

# Tokophobia Pathway

Greater Manchester Mental  
Health

To be read in conjunction with the:

Pan-London Perinatal Mental Health  
Best Practice Toolkit: Fear of Childbirth  
(Tokophobia) and Traumatic Experience  
of Childbirth

Greater Manchester & Eastern Cheshire  
Antenatal and Postnatal Mental Health  
Guide

## Contents

<b>Introduction</b> .....	<b>2</b>
Aims .....	2
Definitions .....	2
Risks of tokophobia .....	2
<b>Assessment &amp; identification</b> .....	<b>3</b>
Initial screening .....	4
Further assessment .....	5
<b>Intervention</b> .....	<b>7</b>
Preconception .....	7
Postnatal.....	7
Pathway to intervention during pregnancy.....	8
<b>Appendix</b> .....	<b>9</b>

## Introduction

This document is a guide for all professionals working with women throughout their pregnancy and postnatally who may present with tokophobia. This includes maternity services, psychological services and perinatal teams across Greater Manchester. This guidance is to be used when a woman/birthing person expresses a fear of childbirth/tokophobia.

### Aims:

Early identification of fear of childbirth (antenatally) and post-traumatic stress disorder after childbirth (postnatally)

Increased signposting to timely interventions for fear of childbirth and/or post-traumatic stress disorder after childbirth

### Definitions:

Tokophobia is defined as a marked fear of childbirth (and sometimes fear of pregnancy).

Fear of childbirth is defined according to two categories:

**Primary tokophobia** is longstanding often since childhood

**Secondary tokophobia** is subsequent to a previous childbirth that was experienced as traumatic.

Secondary tokophobia is therefore commonly conceptualised and treated as a specific form of post-traumatic stress disorder (PTSD) and is more common than primary tokophobia.

It is important to note that a previous childbirth that was experienced as traumatic relates to a person's subjective experience of childbirth independent of whether or not there were any obstetric complications. Evidence suggest that this can include the perceived risk of medical events such as maternal or infant death, but also perceived threats to integrity such as feeling violated, out of control or abandoned.

### Risks of tokophobia:

#### Baby/Foetal Risk:

During the early stages of a pregnancy, individuals with primary tokophobia are likely to be at increased risk of terminating pregnancies, including those which were previously wanted and planned, or resulting from assisted conception. During all stages of pregnancy there is evidence that ongoing anxiety as in primary and secondary tokophobia can impact on emotional and

developmental outcomes for the baby in the longer term. Women/birthing people are likely to find it difficult to form a bond with their baby (known as the attachment relationship), both during pregnancy and postnatally. Sometimes they may develop negative thoughts or feelings towards the baby, because the baby links to their experience of childbirth.

#### Maternal Risk:

There is a very high risk of severe levels of anxiety and depression during pregnancy for women/birthing people with primary tokophobia. There will be symptoms of post-traumatic stress in secondary tokophobia and sometimes also in primary tokophobia. The risk of self-harm and suicide may be raised once a pregnancy progresses beyond 24 weeks' gestation (the legal limit for termination of pregnancy), as people may then feel trapped. It is also the case for many that increasing proximity to the delivery is associated with increasing anxiety.

### Assessment & Identification

On questioning, most women/birthing people will report some degree of anxiety in relation to childbirth and the challenge is to ascertain whether they require intervention. This is further complicated by the fact that many of the risk factors for tokophobia are highly sensitive topics (e.g. history of sexual abuse or rape), which people may hesitate to disclose.

Assessment and identification of tokophobia consists of initial screening followed by additional assessment by a perinatal specialist.

**Early identification of tokophobia is crucial in order to allow time to access appropriate treatment before childbirth.**

## Initial screening:

Initial screening can be carried out by any health professional. **The following assessment tools used either at booking or in clinic can act as a guide and support screening:**

- **How do you feel about the pregnancy?** (Consider ambivalent or negative emotions, anxiety symptoms)
- **What are your thoughts and plans for childbirth?** (If a caesarean section is requested but there is no medical indication for it, explore the reasons why)
- **What are your feelings towards the baby?** (ask during pregnancy as well as postnatal; tokophobia and/or birth trauma are likely to make it more difficult to form a bond with the baby)
- **What was your previous experience of childbirth like?** (look for symptoms of post-traumatic stress disorder such as frequent thoughts/images of the birth, flashbacks, nightmares, avoiding reminders of the birth)
- **Is there anything in your life (past/present) which might make the pregnancy/childbirth more difficult?** For example, fear of birth, trauma, childhood sexual abuse, sexual assault?

A simple indication of severity can be gained by asking the following question concerning feelings about childbirth: *On a scale of 0 to 10 where 0 is not at all anxious and 10 is extremely anxious, how anxious do you feel about childbirth?*

If further information and clarity is needed in relation to the severity of symptoms, the **Fear of Birth Scale (FOBS)** (Haines, 2011) could be administered (see Appendix).

If the screening questions indicate a significant fear of childbirth and/or the FOBS score is higher than 60, a referral should be made to a specialist mental health midwife for further assessment.

### Further assessment:

The clinician carrying out an additional assessment, likely a specialist mental health midwife, will need to consider risk factors, observations, and psychometric tests.

### The following risk factors should be considered:

- Previous adverse medical/surgical experience
- Previous traumatic experience of witnessing childbirth either personally (e.g. family member) or professionally (e.g. as healthcare staff)
- Pre-existing anxiety or mood disorder
- History of sexual abuse or rape
- History of sexual dysfunction
- Previous miscarriage, stillbirth or neonatal death

### Observable concerns or presentation to look out for may include:

- Intense fear of childbirth, not amenable to reassurance and not at normal levels
- Thoughts that this is 'unnatural, wrong'
- Intense fear despite level of desire for child or forgetting the desire for a baby once pregnant
- Intense fear/discomfort regarding pregnancy
- Revulsion regarding 'something growing inside'
- Did not anticipate these feelings
- Avoidance of the pregnancy – discussion of the baby, sharing the news, concealing the bump
- Fear of negative physical consequences of childbirth (rupturing, injury to self or to unborn child, fear of death or of the unknown, losing control, or appearing silly)
- May have a history of remaining childless or delaying conception despite wanting children, or seeking out an obstetrician who will agree to perform a caesarean section pre-conception
- May have a history of terminating wanted/planned (including fertility assisted) pregnancies
- Shame and guilt may be strongly characteristic, perhaps associated with presenting to services late in pregnancy, late termination of pregnancy
- Stigma and embarrassment
- High levels of anxiety and low mood

The **Wijma Delivery Expectancy/Experience Questionnaire (WDEQ-A)** (Wijma, 1998) can be used as a psychometric measure of tokophobia. See appendix for further details.

#### A note on psychometric tests:

Measures can provide additional information on level of needs and inform decision making, but should only be used as part of a holistic assessment. Professional judgement should be made on whether onward referral is required (regardless of scoring) and to consider speaking to services to discuss concerns if unsure. If the clinical concerns do not match the test scores always use clinical judgment when making decisions about onward referral.

Remember to take into account the common occurrence of parents minimising or under reporting their symptoms.

### **Post-Traumatic Stress (PTSD)/Birth Trauma**

When a woman is identified as having symptoms of secondary tokophobia, there may be symptoms of post-traumatic stress from a previous birth. Professionals should be aware of key indicators of birth trauma:

**Re-experiencing:** Frequent thoughts or images of the birth, nightmares, flashbacks, high levels of distress or anxiety.

**Avoidance:** Avoiding reminders of childbirth e.g. hospitals, TV programmes about birth, friends who are pregnant, avoiding talking about or thinking about childbirth.

**Hyperarousal:** Hypervigilance, exaggerated startle response, sleep problems. Some people report emotional numbing.

Using a measure (see Appendix; **Impact of Events Scale-Revised; Weiss & Marmar, 1996**) in relation to birth may provide a useful indication of the severity of these symptoms.

#### **Additional risk factors for PTSD:**

- Previous childbirth experienced as traumatic
- History of childhood abuse
- A strong need to be in control

## Intervention

### **Preconception**

- Access to consultation e.g. Specialist Mental Health Midwife/Consultant Midwife.
- Information about tokophobia and care pathways.
- Access to discussion about previous delivery.
- If necessary, refer for psychological therapy in NHS Talking Therapies (if mild to moderate) or PETALS (if severe/complex).

Tokophobia information leaflet.

### **Postnatal**

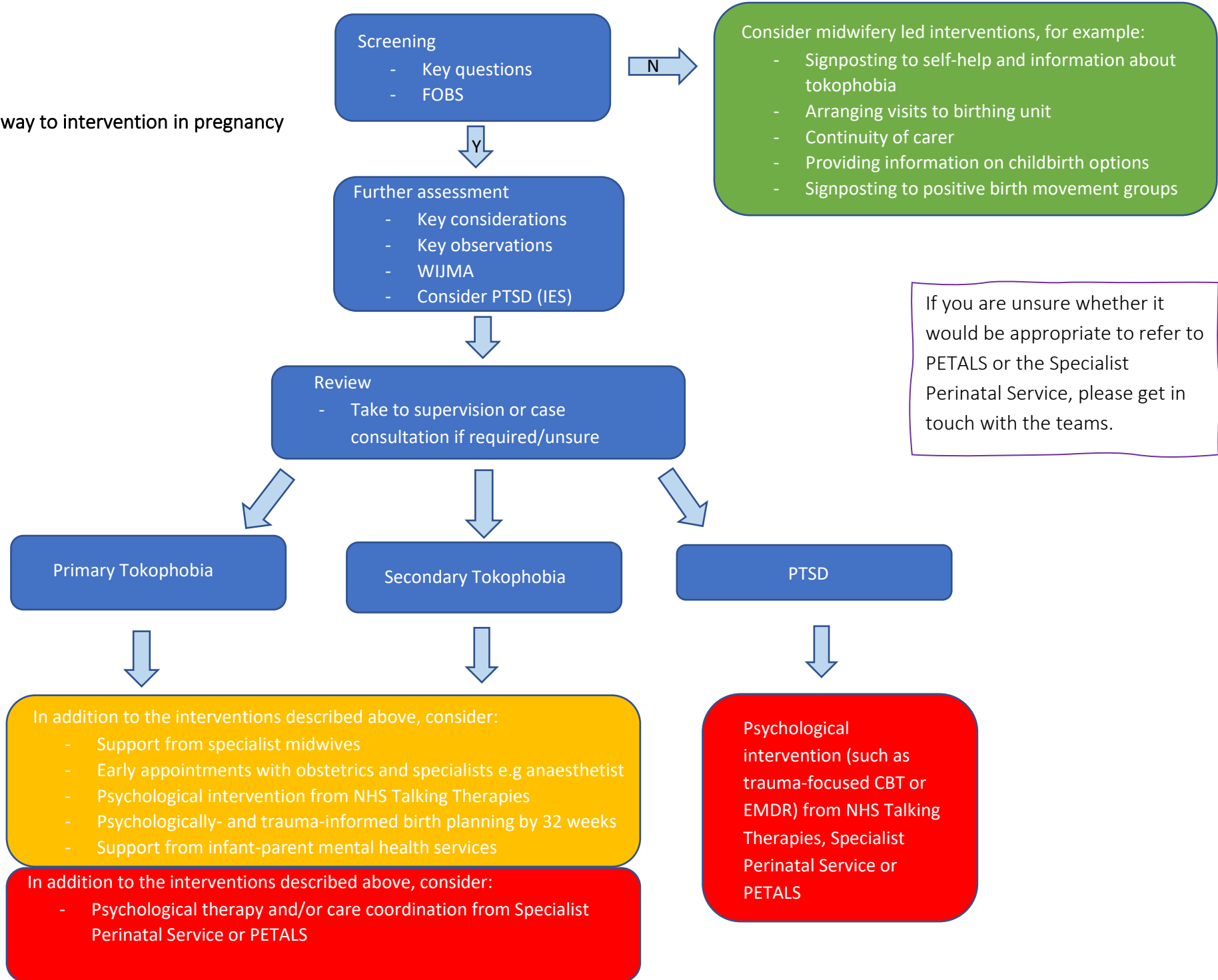
- Postnatal follow up e.g. with Specialist Mental Health Midwife/Consultant Midwife.
- Screen for birth trauma/PTSD.
- Assess mother-baby relationship.
- Access to information about birth/birth reflections appointment.
- If there are PTSD symptoms relating to the birth, please contact PETALS or Specialist Perinatal Service for further advice/support.

Birth Trauma Association Information.

Information about NHS Talking Therapies /Specialist Perinatal services/birth reflections.



Pathway to intervention in pregnancy



If you are unsure whether it would be appropriate to refer to PETALS or the Specialist Perinatal Service, please get in touch with the teams.

## Appendix

### Psychologically informed birth plan

*\*Please ensure that this remains at the front of your pregnancy hospital records\**

Optimising support & communication for your wellbeing during pregnancy and after the birth of your baby

#### YOUR DETAILS:

Name:		DOB:	
NHS No:		EDD:	

#### PEOPLE INVOLVED:

Partner / main support:	<input type="checkbox"/>	Care coordinator	<input type="checkbox"/>
		Perinatal Team:	
GP:	<input type="checkbox"/>	Home Treatment:	<input type="checkbox"/>
Health visitor:	<input type="checkbox"/>	Community midwife:	<input type="checkbox"/>
Psychiatrist:	<input type="checkbox"/>	Specialist Midwife:	<input type="checkbox"/>
Other:			

#### My Brief Summary

My strengths:	
My signs of distress:	
Strategies that work well for me:	
Partner / carer views:	





## ANTENATAL


My current emotional or mental health:	
Medications prescribed:	



## BIRTH and the first few days

Plans for birth:	
What helps my wellbeing during labour and birth?	
Preferred pain relief during labour:	
What will help my wellbeing after birth?	
Plans for how I may feed my baby and the support I think I may need	
Medication plans after birth and how I will get them:	

<b>Mental health review before discharge home:</b>	<ul style="list-style-type: none"> <li>- <i>Is required / is not required</i></li> <li>- <i>Completed by:</i></li> <li>-</li> </ul>
<b>Mental Health concerns whilst in hospital</b>	
Specialist Perinatal Mental Health  Team: (Monday – Friday 9-5pm) Liaison team: / Specialist midwife: 	

 continuing postnatal care at home	
<b>What will help to maximise my wellbeing at home:</b>	
<b>I will take medication:</b>	
<b>Following your hospital discharge and schedule of visits:</b>	

**Emotional Health – Around Birth Care (ABC) Plan**

Fear of Birth Scale (FOBS) (Haines, 2011)

*“How do you feel right now about the approaching birth?”*

Ask the respondent to place a mark on each of **two 100mm** VAS-scales with anchors defined as

(a) “calm” ----- “worried”

(b) “no fear”-----“strong fear”.

Use a ruler to measure in millimetres where the woman marks each scale. The two scores are then averaged to create a total score ranging from 0 to 100, with high scores indicating higher levels of childbirth fear. Women scoring **> 60** are identified as those who may require further assessment.

## IMPACT OF EVENT SCALE - REVISED

**INSTRUCTIONS:** Below is a list of difficulties people sometimes have after stressful life events.

Please read each item, and then indicate how distressing each difficulty has been for you **DURING THE PAST SEVEN DAYS** with respect to \_\_\_\_\_, how much were you distressed or bothered by these difficulties?

		Not at All	A little Bit	Moderately	Quite a Bit	Extremely
1.	Any reminder brought back feelings about it.	0	1	2	3	4
2.	I had trouble staying asleep.	0	1	2	3	4
3.	Other things kept making me think about it.	0	1	2	3	4
4.	I felt irritable and angry.	0	1	2	3	4
5.	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	2	3	4
6.	I thought about it when I didn't mean to.	0	1	2	3	4
7.	I felt as if it hadn't happened or wasn't real.	0	1	2	3	4
8.	I stayed away from reminders about it.	0	1	2	3	4
9.	Pictures about it popped into my mind.	0	1	2	3	4
10.	I was jumpy and easily startled.	0	1	2	3	4
11.	I tried not to think about it.	0	1	2	3	4
12.	I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	2	3	4
13.	My feelings about it were kind of numb.	0	1	2	3	4
14.	I found myself acting or feeling like I was back at that time.	0	1	2	3	4
15.	I had trouble falling asleep.	0	1	2	3	4
16.	I had waves of strong feelings about it.	0	1	2	3	4
17.	I tried to remove it from my memory.	0	1	2	3	4
18.	I had trouble concentrating.	0	1	2	3	4
19.	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	0	1	2	3	4
20.	I had dreams about it.	0	1	2	3	4
21.	I felt watchful and on guard.	0	1	2	3	4
22.	I tried not to talk about it.	0	1	2	3	4

Avoidance Subscale: Mean of items 5, 7, 8, 11, 12, 13, 17, 22

Intrusions Subscale: Mean of items 1, 2, 3, 6, 9, 16, 20

Hyperarousal Subscale: Mean of items 4, 10, 14, 15, 18, 19, 21

Impact of Events - Revised score: Sum of the above three clinical scales.

Note that the Hyperarousal scale is made up of 7 new items (No's 4,10,14,15,18,19,21) added to the original Impact of Events Scale (IES). For valid comparisons with scores from the IES, use just the sum of the Avoidance and Intrusion items.

In J.P. Wilson & T.M. Keane (Eds.), *Assessing psychological trauma and PTSD: A Practitioner's Handbook*. New York: Guilford © 1995: Daniel S. Weiss & Charles R. Marmar



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

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	
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	







**APPENDIX 2 The Wijma Delivery Expectancy/Experience Questionnaire (W-DEQ) version B**

© 1996 K. Wijma & B. Wijma

**Instruction**

This questionnaire is about feelings and thoughts women may have after childbirth.

The answers to each question appear as a scale from 1 to 6. The outermost answers (1 and 6 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 now think** your labour and delivery was.

Please answer **how you now think** your delivery was – not the way you wish it would have been.

I How did you experience your labour and delivery as a whole?

1 1 2 3 4 5 6  
Extremely Not at all  
fantastic fantastic

2 1 2 3 4 5 6  
Extremely Not at all  
frightful frightful

II How did you feel in general during the labour and delivery?

3 1 2 3 4 5 6  
Extremely Not at all  
lonely lonely

4 1 2 3 4 5 6  
Extremely Not at all  
strong strong

5 1 2 3 4 5 6  
Extremely Not at all  
confident confident

6 1 2 3 4 5 6  
Extremely Not at all  
afraid afraid

7 1 2 3 4 5 6  
Extremely Not at all  
deserted deserted

8 1 2 3 4 5 6  
Extremely Not at all  
weak weak

9 1 2 3 4 5 6  
Extremely Not at all  
safe safe

10 1 2 3 4 5 6  
Extremely Not at all  
independent independent

11 1 2 3 4 5 6  
Extremely Not at all  
desolate desolate

12 1 2 3 4 5 6  
Extremely Not at all  
tense tense

13 1 2 3 4 5 6  
Extremely Not at all  
glad glad

14 1 2 3 4 5 6  
Extremely Not at all  
proud proud

15 1 2 3 4 5 6  
Extremely Not at all  
abandoned abandoned

16 1 2 3 4 5 6  
Extremely Not at all  
composed composed

17 1 2 3 4 5 6  
Extremely Not at all  
relaxed relaxed

18 1 2 3 4 5 6  
Extremely Not at all  
happy happy

III What did you feel during the labour and delivery?

19 1 2 3 4 5 6  
Extreme No panic  
panic at all

20 1 2 3 4 5 6  
Extreme No hopeless-  
hopelessness ness at all

21 1 2 3 4 5 6  
Extreme No longing  
longing for the child at all

22 1 2 3 4 5 6  
Extreme No self-  
self-confidence confidence at all

23 1 2 3 4 5 6  
Extreme No trust  
trust at all

24 1 2 3 4 5 6  
Extreme No pain  
pain at all

IV What happened when the labour was most intense?

25 1 2 3 4 5 6  
I behaved I did not  
extremely badly behave  
badly at all

<p>26</p> <p>1 2 3 4 5 6</p> <p>I dared to totally surrender control to my body</p> <p>27</p> <p>1 2 3 4 5 6</p> <p>I lost total control of myself</p> <p>V How was the very moment you delivered the baby?</p> <p>28</p> <p>1 2 3 4 5 6</p> <p>Extremely funny</p> <p>29</p> <p>1 2 3 4 5 6</p> <p>Extremely natural</p>	<p>I did not dare surrender control to my body at all</p> <p>I did not lose control of myself at all</p> <p>Not at all funny</p> <p>Not at all natural</p>	<p>30</p> <p>1 2 3 4 5 6</p> <p>Extremely self-evident</p> <p>31</p> <p>1 2 3 4 5 6</p> <p>Extremely dangerous</p> <p>VI Had you, during the labour and delivery, fantasies like for example...</p> <p>32 ...fantasies that your child would die during labour/delivery?</p> <p>1 2 3 4 5 6</p> <p>Never Very often</p> <p>33 ...fantasies that your child would be injured during labour/delivery?</p> <p>1 2 3 4 5 6</p> <p>Never Very often</p> <p>Would you please now check that you have not forgotten to answer any questions.</p>	<p>Not at all self-evident</p> <p>Not at all dangerous</p>
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