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Guidance Notes for the Fear of Childbirth/Tokophobia Pathway

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1. Background of the Pathway

Tokophobia is defined as a severe fear of pregnancy and/or childbirth. There is significant evidence that tokophobia may have short and long term consequences for the mother and baby. The condition can be further classified into primary tokophobia (affecting women who have never been pregnant and/or not given birth previously), and secondary tokophobia affecting women who have been pregnant and given birth previously. This second group may include women who have experienced miscarriage.

Severe Fear of Childbirth (FoC) is related to women who express a strong anxiety about birth which has impacted upon their daily functioning.

Some of these women come to the attention of the maternity services when they are requesting an elective caesarean section, due to their fear of the birth process. However, some women are fearful, and are not able or willing to discuss this early in their maternity care.

For some women, their level of fear is not to an extent that they will request a caesarean; however their fears and concerns are significantly impacting upon their functioning, and if left untreated and unsupported there are both short and long term risks to the mother and baby.

The current provision for this cohort of women involves referral to either primary mental health or specialist perinatal mental health services, without any specific guidance on determining appropriate levels of support required for the woman's individual needs. Women are often referred late in pregnancy which means that there is a lack of time in order to undertake an appropriate mental health service and/or offer a psychological intervention. Current practice is demonstrating a lack of consistency in the approach from all services in offering support and psycho-education to this group of women. Mental health professionals had received ad hoc referrals from trusted colleagues rather than having a robust integrated pathway of care.

It is important that staff have an improved level of knowledge and confidence in managing women and have clarity regarding appropriate referral pathways and the need for a multi professional package of care. It is essential that partners and the wider family are included in all aspects of care and feel able to approach health professionals for additional help and support for themselves where needed.

2. Aims of the Pathway

The aim is to develop a pathway that will enable equitable support and treatment, as required, to women with Tokophobia / Severe FoC, as they engage with maternity services, at the earliest point in their pregnancy, where booking if possible. This will reduce poor psychological outcomes for the women, her partner, her baby and wider

family, whilst ensuring that all services involved in the care of the woman have robust and clear pathways and processes.

In order for the Pathway to function well, additional training will be given to maternity and wider healthcare staff. Awareness raising amongst other key healthcare professionals such as health Visitors GPs, and core mental health professionals, will be essential.

3. Understanding Tokophobia and Fear of Childbirth

It is common for women to feel anxious about labour and birth. Worries about the pain of contractions, interventions and the uncertainty of the birth process are a frequent aspect of a womans concern particularly as her pregnancy progresses. But for some women, the fear of labour and birth can be so overwhelming that it overshadows their pregnancy and affects daily functioning.

This severe fear of birth is called tokophobia – which literally means a phobia of childbirth. For some women, this also includes a significant fear and avoidance of pregnancy.

Tokophobia can be understood in 2 domains – primary and secondary.

Primary tokophobia occurs in women who have not been pregnant or given birth before. For these women, a fear of birth can be linked to traumatic experiences in their past – including sexual abuse. It can also be linked to witnessing a difficult birth or listening to stories or watching TV programs which portray birth as embarrassing or dangerous. For some women it is unclear why they develop a severe fear of birth.

In **Secondary tokophobia**, women tend to have had a previous traumatic birth experience which has left them with a fear of giving birth again. There may be particular components of the birth that had led to symptoms associated with Post Traumatic Stress Disorder (PTSD), for example severe bleeding, experiencing severe pain, feeling out of control, or not fully supported by the maternity team.

It is difficult to say how common tokophobia is. Research suggests that between 2.5% and 14% of women are affected by tokophobia. But some researchers believe this figure could be as high as 22%. How tokophobia is defined and measured has led to difficulty in determining prevalence rates internationally (Nillson 2018).

4. Morbidity and Mortality

For women with tokophobia there are recognized risks in relation to the mother and baby which should be considered.

To the mother:

- Insomnia/sleeplessness
- Antenatal depression and increased risk of postnatal depression
- Requests for caesarean section
- Longer labours as fear can effect oxytocin production and increased use of epidural analgesia)
- Increased instrumental births
- Post-traumatic stress disorder
- No further pregnancies or large gap between pregnancies
- Subsequent sterilisation
- Risk of self-harm/suicidal behaviour/thinking
- Avoidance of maternity care

To the infant:

- Risk of termination of pregnancy, in order to avoid childbirth or pregnancy itself
- More likely to require neonatal care (intensive or specialist care)
- Impact upon the emotional development of the baby
- Reduced birth weight
- Preterm birth
- Reduced infant – maternal bonding and attachment

5. Identification and Screening

It is normal for women to feel some level of worry or anxiety about childbirth, and routine care is appropriate for these women. It is important to identify women at the earliest stage of pregnancy where an increased level of fear/anxiety about childbirth is present. Professionals may find it helpful to consider asking the woman questions to explore and understand her feelings and belief system relating to childbirth.

Be aware of ambivalence and negative emotions, tearfulness, fear anxiety or the woman's avoidance of appointments with you/your service.

- What are your thoughts/plans for the birth? If the woman requests a caesarean section explore the reasons why.

- Explore attachment/bonding with the baby. This should be explored during pregnancy and postnatal period.

Explore previous experience of childbirth. Consider whether the woman found the birth traumatic. This is often subjective.

6. Outcome Measures for Tokophobia/Fear of Birth

The prevalence of fear of childbirth varies; this may be due in part, to the differing measurement scales or outcome measures (Nillson 2018). To date, the most commonly used outcome measures are the Wijma Delivery Expectancy/Experience Questionnaire (W-DEQ), and the Fear of Birth Scale (FOBS).

The W-DEQ was developed to measure fear of childbirth by means of a woman's cognitive appraisal regarding delivery. It was originally proposed as a 33 item measure, and later recommended as a 25 item measure with subscales which include fear, negative appraisal, loneliness, lack of self-efficacy, lack of positive anticipation and concerns for the child. It has been used in 11 studies, with four different cut-off points; the most commonly used cut-off point is ≥ 85 (Nilsson et al 2018). The revised version of the Wijma (WDEQ-A Revised) is recognised as a measure which can provide researchers with a psychometrically sound tool to explore the differential impact of aspects of childbirth fear (Pallant et al 2016). However a 2 item scale such as the FOBs (Fear of birth scale) (Haines et al 2015) has greater clinical utility.

The FOBs is a two item visual analogue scale that include the constructs of worry and fear. Haines et al (2015) study supports the use of the FOBS measured with a cut point of 54, to identify women with high fear based on the WDEQ-A score of ≥85. When compared with the WDEQ-A, the FOBS has high levels of accuracy with better clinical utility. However, more work in other populations of women is recommended to confirm or adjust the cut-point. The Haines et al (2015) supports the use of the FOBS to open up a conversation between health professionals and women about fears or worries about the pending birth. Nilsson (2018) recommends that future studies on FoC should use either the W-DEQ tool with a cut-off point of ≥85, or a more thoroughly tested version of either the FOBS scale with a higher cut-off point, or a single question such as 'Are you afraid about the birth?'

In a recent study presented at the Society for Reproductive and Infant Psychology (September 2018), 'Identifying fear of childbirth in a UK population; examination of the clarity, acceptability and content validity of existing measurement tools (Sheen et al 2018), none of the measures currently used met the criteria for clarity, acceptability and content validity for measuring fear of childbirth, however the Oxford Worries about Labour Scale (OWLS-9) was considered to be the favoured measure due to its perceived relevance. It is a 10 item scale developed in the UK to assess worries around labour and birth.

7. Risk Factors for Tokophobia

- Subjective experience of previous traumatic childbirth
- Anxious personality types,
- Previous sexual abuse,

- Past traumatic birth or any traumatic experience in health care,
- Previous miscarriages,
- Long duration of infertility,
- Smoking,
- High occupationally functioning
- Low social supports and poor partner relationships
- Difficult adjustments to puberty
- Familial or generational belief that childbirth is dangerous

8. Interventions for Tokophobia

Continuity of Care:

It is key that the women can develop a trusting relationship with her care provider. The evidence suggests strongly that continuity of care is important for women and this continuity should occur with the obstetrician as well as the midwife. This is essential when caring for women who have a heightened level of fear, anxiety and for women who have experienced previous birth trauma.

Our local maternity services provider is developing a specialist multi-disciplinary team who will provide continuity of care to women experiencing tokophobia and women who are under the care of the perinatal mental health liaison team.

The aim is to develop an integrated multi-agency birth plan that the women feels is appropriate for her and takes into account the overall wellbeing of the woman and her baby. The pkan will take into account the concerns and views of the womans partner and other family members where appropriate.

Collaboration with the obstetrician and midwife must be in place in order to discuss and identify options for the birth including taking into account obstetric and psychological risks and benefits for the woman and baby.

- Explaining to women about the birth process, and the body (Psychoeducation).
- Explaining options for birth.
- For some women a discussion/meeting with the anaesthetist will be important, such as severe needle phobia, fear of pain in labour.
- Opportunity to visit the birth environment labour ward or perhaps the theatre
- It is recommended that an assessment of fear of birth, using screening tools to support clinical decision making.

Consider offering at 6 weeks a post-natal follow up to the woman by either mental health services or maternity services where consideration of the woman’s experience of the birth can take place.

9. When to Refer to Mental Health Services

Tokophobia can be assessed by any professional with understanding of perinatal mental health issues, including GP's, Health Visitors, and Social Care staff. Many mild/moderate conditions can be managed with enhanced support from maternity and other related services. A significant proportion of women will benefit from psychological therapy such as counselling or CBT and in these situations can be referred to primary care mental health services.

Women with moderate to severe symptoms of tokophobia or previous birth trauma where Post Traumatic Stress Disorder (PTSD) is suspected are likely to benefit from involvement from the specialist perinatal mental health liaison team, particularly where obstetric liaison is likely to be needed. For example, women who will benefit from joint mental health and maternity appointment or visits to the birthing environment.

It is crucial that a referral for mental health input is made as early as possible, as delay may mean that there is not enough time before the birth to offer a psychological intervention that is appropriate for the woman, or there may not be enough time to develop a mental health birth plan, or visit the birthing environment if required.

10. Psychological Interventions for Tokophobia

For many women in the antenatal period, psychological intervention is the treatment of choice. This includes women with tokophobia. Treatment may take place in primary care (mild -moderate problems) or specialist perinatal mental health liaison services (severe tokophobia with comorbidities or significant risk). Women should be offered evidence based psychological interventions and care based on British Psychological Society (BPS) principles.

This should include:

- Prompt assessment and treatment (assessment within 2 weeks, treatment within 6 weeks of referral).
- Joint working with regular liaison between psychological therapies and maternity staff, to provide an integrated and coordinated care plan that takes account of mental health and obstetric needs.
- Provision of accurate information, psychoeducation and support to the woman, by a professional with comprehensive knowledge of pregnancy, childbirth and the postnatal period.
- Birth planning in pregnancy in conjunction with maternity and psychological services, with consideration to the psychological effect of childbirth and potential outcomes in the postnatal period.

Psychological treatment should be individualised with consideration given to the severity of the problem, comorbidities, stage of pregnancy and risks/ benefits of treating or not.

Psychological intervention should be initiated as soon as possible in the antenatal period in order to maximise the opportunity to effectively treat women prior to childbirth. Women who are referred late in the third trimester are less likely to benefit from psychological intervention due to time limitations. Obstetric liaison and birth planning should take place where there is capacity to do so.

Consideration of the relationship between mother and baby should be a component of any intervention and how this may be affected by fear of childbirth and/or previous traumatic birth experiences. This should be observed both in pregnancy and the postnatal period.

Tokophobia or PTSD symptoms related to birth which are mild/moderate in severity may be treated in Primary Care Psychological services. However if these services are unable to offer timely access to treatment (early intervention) in pregnancy and/or cannot offer the required liaison with maternity services then the woman should be referred to a specialist perinatal mental health liaison team. This may entail joint working between primary care psychological services and specialist teams. If symptoms of Tokophobia or PTSD relating to birth are severe, complex, comorbid with other mental health problems and/or there are high levels of risk to mother and baby these women should also be referred to a specialist perinatal mental health liaison team

11. Guidance for Caesarean Section at Maternal Request Due to Psychiatric or Psychological Reasons

A plan of birth should take into account the maternal and baby's physical and mental health.

Decision making regarding mode of delivery should take place between 32 and 36 weeks of pregnancy by the obstetrician taking into account the woman and the baby's needs and concerns. Where the Specialist Perinatal Mental Health Team is involved they can offer information to help supplement this decision making.

It is essential that a woman's reasons for requesting a caesarean section be taken into account and interventions and care targeted towards her specific needs. For example, a woman requesting a caesarean section due to concerns about a uterine rupture as she has had a previous caesarean section should be provided with information regarding this risk and offered an appointment with the Birth after Caesarean clinic (BAC clinic) at the earliest opportunity. Issues related to specific obstetric risks that women have, cannot be addressed by a mental health team. However if psychological symptoms are present and at a moderate to severe level

then the mental health team may be able to supplement decision making for the woman and the maternity team.

If a women requests an elective caesarean section and there is no clinical justification she should be referred to a specialist midwife, experienced community midwife or primary care mental health team, or in more severe cases the specialist perinatal mental health liaison team who can offer a specific assessment of tokophobia, associated conditions, and identify potential treatment and support needs.

12. Late Maternal Requests for Caesarean Section

All women should be referred for assessment and support from the midwife or/mental health team as soon as concerns about severe fear of childbirth/tokophobia are raised, which will enable time to offer the appropriate interventions and support to the woman. Dependent upon the severity of symptoms if referred late for a psychological intervention there may not be time prior to the childbirth to complete a psychological assessment and treatment.

If women are referred after 35 weeks of pregnancy to the specialist perinatal mental health liaison team, there may not be time for them to be seen for assessment prior to the delivery.

Please take note of the NICE guidelines for maternal request for caesarean section

NICE CG132 Guideline for Caesarean Section

1.2.9 Maternal request for CS

1.2.9.1 When a woman requests a CS explore, discuss and record the specific reasons for the request.

1.2.9.2 If a woman requests a CS when there is no other indication, discuss the overall risks and benefits of CS compared with vaginal birth and record that this discussion has taken place (see box A). Include a discussion with other members of the obstetric team (including the obstetrician, midwife and anaesthetist) if necessary to explore the reasons for the request, and ensure the woman has accurate information.

1.2.9.3 When a woman requests a CS because she has anxiety about childbirth, offer referral to a healthcare professional with expertise in providing perinatal mental health support to help her address her anxiety in a supportive manner.

1.2.9.4 Ensure the healthcare professional providing perinatal mental health support has access to the planned place of birth during the antenatal period in order to provide care.

1.2.9.5 For women requesting a CS, if after discussion and offer of support (including perinatal mental health support for women with anxiety about childbirth), a vaginal birth is still not an acceptable option, offer a planned CS.
1.2.9.6 An obstetrician unwilling to perform a CS should refer the woman to an obstetrician who will carry out the CS

13. Conclusion and Practice examples

Fear of Childbirth and tokophobia occurs on a continuum. For the majority of women some anxiety about the childbirth can be a normal aspect of pregnancy which can be supported and addressed in routine care with the support and information provided from antenatal education/support, and the reassurance and love from their partner and family members.

However, there are some women who will need an enhanced level of information, education, support and psychological treatment. These women's needs and circumstances are varied, as are the levels of fear and anxiety that they experience, and as such the care that they are offered should reflect their individual needs and wishes.

Midwifes, and obstetricians, with input from other support services such as doulas, health visitors and GP's are best placed to offer the majority of women the information and support that they need in order to manage their fear and make decisions about their birth. However in some cases women will need enhanced care from maternity/obstetric services and further support and treatment from either primary mental health care services or the specialist perinatal mental health liaison team.

The Fear of Childbirth/Tokophobia pathway and guidance notes provides health professionals with information and advice on how to identify and screen women with fear of birth and potential interventions and advice that may help (Appendix A).

The following practice examples help to illustrate the kind of help/support/interventions that might be useful in practice.

Practice Example 1

Sam is a 28 year old woman 34 weeks pregnant with her 1st child. She has asked her midwife if she can have a caesarean section for the delivery of her baby. She has missed a number of appointments and it becomes clear that she has high levels of anxiety about the birth and she appears to have been avoiding maternity services, by way of coping with these upsetting feelings. The Specialist Midwife makes a referral to the specialist perinatal mental health liaison team; and the mental health assessment indicates severe fear of childbirth (tokophobia), with a longstanding history of generalised anxiety disorder. Sam's fears and distress appeared to have been escalating as the pregnancy progressed and it is now impacting upon her mood, as she has experienced symptoms of depression over recent weeks. The

specialist perinatal mental health liaison team identifies that due to the late stage of pregnancy there is no time for psychological interventions to be offered before the birth however joint work with the midwife in order to develop birth plan and ongoing support is offered.

A joint appointment with the obstetric consultant and specialist midwife was arranged. The obstetrician arranged an elective caesarean section. Sam will be offered follow up from the specialist perinatal mental health liaison team and offered Cognitive Behavioural therapy in the post-natal period.

Practice Example 2

Ann

Ann is a 37 year old woman who lives in her own house with her husband and 4 children. Ann was not using any contraception prior to her pregnancy.

Her previous obstetric history is of four spontaneous vaginal births without pain relief. At 31 weeks of pregnancy Ann was seen by the obstetric registrar after a referral by the community midwife stating that Ann felt she was having flashbacks and was asking for an elective caesarean section.

She described her last pregnancy as different and more traumatic. The maternity records indicate that she went from 3cms to fully dilated in 3hrs. Ann had an antepartum haemorrhage (APH), which then required that she had continuous fetal monitoring during labour. At the time Ann did not have an epidural.

She presented to the doctor as very anxious about delivery this time and requested an elective caesarean section. The doctor informed her that a vaginal delivery would be the safest form of birth but Ann was adamant at this point that she did not want this because of the anxiety she felt and the effect on her mental health. Ann was referred at this point to the perinatal mental health team for assessment.

Ann had a stable family background, with no history of mental illness herself or in her family.

Ann described having intrusive thoughts/worries, flashbacks and occasional nightmares for a period of 5 months after the birth that she described as traumatic. These symptoms were mostly at night which interfered with sleep. Despite this Ann was able to cope with her responsibilities at home and did not seek help. The symptoms appeared to self-resolve.

At assessment Ann was not found to have any current symptoms of mental health difficulties, aside from mild anxiety and worry regarding the impending birth. Ann expressed at this time that she felt that she would like to pursue a vaginal birth and would like to formulate a birth plan with the aid of a specialist midwife.

Ann was referred by the specialist perinatal mental health liaison nurse back to the specialist midwife for psycho-education. Ann had experienced trauma symptoms

and had anxiety about childbirth. Ann remained tearful when talking about her previous birth experience.

Ann remembers that the last labour was very quick and the contractions started on route to the hospital. Ann states that the contractions were very rapid and close together and didn't allow for a sensation of "getting on top of the pain," as she had been able to do in the previous labours. Ann needed to be continuously monitored, due to an APH, and thought that not being able to move about and adopt more comfortable positions increased her pain. Ann asked for an epidural at three cm, but this was not possible at this point, her labour rapidly progressed which meant that she was too late to have an epidural sited.

The rationale behind when an epidural is sited was discussed and if too early that it could lead to a cascade of interventions. Ann was given information about epidural anaesthesia and about the requirement to continuously monitor the fetal heartrate, during labour.

Ann and her husband were very anxious about this labour and Ann thought that her husband could come across as unfriendly and may question what is happening when they are admitted in labour in order to feel reassured about events.

Birth Plan

- *To consider early assessment when Ann rings up in labour. Ann is very anxious about not getting into hospital in time as she is travelling several miles from a rural village.*
- *If continuous monitoring is required prior to epidural then to consider using telemetry machine, which would allow Ann to adopt comfortable positions.*
- *Ann would like to have an early epidural to manage the pain in this labour.*
- *Keep the couple informed throughout about what is happening at each stage.*

Outcome

Ann had a vaginal birth with an epidural. Ann commented afterwards that she felt she had her fears listened to and addressed which had allowed some control around the birth.

Practice Example 3

Marie is a 37 year old married professional woman 16 weeks pregnant with her first baby. Marie reports she never wanted children but her husband did therefore she re-considered and they planned the pregnancy. She conceived quickly, and felt panic & distress from positive test. Her mood began to deteriorate and she requested referral for psychological help at her booking appointment with the midwife who referred her to the specialist perinatal mental health liaison team.

She was seen at 16 weeks for mental health assessment. She identified high anxiety, fear of childbirth & feelings of revulsion regarding foetal movements and her expanding abdomen. Marie reported feeling as though there was 'an alien growing inside me', but had bonded with unborn baby and thus was also experiencing

feelings of shame and guilt. She reported being scared of her bump growing further and identified several catastrophic thoughts about this. She described being anxious about the sensation of foetal movements and fears of childbirth. She was terrified of having a caesarean section due to her professional medical knowledge but was also frightened of vaginal delivery. She described feeling trapped. Marie was avoiding looking at her bump, she avoided mirrors and any other reflective surfaces. She found it difficult to see pregnant women, or any images/information with any content regarding pregnancy & birth. Her work and family relationships were affected as she found it distressing talking about the pregnancy and was highly anxious people would want to touch her stomach.

Cognitive Behavioural Therapy was initiated immediately with the Specialist Perinatal Mental Health Liaison Team. This comprised of; formulation to generate an understanding of contributing factors in development of Tokophobia and the maintaining factors in here and now. Psychoeducation of Tokophobia as a condition, psychoeducation of anxiety as a normal response (reducing shame).Cognitive work to identify and challenge biases in thinking, identify gaps in knowledge and misinterpretations.

Psychoeducation around the stages of pregnancy and labour.

Exposure work – graded process, looking at images of 'pregnant bumps' videos of foetal movements in utero, touching/stroking own bump, reducing mirror avoidance. At 30 weeks an appointment was made with the Specialist Midwife for Marie and her husband to visit the birth unit, discuss modes of delivery and any fears and concerns. Birth planning took place with the psychological therapist in liaison with maternity and Marie chose to work towards a vaginal delivery. She went into spontaneous labour and laboured at home well with support of her husband. She had a vaginal delivery, assisted with forceps and described the birth as a positive experience. Marie and her baby were physically well and discharged the next day from the ward. A telephone review was conducted at one and two week's post-partum and there were no psychological issues identified. At 4 weeks post-partum Marie attended at clinic for a face to face review. Her mental health was very good, she had no difficulties bonding with baby and expressed no concerns from her about maternal competence. Marie was discharged from the Specialist Perinatal Mental Health Liaison Team

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Appendix 1

Tokophobia Pathway for Hospital or Community Setting