear usually increasing in the latter stages of pregnancy. Being aware of fear of childbirth in pregnant women offers a chance to deliver comprehensive emotional support, aiming to provide a positive birth experience which sets a woman up to be prepared, confident and competent.

In terms of research, in the 1980s in Sweden, high fear of childbirth was identified as an issue for women in pregnancy, impairing their quality of life (Areskog, 1981; Areskog, 1982; Areskog, 1983). Areskog interviewed women and reported that a number attending the antenatal clinic were fearful for their lives, despite declining mortality rates globally and introduced the term 'childbirth anxiety', manifesting in nightmares, psychosomatic symptoms and a request for caesarean section (Calderani et al, 2019; Areskog, 1983). Following on from this, the Swedish team developed a plethora of research and devised the Wijma Delivery Expectancy Questionnaire which aimed to quantify childbirth fear. This measure (Wijma, 1998) is now internationally accepted as the 'gold standard' and has been translated from Swedish and validated in many languages. A cut-off on the scale of greater than 85 is considered 'severe fear' or 'tocophobia'. In 2000 two psychiatrists introduced the term 'tocophobia' in the literature, classifying primary and secondary tocophobia- the former in nulliparous and the latter in multiparous women (Hofberg and Brockington, 2000), but there is lack of clarity on the aetiology and some overlap between anxiety and secondary, post-traumatic stress disorder. An observational, longitudinal study in Italy (Calderani et al, 2019) compared the WDEQA greater than 85 with a DSM psychiatric assessment and found good reliability between Specific Phobia DSM 5 and WDEQA (85 cut-off) and concluded that accurate psychopathological investigation must be administered to women who meet this criterion. Nevertheless, the two terms are not synonymous and while it may give an indication, this tool is not diagnostic although can support a 'diagnosis'.

The Lancet series on Perinatal Mental Health highlighted the importance of mental health in the perinatal period and recognised anxiety, fear and trauma in the spectrum of issues (Howard 2014). The term 'tocophobia' however has been conflated with high to severe fear of childbirth, which we suggest may be inaccurate and have consequences. There is wide variation in reported prevalence rates of tocophobia globally, possibly due to cultural differences, but more likely due to the lack of clarity in definition of the concept, along with inadequacy of screening or measurement tools (Slade et al, 2020; O'Connell et al, 2017). An Irish study using the WDEQA found that more than 40% of first-time mothers and more than 30% of multiparous women have high fear of childbirth (O'Connell et al, 2019). This did not include women at the true phobic end of the spectrum and as levels of fear of childbirth can fluctuate, cross-sectional prevalence studies only capture levels at that timepoint. To treat women with tocophobia and

provide adequate support to meet individual needs, there needs to be an understanding of the aetiology. The world has changed significantly since the 1980s with evolving feminism, birth and sexuality rights, access to social media and information. Furthermore, in maternity care we are working towards true collaboration and partnership in shared decision-making with women. A key tenet of this is that women are equal and work in collaboration with clinicians to make decisions about their health care. A request for a caesarean section does not mean a diagnosis of tocophobia. In this paper we would like to reconsider recent evidence in relation to fear of childbirth and widespread use of the term tocophobia.

## Defining fear of childbirth and tocophobia

Fear exists on a spectrum from low to high and in the extreme, phobic fear, with avoidance behaviours which typify a phobic condition. At the phobic end of the spectrum, women may be scrupulous with contraception or resort to the termination of a wanted pregnancy due to severe fear (O'Connell et al, 2015), with little known about the experiences of these women. Most research has focused on fear of childbirth during pregnancy. The terms 'fear of childbirth' (FOC) and more recently 'tocophobia' (or tokophobia) have been used in the academic literature and media, placing them into the public consciousness and creating a context in which women might recognise themselves and wish to seek treatment. The intellectual and clinical challenge is that the labelling of the construct has occurred before the evidence base. A lack of aetiological understanding, limited capacity to effectively assess and limited evidence of effective treatment render this an inherent problem. Tocophobia is more commonly used in a biomedical discourse by clinicians and women, and FOC can encompass a broad range of emotional challenges in pregnancy including anxiety and stress, which may also reflect a spectrum of maternal distress (O'Connell et al 2020; Fontein-Kuipers et al 2015).

Tocophobia and FOC are used interchangeably (O'Connell et al, 2017; Nilsson 2018), which may be inaccurate and unhelpful for pregnant women. However, conversely using these terms may help pregnant women to seek help (Fontein-Kuipers et al 2015). Most pregnant women are likely to experience what could be deemed a rational fear associated with giving birth, especially in a biomedical model of care. Consequently, women may have negative expectations of birth rather than a psychopathological fear. Moreover, the profound complexity of experiential reality is eluded when childbirth is viewed and interpreted in linear terms and dichotomies, becoming social rhetoric in an attempt to rationalise the non-rational (Parratt 2008; Downe & McCourt 2019) and contextual influences must be considered when assessing every individual. Dahlen (2010) argued that perception of fear is misplaced as it could reflect health care professionals' fear rather than women's fears. She posed the question- are women afraid or are we? -and highlighted the importance of relationship-based models of care to reduce fear. Dahlen (2010) also highlighted that while obstetricians reported a rise in maternal request caesarean section, this may be due to a change in obstetric practice with women reporting pressure to have a caesarean. She concluded that we must trust and have faith in women's ability to birth and not be unreasoned by fear and perceived risk (Dahlen, 2010).

Studies confirm that women may have fears related to the birth environment, including unfriendly staff, being left alone in labour and not involved in decisions about their care (Fenwick et al, 2009). In one longitudinal Australian study (n=499), women who experienced both a high level of obstetric intervention in labour and dissatisfaction with their labour were more likely to have post-traumatic stress disorder (Creedy, Shochat and Horsfall, 2001). Antenatal variables including social support, childbirth preparation, obstetric risk and anticipatory anxiety did not predict trauma symptoms (Creedy, Shochat and Horsfall, 2001). This has implications for practice and emphasises the importance of being treated with kindness, respect and involvement in decision-making. A survey from Switzerland (Oelhafen et al, 2021) found that a quarter of women experienced informal coercion in labour, with migrant women particularly affected, which was associated with postpartum depression. This supports the importance of shared decision-making from an approach which views the woman as equal.

Pathologizing women with 'normal fear' also denies women with severe tocophobia from receiving appropriate treatment, with little research into targeted interventions for women with this specific condition.

## On Routine Screening for FOC

Measuring FOC on a specific scale is convenient from a research perspective, but screening and triaging for women who may require more specialist care may be impractical and a reductionist approach to a complex human experience. By ignoring nuances in women's experiences, the opportunity to transform these may be missed by focusing on the undesired outcome. Maintaining a sense of well-being in the birth process must integrate a sense of the non-rationality, acknowledging the intimacy of the moment and the 'wholeness of the woman' and her boundaries, embodying spirit and soul (Parratt 2008). The Lancet Midwifery Series (2014) highlighted the need to move from fragmented maternity care and focus on identifying and treating pathology, towards a more holistic and whole system, collaborative approach providing responsive, relational and skilled care for all (De Jonge et al, 2021; Cheyney and Peters, 2019; ten Hoop-Bender 2014). In addition, as midwives have to undertake an increasing number of routine assessments in antenatal care, introducing yet another assessment runs the risk of reducing this to a 'tick-box' exercise.

In clinical practice, mental health screening is a relatively poorly developed skill relying on a midwife's personal characteristics, interest in the area and experience. It may be more reasonable to ask women about the broader construct of antenatal emotional health and well-being, rather than stressing one construct using a non-fragmented approach (Fontein-Kuipers et al 2015; Jomeen 2004). One systematic review concluded that preventive antenatal interventions for maternal distress are not effective and antenatal interventions per se show little effect (Fontein-Kuipers et al 2014). A more recent systematic review of antenatal interventions for maternal distress described more promising results, showing reduced depression and anxiety symptoms (Fassaie et al, 2020). It could be hypothesised that asking

women more broadly about their emotional well-being will encompass fear of childbirth in the absence of definitive evidence to support introduction of screening for FOC.

## Is it normal to have fear of childbirth during pregnancy? If not, at what level of fear do women need support? How can we distinguish 'normal fear' from phobia?

Fear of childbirth comes under the umbrella of anxiety disorders, but fear is a separate concept to anxiety. There is a physiological response to fear known as 'fight or flight' where when faced with a fear stimulus, the fear centre in the brain, the amygdala, is triggered. Stress hormones are released and an individual's decision-making capacity affected. This has implications for women with fear of childbirth during pregnancy and in labour. Pregnant women with high FOC avoid talking about the pregnancy and birth, this disengagement potentially leading to reduced infant attachment or difficulty in psychological transition to parenthood. In addition, anxiety may cause fear of childbirth and fear of childbirth may cause anxiety, perpetuating a cycle if unresolved.

From a philosophical perspective, when women enter labour there is a physical and emotional threat to their integrity and they tread a border between life and death, uncertain as to whether they will emerge intact. Thus, it is usual for women to feel fearful because they value their own lives and those of their unborn babies. Some theorists argue that the developed world is entrenched in fear and to be fearful in dangerous situations is normal and sensible (Hall, 2008), and fear which becomes all-encompassing and leading to paralysis in everyday life could be a 'spiritual emergency' (Fahy and Hastie, 2008). Relieving fear of childbirth could be a spiritual need to prevent an existential crisis, where hope is taken away and the individual unable to form trusting relationships (Hall, 2008). From an individual point of view, a person's values and beliefs informs their choices in relation to risk and perceived safety, some women will view hospital as safer, whereas others will feel safer at home. Providing a sense of security and safety is a crucial birth right.

Midwives and obstetricians should work together with women in shared decision-making and ensure at the outset that women are treated as equals. We suggest that in some cases, giving women a 'tocophobia' label may place them 'on the backfoot' disempowering rather than offering agency. The challenge here is language used as fear of childbirth and tocophobia are not synonymous and it may be harmful to aggregate all levels of childbirth fear. As an example, in the UK in early 2021 there were two cases of women diagnosed with 'agoraphobia' where courts ruled in favour of a forced hospital birth as the women were deemed unfit to decide about place of birth (Kitzinger, 2021; Gutteridge, 2021). Inherent in the word 'agoraphobia' is the fact that home is where the person feels safe and secure, a crucial aspect of psychologically safe birthing. In the same month in Ireland, the courts ruled in favour of a forced C-Section for a woman deemed 'mentally ill' (O Faolain, 2021). In precedent, in 2017 there was the first case of a

woman in Ireland having the right to refuse a forced C-Section against her will when she was deemed 'competent' to make a decision (Wade, 2017). The question is how we as midwives support and advocate for women with a mental illness diagnosis in making decisions about their place of birth. Mental illness does not necessarily equate to incapacity to make decisions, but early intervention and planning for birth is critical. In each of these cases, the lack of midwifery input was apparent. While mental illness should not carry stigma, we argue the widespread use of 'tocophobia' which may be stigmatising for women should be reconsidered. Midwives can work with women who have phobias to achieve a positive birth experience by offering continuity of carer and options for place of birth (Ashwin, 2016) as systems fail women when these evidence-based options are not offered. When women have a positive experience of pregnancy, birth and respectful, individualised care they emerge more confident and prepared for motherhood (Hildingsson, Johanssen, Karlstrom and Fenwick, 2013).

More work is needed to diagnose tocophobia, which takes account of a spectrum of fear. Preconceptional and postpartum women should be offered an effective, evidenced-based screen for potential FOC issues. Screening measures should be acceptable to women and robustly evaluated, in addition to reflecting on the strengths and limitations of the current battery of perinatal screening tools. As the phenomenon of FOC is fundamentally anxiety-related, researchers and clinicians working in partnership to develop measures with high sensitivity and specificity need to be aware that the administration of a measure may in itself, induce anxiety. Careful selection of items and attention to detail in the wording could mitigate this.

Emerging evidence suggests negative outcomes associated with high FOC, particularly at its most severe (Dencker et al, 2019). This raises questions about whether there is a need to identify and assess FOC routinely within pathways of maternity care. This sits within the wider context of the increasing focus on perinatal mental health, with guidelines to standardise identification and management of mental health issues across the childbirth spectrum, and an apparent increased willingness among women to report symptoms as the profile of perinatal mental health has increased (Noonan, Doody, Jomeen, & Galvin, 2017; Noonan, Doody, O'Regan, Jomeen, & Galvin, 2018). The challenge with FOC is whether we run the risk of pathologizing a construct that for most women is a normative reaction to pregnancy and birth (Richens, 2018). On a pragmatic level, for clinicians dealing with childbirth-related fear, it is helpful to make a distinction between a level of fear that seems manageable to women on a daily basis, and a level of fear that requires support beyond routine maternity care (Jomeen et al., 2020). It would seem sensible to suggest that identifying tokophobia would facilitate early intervention and support for women, who require it. However, this raises the question of measures to assess tokophobia. That debate also must consider the construct a continuum of FOC or as a distinct phobic pathology.

Current NICE guidance [CG192] on caesarean birth for maternal request directs health care professionals to discuss and record reasons for the request, ensure women have accurate information and to refer women with anxiety or tocophobia for perinatal mental health support as appropriate (National Institute

for Health and Care Excellence (NICE), 2021). This guidance is used in conjunction with CG192 Section 1.8 Interventions for anxiety disorders. Several interventions are recommended in a stepped approach appropriate to need, including CBT self-help with support as first line for women with persistent subthreshold symptoms and high intensity interventions for those with Post Traumatic Stress Disorder symptoms or Social Anxiety (NICE, 2021). However firstly, access to perinatal mental health services is limited for fear of childbirth with just half of units providing relevant care according to a UK national survey in 2015 (Richens, Hindley and Lavender, 2018). Secondly, the availability of interventions may be limited and thirdly, it may be challenging to distinguish the spectrum of childbirth-related fear. Assessment measures benefit from being theoretically and conceptually anchored in the aetiology and presentation of the condition (Slade et al., 2019; Slade, Pais, Fairlie, Simpson, & Sheen, 2016), which at this stage remains unclear. This runs the risk of over assessment and pathologization of FOC, which in turn can lead to stigma for women and placing additional burden on perinatal mental health services.

## Treating fear of childbirth and tokophobia; recognising individual needs

So, let us consider the desired outcome of interventions for fear of childbirth and tokophobia. Fear free birth may not be the norm. Even after interventions for FOC, fear may not resolve as such. The level of fear may or may not be reduced, but women could move from being fearful and disengaged in the birth process, to taking an active and empowered part in their birth. Women manage their fear with a sense of security, feeling prepared and gain control (O'Connell et al, 2020). It could be derived that some women may have fear related to the maternity system which does not meet their needs, rather than fear of birth. Fear of birth can be self-managed but having a sense of trust in the maternity team is imperative. One way of building this trust is relational care from a known midwife/ team. In cases of severe fear, women who participated in randomised controlled trials expressed that interventions like cognitive behavioural therapy, midwifery counselling or art therapy were helpful in working through and managing the fear, peer support can also be useful (O'Connell, Khashan and Leahy-Warren, 2020). The importance of understanding the nature of the fear to individualise care and give women options for treatment to meet their needs was highlighted (O'Connell, Khashan and Leahy-Warren, 2020).

In trials of interventions for FOC including tokophobia to date, primary outcomes have been FOC and caesarean birth preference. No trials of interventions for FOC reported birth satisfaction or anxiety as outcomes and limited studies have measured childbirth self-efficacy. This is surprising considering the overlap between the constructs of fear and anxiety. Interventions for FOC should aim to transform the birth experience and postpartum outcomes through positive preparation for birth, cultivating positive emotions around birth and empowering women to take control, an important variable in terms of psychological outcomes (Jomeen, 2010). A paradoxical situation has been outlined where women need to feel safe and sufficiently in control to allow themselves to be vulnerable to give birth (Hall, 2008). How

can we help women reach this deep level of trust at the most intimate time in their lives? When women are prepared, supported adequately and feel a sense of control as regards decision-making about birth processes, even an emergency which may be perceived to be traumatic may not be experienced as such for women. Furthering our understanding of the complex nuances of women's experiences of FOC and tocophobia and barriers and facilitators of engaging with existing interventions or services is vital to underpin effective intervention development. This may be achieved by involving service users and listening to their opinions.

## Using the label 'tokophobia'

Anxiety is distinct from fear, although the distinction is more attributional than physiological. A certain degree of anxiety around childbirth is normal but fear is a value-laden term and construes a psychobiological dimension invariably perceived negatively. It is not a semantic distinction either because as we know from studies of language use, attributions about an individual will be made based on such terms which can lead to positive and negative evaluations of the individual. Consider 'anxiety of childbirth' (AOC) in contrast to 'fear of childbirth', the terminology makes a difference ('anxiety' contrasted with 'fear' to perception of the phenomenon even though they may be fundamentally the same. Consequently, how might our unconscious biases respond in relation to such terms? Given that unconscious bias influences how we appraise and evaluate a situation, we may in relation to FOC be at risk of pathologising the experience that may be within a range that could be considered normal. This may consequentially have a deleterious impact on the quality of interaction with the woman. That is how a general attributional theory account may be contextualised within FOC. However, despite an extensive body of research in the social sciences in relation to attribution theory more generally, there is a dearth of research within the context of FOC. This is critical given the impact of language use both on perception of the individual and of course the individual's perception of themselves.

There are other examples where inappropriate use of language creeps into the clinical arena which may have consequences for the individual. In clinical practice the word 'tokophobe' has been used. This term emphasises distinctiveness (negatively) rather than normality. The potential impact of stereotyping the individual as not only 'having something wrong with them' but conceptualised within attributional theory accounts a construct that is stable, thus 'once a tokophobe, always a tokophobe'. Great strides have been made in the use and awareness of language in the clinical context because of the influence on individual well-being. For instance the 'language matters' work in Australia which has focused on patients with diabetes (Speight et al, 2021). It is thus incumbent on health professionals to be aware that language can be both empowering and disempowering in the context of FOC and moreover highlights the importance and relevance to undertake research in this area.

## Conclusion/ Implications for practice

The lack of clarity and consensus even amongst experts in the field of the concept leads to the conclusion that more work is required to refine and define the issue. For now, the implications of applying this label in practice should be reconsidered within holistic and person-centred care. Compassion, kindness and respectful maternity care are vital to promote post-partum psychological well-being. Introducing yet another antenatal screening tool may not be necessary for all women, as using a more general emotional well-being assessment may bring issues to the surface. Continuity of carer can provide women a trusting, safe environment for birth. Health care professionals need to offer women emotional support during pregnancy and endeavour to meet their specific needs during labour and birth. Using 'tocophobia' as a label should be done with caution, as it may be construed negatively and potentially affect a woman's self-perception. Further research is needed to better understand aetiology and experience.

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