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Stillbirth: Women´s long-term quality of life, mental health and the subsequent pregnancy

Results from two observational studies on women with
a history of stillbirth

By Ida Kathrine Gravensteen

Department of Haematology, Oslo University Hospital

&

Institute of Basic Medical Sciences and Institute of Clinical Medicine,
University of Oslo

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Table of contents

1	Acknowledgements	5
2	List of papers	7
3	Abbreviations	8
4	Summary	9
5	Introduction	11
5.1	The epidemiology of stillbirth	12
5.1.1	Definition and incidence	12
5.1.2	Causes and risk factors	13
5.1.3	Risk of recurrent stillbirth and adverse perinatal outcomes	14
5.1.4	Stillbirth as a risk marker for morbidity and mortality in women	14
5.2	Psychological distress	15
5.2.1	Depression	15
5.2.2	Anxiety	16
5.2.3	Post-traumatic stress	17
5.3	Quality of life, well-being and relationship satisfaction	19
5.3.1	Quality of life	19
5.3.2	Well-being	19
5.3.3	Relationship satisfaction	20
5.4	Basic properties and interpretation of psychometric scales	21
5.5	Psychosocial consequences of stillbirth	23
5.5.1	Mourning and short-term (<1 year) psychological reactions	23
5.5.2	Long-term psychological distress and quality of life	23
5.5.3	Consequences for social relations and relationship with partner	26
5.5.4	Women's experiences in relation to stillbirth and risk factors for psychological distress	26
5.5.5	Psychological distress in the subsequent pregnancy	29
5.5.6	Healthcare utilisation in the subsequent pregnancy	30
5.5.7	Induced labour and mode of delivery in the subsequent pregnancy	31
6	Aims	35
7	Materials and methods	37
7.1	Study populations	38
7.1.1	First study (papers I and II)	38
7.1.2	Second study (papers III and IV)	39
7.2	Measures	42
7.2.1	First study (papers I and II)	42

7.2.2 Second study (papers III and IV)	47
7.3 Statistical procedure	50
7.4 Power analyses.....	53
7.5 Ethical aspects	54
8 Summary of results	55
8.1 Paper I.....	55
8.2 Paper II	56
8.3 Paper III.....	57
8.4 Paper IV	58
9 Discussion.....	59
9.1 Main findings.....	59
9.2 Methodological considerations.....	60
9.2.1 Strengths and limitations	60
9.2.2 Definition of stillbirth.....	61
9.2.3 Study populations, selection bias and generalisability	61
9.2.4 Information bias	66
9.2.5 Covariates and confounding	66
9.2.6 Validity and reliability of the psychometric scales	67
9.2.7 Missing data	71
9.2.8 Statistical considerations	71
9.3 Interpretation of main findings.....	74
9.3.1 Long-term quality of life, well-being and depression after stillbirth.....	74
9.3.2 Women's experiences in relation to stillbirth	74
9.3.3 Frequency and predictors for long-term PTSS after stillbirth	75
9.3.4 Anxiety, depression and relationship satisfaction in the subsequent pregnancy	77
9.3.5 Healthcare utilisation in the subsequent pregnancy	78
9.3.6 Induced labour and caesarean section in the subsequent pregnancy	79
10 Clinical implications.....	81
11 Future work	83
12 Conclusions	85
13 References	87
Papers I-IV	
Appendix	

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2 List of papers

Paper I.

Gravensteen IK, Helgadottir LB, Jacobsen EM, Sandset PM, Ekeberg O. **Long-term impact of intrauterine fetal death on quality of life and depression: a case-control study.** BMC Pregnancy and Childbirth. 2012;12:43.

Paper II.

Gravensteen IK, Helgadottir LB, Jacobsen EM, Radestad I, Sandset PM, Ekeberg O. **Women's experiences in relation to stillbirth and risk factors for long-term post-traumatic stress symptoms: a retrospective study.** BMJ Open. 2013;3(10):e003323.

Paper III.

Gravensteen IK, Jacobsen EM, Sandset PM, Helgadottir LB, Rådestad I, Sandvik L, Ekeberg Ø. **Anxiety, depression and relationship dissatisfaction in the pregnancy following stillbirth and after the birth of a liveborn baby: a prospective study.** Submitted.

Paper IV.

Gravensteen IK, Jacobsen EM, Sandset PM, Helgadottir LB, Rådestad I, Sandvik L, Ekeberg Ø. **Healthcare utilisation, induced labour and caesarean section in the pregnancy after stillbirth: a prospective study.** Submitted.

3 Abbreviations

B: Beta value

aB: Adjusted beta value

CES- D: The Center for Epidemiological Studies Depression Scale

CI: Confidence interval

DSM: Diagnostic and Statistical Manual for Mental Disorders

ICD: International Classification of Diseases

IES: Impact of Event Scale

IUFD: Intrauterine fetal death

GHQ-20: The General Health Questionnaire, 20-items version

MBRN: The Medical Birth Registry of Norway

MID: The Minimal Important Difference

MoBa: The Norwegian Mother and Child Cohort study

OR: Odds ratio

aOR: Adjusted odds ratio

PTSD: Post-traumatic stress disorder

PTSS: Post-traumatic stress symptoms

QOL: Quality of life

QLI: The Quality of Life Index

RS10: The Relationship Satisfaction Scale, 10-items version

RS5: The Relationship Satisfaction Scale, 5-items version

SCL-25: The Hopkins Symptoms Checklist, 25-items version

SCL-8: The Hopkins Symptoms Checklist, 8-items version

SCL-4a: The Hopkins Symptoms Checklist, 4-items anxiety subscale

SCL-4d: The Hopkins Symptoms Checklist, 4-items depression subscale

SD: Standard deviation

VIP: The Venous Thromboembolism in Pregnancy study

WHO: World Health Organization

4 Summary

Background: Experiencing a stillbirth is known to strongly affect women's mental health in the short term, while the long-term impact on quality of life (QOL) and mental health remains uncertain. Psychological distress is common in the subsequent pregnancy and may be a challenge for healthcare professionals who provide guidance for these women. Interventions during childbirth, such as induced labour and elective caesarean section are more common in this group.

Objectives: 1) To measure long-term QOL, well-being, depression and post-traumatic stress symptoms (PTSS) in women with a history of stillbirth, 2) to investigate experiences at the time of stillbirth and identify predictors for long-term PTSS, 3) to estimate the proportions with case-level anxiety, depression and relationship dissatisfaction during and after the subsequent pregnancy and 4) to assess healthcare utilisation, induced labour and caesarean section, and anxiety and dread of childbirth as potential mediators for these outcomes.

Methods: This thesis is based on findings from two observational studies. The first study is a retrospective study including 106 women with a history of stillbirth 5-18 years previously, and 262 women with live births. The second study is a prospective cohort including 174 women pregnant after a stillbirth, 362 women pregnant after a live birth and 365 nulliparous women. Bivariate and multivariate linear and logistic regression models were used to quantify the association between previous stillbirth and the various outcomes.

Results: A history of stillbirth was not associated with long-term global QOL, subjective well-being or global depression after adjustments for sociodemographic and health-related variables. The majority with a history of stillbirth had seen and held their baby and was satisfied with the support from healthcare professionals. One third showed clinically significant PTSS at follow up, while 13% scored above a (possible) post-traumatic stress disorder (PTSD) level. Risk factors for PTSS were younger age (OR 6.60, $p = 0.002$), induced abortion prior to stillbirth (OR 5.78, $p = 0.009$) and higher parity at the time of stillbirth (OR 3.46, $p = 0.023$). Having held the baby appeared to be protective (OR 0.17, $p = 0.004$).

In the subsequent pregnancy, women with a previous stillbirth were at higher risk of case-level anxiety (22.5%) and depression (19.7%) compared with women with a previous live birth (4.4% and 10.3% respectively) and previously nulliparous women (5.5% and 9.9% respectively). The differences remained significant in the multivariate analyses. Gestational age at stillbirth (> 30 weeks) and inter-pregnancy interval < 12 months were not significantly associated with case-level depression and/or anxiety. The proportions with case-level anxiety and depression were similar to the reference groups six to 18 months after the birth of a live born baby, but increased slightly 36 months postpartum. Relationship satisfaction did not

differ between groups at any time point. Women pregnant after stillbirth had more frequent antenatal visits (mean 10.0 vs. 6.0 and 6.3) and more often induced labour (42.0% vs. 9.4% and 17.8%) and caesarean section (32.2% vs. 11.0% and 16.4%) compared with women with previous live births and previously nulliparous women. Anxiety was a significant, but minor, mediator for the association between previous stillbirth and frequency of antenatal visits. Dread of childbirth was not a significant mediator for the association between previous stillbirth and elective caesarean section.

Conclusions: On group level, long-term QOL, well-being, and depression was not affected by a previous stillbirth in our study. However, the stillbirth clearly remains a significant event in many women's lives as one in three women presented with clinically significant PTSS in the long term. Our findings support common guidelines that encourage women to have contact with their stillborn baby. Case-level anxiety and depression was prevalent in the subsequent pregnancy and antenatal visits, induced labour and caesarean section was more frequent. The psychosocial care provided for this group should be evaluated. Other factors than general anxiety and dread of childbirth could be stronger mediators for the high frequency of elective caesarean sections in the pregnancy after stillbirth, and this should be assessed in future studies.

5 Introduction

In high-income countries the general expectation is that every pregnancy that survives the first trimester will lead to the birth of a healthy baby. However, in Norway, more than 200 infants are stillborn each year (1), a substantial shock and a devastating loss for the parents (2). Unlike the mourning process experienced after the death of other loved ones, the prenatal death of a desired baby may represent a lonely grief, involving loss of self-esteem in the role as a parent and loss of confidence in the ability to produce a healthy child (3). Mothers in particular, may suffer from complicated grief and psychological distress for months and possibly years after the incident (4, 5). Little is known about how a stillbirth affects women's mental health in the longer term, and if they can expect their quality of life to be restored.

The pregnancy after a stillbirth is a vulnerable period as it may reactivate psychological symptoms (6), possibly representing a challenge for healthcare professionals who provide guidance for these women and their partners. Current knowledge about psychological distress during and after the subsequent pregnancy after a stillbirth is limited, and women's satisfaction with their partner relationship during this transitional phase has not been previously explored. Women's use of healthcare services in the subsequent pregnancy is poorly investigated and feelings of threat and anxiety could potentially account for more frequent antenatal visits (7). Further, in the general obstetric population, it has been speculated that fear related to childbirth may result in more liberal use of interventions, such as elective caesarean section (8), which may not be justified by overall cost-benefit effects. Anxiety and fear of childbirth as mediators for health care utilisation and elective caesarean sections in the pregnancy after stillbirth has, to our knowledge, not been studied previously.

Knowledge about the expected course of psychological symptoms in the short term, in the subsequent pregnancy and in the longer term is essential to implement adequate follow-up for women who have experienced stillbirth. It is also important to evaluate the care and management currently provided to identify subgroups potentially in need of additional interventions.

5.1 The epidemiology of stillbirth

5.1.1 Definition and incidence

Defining intrauterine fetal death (IUFD) or stillbirth (I will use both terms interchangeably in the thesis) is complicated. The terminology has changed over time and definitions varies between countries, particularly in the developed region (9). Worldwide, the thresholds for reporting fetal deaths ranges from ≥ 16 to ≥ 28 completed weeks of gestation or birth weight ≥ 400 to ≥ 1000 grams (10).

The World Health Organization (WHO) defines "fetal death" as death prior to complete expulsion from the mother, irrespective of the duration of pregnancy (11). However, when reporting national fetal death rates, the use of viability criterion is recommended. Specifically, birth weight ≥ 500 g, gestational age ≥ 22 weeks or crown-heel length ≥ 25 cm are used as criteria for reporting fetal death and distinguish a stillbirth from a miscarriage. For international comparisons, the WHO recommends reporting stillbirths of infants with birth weight ≥ 1000 g, gestational age ≥ 28 weeks or crown-heel length ≥ 28 cm (11). In these definitions birth weight takes priority over gestational age, but since the accuracy and availability of early ultrasound dating of pregnancy has increased, the use of gestational age is preferred (10, 12). Because preterm fetal deaths tend to be more growth-restricted than preterm live births (13), a birth weight criterion results in lower fetal death counts as compared to the corresponding gestational age criterion (12). The term perinatal death includes deaths within the first week of life in addition to stillbirths (11).

Approximately 98% of third trimester stillbirths occur in low- and middle-income countries (14). In 2015, the worldwide estimated stillbirth rate, defined as 28 or more gestational weeks, was 18.4 per 1000 births, down from 24.7 per 1000 births in 2000 (15). The highest estimated rate was in Pakistan (43.1 per 1000), while the lowest was in Iceland (1.3 per 1000). The overall rate for developed countries was 3.4 per 1000 births. Early stillbirths, occurring before 28 gestational weeks, are rarely reported in low-income countries (16), and numbers are often not estimated in high-income countries even though these can represent one third of all stillbirths (17). The Medical Birth Registry of Norway (MBRN) publishes both early and late fetal death statistics, and in 2015 the rate of stillbirths defined as birth weight ≥ 500 g or gestational age ≥ 22 weeks was 3.5 per 1000 births in Norway (1).

Mainly attributed to improvements in antenatal care, the rate of late stillbirths (≥ 28 weeks) in high-income countries has decreased substantially over the last 50-60 years (18, 19). However, in recent decades, the decline has halted, and there has hardly been any reduction in

early stillbirths (17, 20). Currently, stillbirths account for more than half of all perinatal deaths in high-income countries (21, 22) and the annual frequency is more than ten-fold that of sudden infant death syndrome (SIDS) (23).

5.1.2 Causes and risk factors

A variety of maternal, fetal and placental disorders can result in stillbirth. However, classification is complicated by the use of varying classifications systems and the fact that relatively few losses have a completely understood cause of death (24). The most common reported causes of stillbirth worldwide are complications of childbirth, maternal infections in pregnancy, maternal disorders, fetal growth restriction and congenital anomalies (14). Causes and risk factors vary between low- and high-income countries (25-27), partly because of their true prevalence, but also because of different potentials in identifying causes (16).

Recent estimates in high income countries report that approximately 29% of stillbirths are caused by placenta pathology (for example placenta dysfunction with intrauterine growth restriction or placental abruption), 12% by infections, 7% by maternal medical conditions (such as diabetes or hypertension), 9% by umbilical cord accidents and 3% by other labour complications (mainly asphyxia) (17). Fetal conditions (mainly malformations and chromosomal disorders) are reported to account for 5-10% of stillbirths (17, 28). A large proportion (20-40%) of stillbirths remains unexplained (17, 28-31) and this proportion increases with advancing gestational age (32).

A range of independent, but variable risk factors for stillbirth has been identified. Important maternal risk factors in high-income countries include:

- Advanced maternal age (≥ 35 years) (29, 32-34)
- Primi-parity (33, 35)
- High parity (≥ 3 previous births) (33, 35)
- Overweight/obesity (32, 36-38)
- A variety of maternal medical conditions, most importantly hypertensive disorders and diabetes mellitus/gestational diabetes (39-41)
- Smoking (21, 42), use of Swedish snuff (snus) (43), alcohol consumption (44, 45) and illicit drug use (46) in pregnancy
- Factors associated with low socioeconomic status such as low educational level, unemployment and low income (35, 38, 47)
- Ethnic minority (48-51)
- Previous stillbirth or other adverse pregnancy outcomes (52-55)

A major risk factor in an ongoing pregnancy is the presence of intrauterine growth restriction (29, 56, 57). Other risk factors include macrosomia (35), multiple pregnancy (58) and suboptimal care (17, 51). The risk of stillbirth in ongoing pregnancies increases gradually from 36 gestational weeks, with a steep increase post-term (57, 59-61). As the pregnancy advances, reduced fetal movements and antepartum haemorrhage are key symptoms associated with increased risk of stillbirth (24, 62).

5.1.3 Risk of recurrent stillbirth and adverse perinatal outcomes

The overall recurrence risk for stillbirth is increased two- to 10-fold in the subsequent pregnancy (63, 64). A recent review found that women with a history of stillbirth were almost five times more likely to experience stillbirth in a subsequent pregnancy compared with multiparous women with no such history (52). Some studies have not found an increased recurrence risk, but these are mostly restricted to unexplained stillbirths (65, 66). The individual recurrence risk depends on the cause of the prior stillbirth and characteristics such as fetal growth restriction, gestational age (increased risk if preterm stillbirth), and ethnicity (increased risk in African Americans compared with Caucasians) (67, 68). In a study by Surkan et al. based on data from the Swedish Medical Birth Registry, a history of previous stillbirth almost quadrupled the risk of preterm stillbirth in the subsequent pregnancy, but was not associated with an increased risk of term stillbirth (63). Pregnancies following stillbirth may also be at increased risk for other adverse perinatal outcomes such as placental abruption, preterm birth, low birth weight and early neonatal mortality, but the overall probability of a favourable outcome is high (66, 69, 70).

5.1.4 Stillbirth as a risk marker for morbidity and mortality in women

There is a growing body of evidence on the association between obstetric complications, and maternal morbidity and mortality later in life. Risk factors for stillbirth, such as preeclampsia, intrauterine fetal growth restriction and preterm birth are associated with increased morbidity and mortality in women, particularly from cardiovascular disease (71-75). An already increased risk of cardiovascular hospitalisation among women with previous placental syndromes such as pregnancy induced hypertensive disorders, and infarction or abruption of the placenta, may double if the woman has also experienced stillbirth (76). An Israeli study reported increased long-term mortality for women with a history of stillbirths, with increased risk of death due to coronary heart diseases, circulatory and renal causes (77). The mortality risk remained significantly increased after adjustments for sociodemographic variables, maternal diseases in pregnancy, placental abruption, and preeclampsia.

5.2 Psychological distress

In this thesis, the participating women's levels of psychological distress, defined as depression, anxiety and post-traumatic stress symptoms are used as indicators of mental health. Psychiatric screening instruments can indicate the presence or absence of common psychiatric disorders in a clinical population if a high symptom score show high sensitivity and specificity (78), but a psychiatric interview is the gold standard. Although this thesis only addresses symptom levels and not exact diagnoses, the use of pre-validated cut-off values gives an estimate of the proportion at risk of psychological morbidity.

5.2.1 Depression

Depression is the most common psychiatric disorder in the general population (79), and depressive symptoms are frequently measured when assessing the psychological impact after the loss of a loved one or other negative life events.

According to the WHO's International Classification of Diseases (ICD-10) (11), a depressive episode is characterised by depressed mood, loss of interest and pleasure, and loss of energy leading to tiredness and reduced activity. To diagnose a depressive episode, four or more of the symptoms in Table 1 have to be present for at least two weeks and cause distress or functional impairment. Two of the symptoms have to be depressed mood, loss of interest or reduced energy. A depressive episode can be classified as mild, moderate or severe dependent on the number and severity of symptoms present and the degree of functional impairment.

Table 1. Manifestations of a depressive episode according to the ICD-10

- Depressed mood*
- Loss of interest or pleasure in most or all activities*
- Reduced energy*
- Loss of confidence or self-esteem
- Poor concentration or indecisiveness
- Feelings of worthlessness or inappropriate guilt
- Recurrent thoughts of death or suicide
- Insomnia or hypersomnia
- Significant change in weight or appetite
- Psychomotor retardation or agitation

*Core symptoms

The prevalence of major depression around the world appears to be increasing with lifetime estimates ranging from 3% in Japan to 16.9% in the United States, and for the majority of countries in the range of 8% to 12% (80). The prevalence in 18- to 29-year-olds is three times higher than in individuals aged 60 years or older and 1.5- to 3-fold higher in females compared to males (81, 82). Risk factors for depression are temperamental (neuroticism or negative affect), genetic, medical, environmental, and social and include stressful life events (83). Untreated depression is associated with decreased quality of life, increased risk of mortality and poorer physical health when co-occurring with other chronic diseases (84-86). Antenatal maternal depression, occurring in 8.5-11% of pregnancies, is associated with adverse pregnancy outcomes such as increased odds of premature delivery (87, 88). Depression may exist as a sole diagnosis, but comorbidity with other mental disorders, such as anxiety disorders is common (89).

5.2.2 Anxiety

Anxiety is an emotion characterised by feelings of dread or worry, often accompanied by nervous behaviour and physical reactions like increased blood pressure or palpitations (90). Fear and anxiety share similar patterns of emotional and physiological activation, but can to some degree be differentiated based on whether the threat is certain and imminent or anticipated and uncertain. Fear denotes apprehension or dread of an impending stimulus and involves surges of autonomic arousal and escape behaviours. The response subsides when the threatening stimulus terminates. Anxiety on the other hand is a state of usually longer lasting and more general distress involving anticipation of a less explicit threatening event and is more associated with muscle tension, vigilance or avoidance rather than organised functional behaviour (91).

As opposed to transient anxiety or fear, anxiety disorders are according to the ICD-10 system characterised by excessive and persistent apprehension of danger and dread resulting in impaired functioning (11). Anxiety disorders differ in the types of situations being feared or avoided and the content of associated thoughts, but tend to be highly comorbid with each other and with concurrent depression (92). Panic attacks are commonly occurring as a specific fear response within the anxiety disorders. In generalised anxiety disorder, the anxiety or worry is not limited to specific situations or activities as opposed to for example phobias (11). The core trait of generalised anxiety disorder is a period of at least six months with prominent tension, persistent nervousness, worry or apprehension about everyday problems that is difficult to control. Additional symptoms include irritability, sleeping problems, difficulty in concentrating and bodily symptoms such as palpitations, sweating, numbness, trembling or shaking, dyspnea, muscle tensions, dizziness and abdominal discomfort (11).

Anxiety disorders are frequently occurring in the general population. A recent review of epidemiological studies in Europe found a 12-month prevalence of 14.0% for all anxiety disorders and 1.7% to 3.4% for generalised anxiety disorder (92). The aetiology of anxiety disorders is not clearly determined, but both individual susceptibility and environmental factors are thought to be important. Women are more often affected by anxiety disorders than men (92) and the prevalence of generalised anxiety disorder peaks in mid-life (93).

5.2.3 Post-traumatic stress

The post-traumatic stress disorder (PTSD) achieved diagnostic status in 1980 when included in the third edition of the Diagnostic and Statistical Manual for Mental Disorders (DSM-III). Currently, the DSM-V (94) or ICD-10 (11) are used. In the ICD-10 system, post-traumatic stress disorder is classified as an adjustment and stressor-related disorder with close relationship to anxiety disorders, obsessive-compulsive disorders and dissociative disorders. The essential feature of PTSD is the development of intrusive memories, nightmares and flashbacks, actual or preferred avoidance and hypervigilance following exposure to a traumatic event that is exceptionally threatening or catastrophic, such as violence, natural catastrophes, accidents, and sudden catastrophic medical events including traumatic childbirth and the unexpected death of a child. To diagnose PTSD according to the ICD-10 system, eight criteria have to be present (Table 2).

Table 2. Diagnostic criteria for PTSD according to ICD-10 (11)

- Exposure to an exceptionally traumatic stressor or event
- Persistent remembering or re-experiencing of the event
- Actual or preferred avoidance of event-related stimuli

At least one of the following:

- 1) Inability to partially or completely recall important aspects of the period under stress
- 2) Persistent and increased psychological sensitivity or arousal shown by at least two of the following symptoms:
 - difficulty sleeping
 - irritability or outbursts of anger
 - hypervigilance
 - exaggerated startle response

In the European Study of Epidemiology of Mental Disorders the estimated the 12-month prevalence of PTSD was 0.9%, with a higher prevalence for women than men (1.3% vs.

0.4%) (95). While the prevalence of postpartum PTSD has ranged from 1 to 30% in the research literature, a recent meta-analysis found prevalence rates of 3.1% for general community samples and 15.7 in at risk samples (96).

The development of PTSD is dependent on the severity and objective nature of the trauma, occurring more frequently as a response to trauma inflicted by other people, such as physical or sexual violence, than after a natural or coincidental event such as a medical emergency or a natural disaster (97, 98). A number of subjective factors such as female gender, younger age, lower socioeconomic status, ethnic minority and low educational level are well-known subjective risk factors for PTSD (99, 100). Additionally, a range of other factors such as lack of social support, prior traumatic experiences, other mental disorders, neuroticism and ineffective coping pattern are associated with higher symptom levels (101).

5.3 Quality of life, well-being and relationship satisfaction

5.3.1 Quality of life

In 1948, the WHO broadened their definition of health to include physical, mental and social well-being, in addition to absence of disease or infirmity (102). In the recent decades, the research literature has shifted away from an emphasis on clinical and laboratory indicators of illness, to incorporate the patient's subjective experience in the medical evaluation (103). Taking quality of life (QOL) and positive mental health into account has become increasingly important, especially in psychological research and in clinical trials on patients with chronic illnesses (104-106).

A main challenge in QOL research is the lack of a universally accepted definition of the concept. QOL represents a wide range of human experiences (107), and is highly subjective. As an example, two people with apparently similar life conditions may have completely different QOL depending on their expectations and ability to cope with limitations. The WHO QOL-group defined quality of life as *"individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"*(108). Accordingly, for use in the social and medical sciences the concept of QOL is often summarised to incorporate the physical, mental, social and material domains of life that are influenced by personal and contextual perceptions (109-111). While generic QOL refers to a person's perception of their life as a whole, health-related quality of life is a narrower term that focuses on aspects of QOL most relevant for disease and treatment, such as optimal functioning (103). However, while functioning and subjective symptom levels are important aspects of an individual's perception of health, they are not synonymous to QOL in the widest term (112).

It is generally accepted that the patient should be the primary source of information regarding his or her QOL, and assessments made by proxy are documented to be poor estimates of individual QOL (113, 114). QOL questionnaires should be multidimensional and include at least three domains; physical, psychological and social, in addition to a question regarding overall QOL (115).

5.3.2 Well-being

Well-being may be defined as a broader concept of general psychological health that refers to happiness and effective functioning (116). In 2001, the WHO defined positive mental health as "a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a

contribution to his or her community”(117). As an operational definition, subjective well-being is interpreted to mean experiencing high levels of pleasant emotions (positive affect), low levels of negative moods (negative affect) and a cognitive appraisal that one’s life is good (life satisfaction) (116, 118). The concept of well-being clearly overlaps with QOL or lack of psychological distress, but is also applied in social sciences and clinical research as a separate outcome (118-120).

5.3.3 Relationship satisfaction

Couple relationships represent a core aspect in the social life of many adults. Various studies have linked the duration of marriage and cohabitation to higher quality of life, lower rates of psychiatric disorders and lower risk of all cause morbidity, even after adjustments for prior mental disorders and other potential confounders (121-123). Conversely, poor marital functioning is associated with compromised physical and mental health (124, 125), and the partner relationship plays a critical role in the creation, transmission and maintenance of depression symptoms (126). A review of the literature demonstrated that marital discord is a predictor for depression and vice versa (127). During pregnancy and childbirth the quality of the couple relationship is particularly important as vulnerability to mental health problems may increase (128) and the transition into parenthood is in itself associated with a decline in relationship satisfaction (129). A recent study based on the Norwegian Mother and Child cohort demonstrated that maternal relationship dissatisfaction is related to psychological distress in pregnancy, while relationship satisfaction may be protective in the presence of other stressors (130).

Several measurements have been developed to measure relationship satisfaction, including the Relationship Satisfaction scale used in the present study (131). Such scales are valuable in terms of predicting important outcomes such as marital dissolution, of which female relationship dissatisfaction may be one of the strongest predictors (132).

5.4 Basic properties and interpretation of psychometric scales

To be clinically useful, instruments measuring QOL, subjective well-being and psychological distress should incorporate the basic properties; validity, reliability, sensitivity and responsiveness, and translated questionnaires should adhere to suggested guidelines (133).

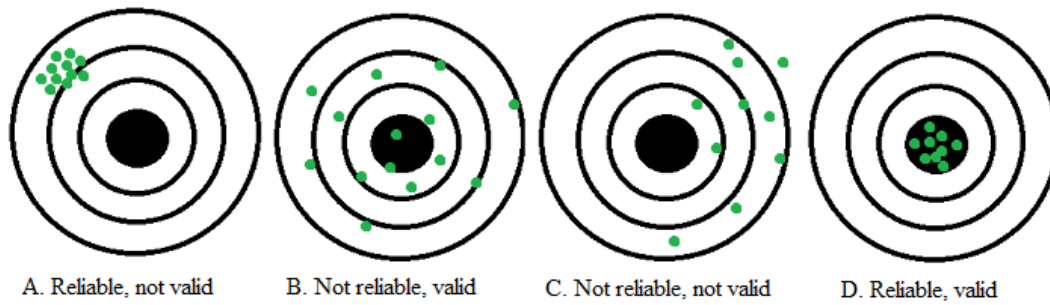
Validity describes the ability of an instrument to measure the concept of interest and is often divided into three aspects; content, criterion and construct validity (133). *Content validity* is that the items of the instrument are sensible and reflects the domain of interest. *Criterion validity* is the ability of an instrument to correspond with a pre-established gold standard; however, in social sciences such gold standards are not often available. *Construct validity* is the ability of an instrument to reflect on the prior hypotheses of what it was designed to measure.

Reliability refers to an instrument's ability to yield the same result on repeated measures if the patient's condition has not changed (133). Internal reliability or consistency can be assessed by Cronbach's alpha, which is a function of the number of items in a scale and their inter correlation, and refers to the homogeneity of multi-items scales. A generally acceptable value of Cronbach's alpha for psychometric scales is considered to be >0.7 (134). Test-retest reliability means that the measurements are stable over time in patients with a stable condition.

In short, validity describes accuracy, while reliability describes precision. However, poor reliability limits the overall validity of an instrument. E.g. if a QOL instrument yields a different score when administered to the same person within a short period of time, the instrument cannot be perfectly valid. A commonly used metaphor for the relationship between reliability and validity is a target where the centre represents the concept you are trying to measure (Figure 1).

Sensitivity refers to the instruments ability to detect true differences between people or groups of people. In diagnostic terms, sensitivity refers to the ability of a test to correctly identify patients or people with a specific condition (135). In contrast, *specificity* refers to the ability of the test to correctly identify people without the condition. *Responsiveness* refers to the ability to detect changes, and is an important aspect in longitudinal assessments (136).

Figure 1. Validity and reliability



Scenario A: The same results are obtained on repeated measures, but the concept of interest is not captured. I.e. the measurements are consistent, but wrong

Scenario B: The results are randomly spread on repeated measures, but are correct on average. I.e. on group level, the concept of interest is captured, but the measurements are inconsistent.

Scenario C: The results are randomly spread on repeated measures, and on average the results are incorrect. I.e. the measurements are inconsistent and wrong.

Scenario D: The same results are obtained on repeated measures and the concept of interest is consistently measured.

When interpreting results from psychometric scales, a statistically significant difference does not necessarily equal a clinically meaningful difference. Ideally, interpretations of differences in QOL and mental health measures should be based on the minimal important difference (MID) (137). The MID is defined as the smallest difference in the domain of interest that is perceived as beneficial or harmful and that in a clinical setting could lead to a change in management (138). In the absence of a predetermined MID, effect size statistics is widely used to evaluate results in clinical and epidemiological research. Effect sizes can be calculated by dividing the observed difference in a score by the baseline standard deviation (SD), and according to Cohens index, $0.50 \times SD_{\text{baseline}}$ represents a moderate effect size (139).

5.5 Psychosocial consequences of stillbirth

5.5.1 Mourning and short-term (<1 year) psychological reactions

Throughout the pregnancy, bonding between a mother and her unborn child develops (140), a process enhanced after the birth, possibly mediated by high oxytocin levels in the maternal blood (141). Increased prenatal attachment associated with modern obstetric practices, such as ultrasound imaging, has been linked to the intensity of parental grief after perinatal death (142). In any case, a stillbirth is a major challenge for the mother, having to adjust from the expectation of getting a healthy baby to the realisation that her child is dead. This causes normal grief reactions (143), but can also result in complicated grief or psychological distress (144-146). Late miscarriages and stillbirths have previously been identified to be potent stressors for development of short-term post-traumatic stress symptoms (147, 148), and women affected by stillbirth manifest high levels of postpartum anxiety and depression symptoms compared with women with live births (149, 150). The risk of psychological distress is generally higher in mothers than fathers (149, 151).

In the 1970-80ies researchers took an interest in systematically studying grief reactions after stillbirth and neonatal death (144, 152). In 1982 LaRoche et al. described complicated grief in six of 30 mothers receiving psychosocial interventions up to three months after perinatal death (144). In a study of support and counselling after stillbirth and neonatal death, Forrest et al. found that about half of the mothers displayed high levels of anxiety and depression symptoms after six months, and 20% had not recovered by 14 months (152). Vance and colleagues similarly reported that women with a stillbirth had a five-fold increased risk of anxiety (28.9% vs. 5.7%) and an almost seven fold increased risk of depression (20.7% vs. 3.1%) after two months compared with women with a live birth (149). By eight months the risk had dropped to a three- and two-fold for anxiety and depression, respectively (4). In a recent population based nine-month follow-up study from USA, women who had lost a child in stillbirth or neonatal death had nearly four-fold higher odds of having a positive screen for depression, a seven-fold higher odds of a positive screen for post-traumatic stress disorder and two-fold higher odds of general anxiety disorder after controlling for demographic and personal risk factors (153-155). No significant differences were found between women who lost a child in stillbirth compared with neonatal death.

5.5.2 Long-term psychological distress and quality of life

Studies that have assessed long-term psychological distress (more than one year follow-up) after stillbirth are few and often limited by small numbers (6, 156), self-selection (6, 156) or

lack of multivariate models (5). Table 3 displays an overview on core studies comparing women's long-term mental health after stillbirth with a reference population.

Forrest and colleagues reported that the severity of psychiatric symptoms after stillbirth diminish throughout the first year (152). Similarly, Boyle and colleagues reported a gradual decline in psychological distress following stillbirth ($n = 78$) and the differences were not statistically significant by 15 months with respect to depression (5.4 vs. 2.0%, n.s.), and by 30 months with respect to anxiety (12.3 vs. 5.9%, n.s.) (157). Bereaved mothers who were not distressed at two months follow-up were unlikely to become so later, but those still distressed at eight months were likely to remain so subsequently. In the more recent internet-based Maternal Observations and Memories of Stillbirth study ($n = 2,292$), women with a recent stillbirth (<1 year) had more symptoms of depression and anxiety than those with a more distant loss (158).

Although symptoms often diminish with time, women who experience a stillbirth may be at risk of psychological distress for years after the event. In a study including 314 Swedish women who lost a child in stillbirth in 1991, Rådestad and colleagues reported that women with previous stillbirth ($n = 314$) were twice as likely to experience frequent anxiety symptoms after three years compared with women with a live birth (10% vs. 5%) (5). In a nested case-control study on women who were initially in the pregnancy subsequent to stillbirth, Turton et al. found no difference in the level of case-level depression and PTSD between cases ($n = 52$) and controls ($n = 51$) 6–8 years after the birth of the next child (156). Notably, women who had case-level PTSD in the subsequent pregnancy continued to regard their stillbirth as traumatic and to have significantly higher symptom levels, and 80.8% of women with a previous stillbirth had above-threshold scores on intrusion symptoms.

The death of a child is shown to be negatively associated with parents long-term health-related QOL, particularly if the child died in violent circumstances (159). To our knowledge, there are no long-term follow-up studies after stillbirths that have included measures of quality of life.

Table 3. Core studies addressing mental health outcomes in the long-term (>1 year) or in the subsequent pregnancy among women bereaved by stillbirth*

First author, year, country	Study population	Methods	Main results
Rådestad, 1996, Sweden (5)	314 women who had a stillborn child (≥ 28 gestational weeks) and 322 who had a non-deformed liveborn child. 84% response rate.	Anxiety and depression symptoms assessed by questionnaire three years post-loss.	Ratio of 2.1 for anxiety symptoms above the 90 th centile. Similar findings for depression symptoms, but less accentuated (data not shown).
Boyle, 1996, Australia (157)	194 women who experienced stillbirth (n = 78), neonatal death or SIDS and 203 women with a surviving infant. 63% response rate and 79% retention rate for the stillbirth group.	Anxiety and depression symptoms measured by questionnaire at 2, 8, 15 and 30 months post-loss.	15 months follow-up: ratio for anxiety 2.65 and ratio for depression 2.65 (n.s.). 30 months follow-up: ratio for anxiety 2.09 (n.s.), ratio for depression 2.78 (n.s.).
Hughes, 1999 and 2002, United Kingdom (6, 160)	60 women whose previous pregnancy ended in stillbirth (≥ 18 gestational weeks) and 60 primi-gravid controls matched on age, ethnic origin and socioeconomic group. Response rate not given.	Anxiety and depression symptoms assessed by clinical interview from the third trimester of the subsequent pregnancy and up to one year postpartum.	Higher levels of depression, state anxiety and PTSD in the subsequent pregnancy after stillbirth. No significant differences 6 and 26 weeks postpartum, but a trend towards more depression (19% vs. 8%) one year postpartum.
Turton, 2009, United Kingdom (156)	52 women who gave birth to a living child after a previous stillbirth and 51 controls (same study population as the above).	Depression and PTSD symptoms assessed by clinical interview 6-8 years after the birth of a subsequently healthy baby.	No differences in case-level depression or PTSD. Women with case-level PTSD in the subsequent pregnancy continued to show higher symptom levels than others.
Hogue, 2015, United States (161)	275 women with a stillbirth (≥ 20 weeks) and 522 women who delivered a healthy live baby. Response rate not given.	Depressive symptoms assessed by telephone interview 6-36 months post-loss.	Higher prevalence of depression (14.8% vs. 8.3%). Association not significant after adjustment for history of depression and other confounders, except for women with no history of depression.

*A search for relevant subject headings in the Ovid Maternity & Infant Care database on Dec 22nd 2016 yielded 394 abstracts. Original research articles, with quantitative mental health or quality of life assessments in the long term (>1 year) or in the subsequent pregnancy after stillbirth, are included in this overview. Studies that were published before 1990, that do not provide comparisons with a reference population (no loss group) or mainly addresses miscarriages are not included.

5.5.3 Consequences for social relations and relationship with partner

Contrary to the loss of a live born child, stillbirths have historically been minimised by caregivers and society in general and parents may feel invalidated in their grief (4, 162-164). Although in western societies, stillbirths are no longer managed as a non-events, healthcare professionals recognition of their emotional and psychological impact is far from universal (146, 165, 166). Further, women who have been through stillbirth may become disenfranchised from their social groups (167, 168), and report lower self-esteem and less social appreciation compared with controls (169).

The relationship with the baby's father may also be affected by pregnancy loss. Bereaved women, especially those experiencing short-term psychological distress, but has a non-distressed partner, report lower marital satisfaction in the longer term (151). While some studies suggest that women with a previous stillbirth are more likely to experience subsequent relationship breakdown (156, 170), others have found similar rates of separation/divorce, and women's satisfaction with their partner relationship and domestic situation may even increase after experiencing stillbirth (169, 171). In a recent Finnish internet survey, parents affected by stillbirth reported to be more satisfied with their partner relationship than parents affected by child death due to other causes (172).

5.5.4 Women's experiences in relation to stillbirth and risk factors for psychological distress

In high-income countries the majority of stillbirths occur antepartum (14), and with the opportunity of modern ultrasound, most women are aware of their baby's death before the delivery. Often as a result of reduced fetal movements, many women report in retrospect that they had a premonition that something was wrong with the baby, but may be reluctant to contact healthcare services (173). When the diagnosis of death in utero is made, parents generally prefer healthcare professionals to be empathic, but straightforward about the results of examinations (2, 174). All stages of the process from having their greatest fear confirmed to going through labour, meeting and parting with their stillborn baby and being asked to consent to an autopsy, is potentially challenging for women and their partners (2, 174, 175).

In 2008 Line Christoffersen conducted a survey on 20 couples aiming to define critical incidents in the interaction with the Norwegian public healthcare service before, during and after stillbirth (174). Both Christoffersen, Rådestad and others emphasise that healthcare professionals play an important role in supporting the parents of stillborn babies during all phases of their stay in the hospital (174, 176, 177). Parents want guidance and advice, but

there should also be room for their own wishes (174), and mourning rituals should not be enforced (5). This is a delicate and sometimes difficult balance.

In the Swedish study from 1994, 80-90% of the participating women stated that the healthcare professionals showed respect and tenderness towards their baby and 70% reported that the hospital had good routines in supporting mothers of stillborn children (165). However, almost 40% reported feelings of sadness and having been deeply hurt or angered by the medical staff, and one third wished that the healthcare professionals had been more active in suggesting things to do with the baby. Most women stressed the importance of investigating causative factors and to have an explanation for the baby's death, in order to come to terms with their loss (175).

To reduce the risk of long-term psychological distress after stillbirth, it is important to study and evaluate current guidelines aiming to help women cope with this traumatic event and identify factors associated with increased risk of complicated grief or long-term psychological morbidity.

Fifty years ago, it was uncommon for parents to see or hold their stillborn infant (163). A stillbirth was considered a "non-event" and this still applies in many cultures (163, 164, 166). In high-income countries, such avoidance practices have now become rare and encouraging mothers and other close relatives to see, hold and dress the stillborn baby is procedure in many hospitals (166). In the study on 314 Swedish women who lost a child in stillbirth in 1991, Rådestad and colleagues reported that nearly every mother had seen and 80% had caressed their baby (165). Perceived support from healthcare professionals influence whether or not parents end up seeing and holding the baby, and how they experience these events (174, 176-179).

The evidence base for encouraging mothers to have contact with their stillborn is somewhat disputed. Observational studies demonstrate that women who did not see or hold their baby after stillbirth tend to regret this decision later as opposed to women who had this contact (158). Further, Rådestad and colleagues reported that women who in retrospect reported not being with their baby as long as they wished, had almost a seven-fold increase of depression symptoms and two-fold increase of anxiety symptoms after three years (5, 180). Mothers who did not hold their stillborn baby born after 37 gestational weeks had significantly higher risks for headache and sleep disorders, while the effect for mothers of stillborn babies born at 28-37 gestational weeks were uncertain (176). In a later study by Cacciatore, Rådestad and Frøen, women who were non-pregnant at follow-up, that had seen and held their stillborn

baby at the time of stillbirth, had fewer symptoms of anxiety and a tendency towards fewer symptoms of depression (158). Participants who were pregnant also had less depression symptoms, but more symptoms of anxiety if they had seen and held their baby. However, some researchers have called the benefit of confronting the baby into question. An observational study performed by Hughes, Turton and colleagues found that seeing and holding the stillborn infant was associated with more depression, anxiety and post-traumatic stress symptoms in the subsequent pregnancy and postpartum period, and increased risk of post-traumatic stress symptoms (PTSS) in the longer term (156, 160). A recent Australian study (n = 26) reported that seeing and holding the baby was associated with more active short-term grief, but not with coping or mental health (181).

Sharing memories of the baby and social and professional support is associated with better mental health following stillbirth (152, 168, 182, 183), with support from family members reported as most important (158). Cacciatore reported in a qualitative study that women with stillbirth who attended a support group, after adjusting for time, had fewer post-traumatic stress symptoms (148). However, although counselling and psychological support after perinatal death is offered routinely and are often valued by parents, Cochrane reviews from 2000, 2008 and 2013 have found no randomised controlled trials that demonstrate the benefits (184-186).

Other factors shown to be associated with psychological distress in women following stillbirth are: a long time from diagnosis to delivery (≥ 25 hours) (5), not possessing any token of remembrance (5), being unmarried, lower education or younger age (158, 168), a short time since the stillbirth (158, 182, 183), high parity at the time of loss and no subsequent pregnancy (180). Lack of children at home, older age, neurotic personality, and pre-loss psychiatric symptoms were associated with increased intensity of grief reactions in a study of women after miscarriage or stillbirth (187). The gestational age at the time of stillbirth may also affect the risk of psychological distress. Grief reactions after stillbirth are demonstrated to be generally stronger than those experienced after miscarriages (188-190), and may be stronger in women with late stillbirths compared with early stillbirths (174). However, Cacciatore and colleagues found third trimester losses to be associated with less anxiety symptoms than second trimester losses (158).

How experiences at the time of stillbirth are remembered and how specific actions of care affect women's mental health in the longer term remain uncertain.

5.5.5 Psychological distress in the subsequent pregnancy

Couples who experience stillbirth often quickly develop a strong desire to become pregnant again, and most embark on a subsequent pregnancy, about 50% within a year (6, 191). Some research indicate that the subsequent pregnancy serves as a reactivating stressor that may interfere with the normal grief process, and predispose women to more psychological distress (6, 182, 192). Observational studies describe elevated levels of depression symptoms (6), anxiety symptoms (6, 158), post-traumatic stress symptoms (182) and reduced levels of prenatal attachment in pregnancies following stillbirth (182).

Few studies have aimed to estimate the prevalence of psychological distress among women pregnant after stillbirth. In a prospective study on 60 women whose previous pregnancy ended in stillbirth (after 18 weeks of gestation) and 60 primi-gravidae, Hughes and colleagues reported third trimester case-level depression among 28% in the stillbirth group compared with 8% in the control group (p -value = 0.01)(6). The same study reported that 20% of the women pregnant after stillbirth fulfilled the criteria of PTSD compared with a general population prevalence of 0.4% to 4.6% (182). One year after the birth of a healthy baby, the prevalence of PTSD had decreased to about 5%.

Hughes, Turton and colleagues found that the elevated symptoms of anxiety and depression in the subsequent pregnancy were accounted for by women who conceived less than 12 months after the stillbirth (6). Post-traumatic stress disorder was also more prevalent among women with a short inter-pregnancy interval (182). Based on these findings, the researchers stated a potential advantage in delaying conception for at least a year. In contrast, other researchers have found that grief reactions may become stronger if a woman struggles for a long time to become pregnant (174, 193) and women pregnant after a stillbirth show less symptoms of depression compared with their non-pregnant counterparts (158). Thus, the subsequent pregnancy may also function as a reparative process for grief reactions and depressive symptoms after stillbirth.

Studies are somewhat conflicting as to whether symptoms of anxiety and depression following pregnancy loss diminish after the birth of a healthy baby. Hughes, Turton and colleagues found the subsequent pregnancy to be a reactivating, but self-limiting stressor after stillbirth (6, 182). Psychological distress diminished after the birth of a live born baby and symptoms of anxiety and depression were statistically indistinguishable between groups at six weeks and one year postpartum. Armstrong et al. similarly found decreased levels of depressive and anxiety symptoms three and eight months after the birth of a subsequently

healthy baby among 36 women with a history of miscarriage, stillbirth or neonatal death (194). Post-traumatic stress, however, remained in the moderate range eight months after the subsequent delivery. Conversely, in a more recent study by Blackmore et al. on women pregnant after previous pregnancy loss (mainly miscarriages), symptoms of depression and anxiety showed a persistent pattern up to 33 months after the birth of a healthy child (195).

To our knowledge, little data exists regarding the effects of a previous stillbirth on partner relationship in the subsequent pregnancy.

5.5.6 Healthcare utilisation in the subsequent pregnancy

In Norway, antenatal care is mainly conducted by primary healthcare services within the municipalities, while the specialist health services are responsible for care during birth and the early postnatal period (196). The routine antenatal care includes eight antenatal visits including one second-trimester ultrasound scan, with additional care as needed. The 5th consultation is usually carried out in week 32 of the pregnancy. Antenatal care is free of charge and provided as cooperation between midwives and physicians, mainly general practitioners. Currently, national guidelines on antenatal care for women pregnant after stillbirth are non-existent in Norway. However, according to colleagues in the obstetric field, the majority of women pregnant after stillbirth are probably offered additional antenatal care, often within the specialist healthcare services. In a recent international web-based survey, the majority of participating parents reported having attended additional antenatal visits and ultrasound scans, while care addressing psychosocial needs was less frequently reported (197).

Mothers pregnant after miscarriage or stillbirth often describe a sense of threat of an additional loss that remains heightened throughout the pregnancy, irrespective of individual medical risk (198, 199). This has been related to increased generalised and pregnancy specific anxiety (7, 199-203). Pregnancy specific anxiety often decreases over time among women with a history of early miscarriage (199). For women who have experienced pregnancy losses of more advanced gestation, anxiety levels may remain high or even increase closer to term (204, 205). Pregnant women with a prior loss often attempt to cope with their anxiety by telephoning healthcare professionals between visits, asking more questions and requesting additional tests (201, 205, 206). In a previous study including 36 women pregnant after miscarriage, stillbirth or neonatal loss, more frequent contacts with healthcare services regarding concerns about the baby was associated with maternal state anxiety and intrusion symptoms (7). However, anxiety as a potential mediator for increased healthcare utilisation in subsequent pregnancy has as far as we know not been previously investigated.

5.5.7 Induced labour and mode of delivery in the subsequent pregnancy

Although the caesarean section rate in Norway is relatively low compared to many other western countries, it increased from 4% in 1975 to 12.8% in 1987 and 16.8% in 2012 (1) . Induction of labour has also become more frequent, with current rates of about 18% (1). Although a caesarean section may be necessary to prevent a medical emergency, it is associated with both short-term complications (207) and complications in later pregnancies, such as uterine rupture, postpartum haemorrhage, placenta complications, and preterm delivery (208). The worldwide increasing use of interventions during childbirth, particularly caesarean section is of concern (209, 210) and cannot be fully explained by maternal medical factors or pregnancy and delivery complications (211). Some research indicates that increased caesarean section rate is partly a result of maternal requests, which in turn may be related to fear of childbirth (8, 209, 212-214).

Previous miscarriages and a variety of delivery experiences have been shown to be associated with fear of childbirth in subsequent pregnancies (215, 216). However, the potential relationship between a previous stillbirth, fear of childbirth and preferences for mode of delivery is not clearly established. In her qualitative report Christoffersen found that the majority of women with a previous stillbirth wished for a caesarean delivery in the subsequent pregnancy (174). However, in the follow-up study, Christoffersen and Teigen reported that many changed their minds after conversations with healthcare professionals (198). For the majority of the participating women in the latter study (16 out of 28), the subsequent delivery started by induced labour, however both elective and emergency caesarean sections were common. In a 2010 Australian internet survey investigating women's wishes for management in the pregnancy after unexplained stillbirth, 81% of the responders wanted delivery before the due date, but only 26% wanted caesarean section (206).

In 2000, Heinonen and colleagues assessed the subsequent pregnancy and delivery of 92 Finnish women with stillbirth due to other causes than maternal condition and fetal abnormalities (66). Stillbirth in the previous pregnancy was associated with significantly higher frequencies of caesarean section (30.4% vs. 13.4%) in unadjusted estimates. A retrospective Australian study by Robson et al. on 316 subsequent births after unexplained stillbirth, reported increased rates of preterm birth, induced labour, forceps delivery and caesarean delivery, both elective and emergency (65). The outcomes were only adjusted for age and parity, not comorbidity or obstetrical factors. A later study by Black et al. found similar results among women with previous stillbirths from all causes compared with women

with previous live births (70). The adjusted odds ratios were 3.2 for induced labour, 2.1 for caesarean section (all) and 3.1 for elective caesarean section.

Since there are no previous quantitative studies regarding mode of delivery in the pregnancy after a stillbirth in Norway and few international studies, further investigation is warranted. In order to optimise care, it is valuable to investigate factors that could account for increased use of interventions in pregnancies following stillbirth. Anxiety and fear of childbirth as potential mediators for elective caesarean section in this group has to our knowledge not been investigated previously.

Key messages from the introduction

- A stillbirth is a substantial loss for the parents and a potentially traumatic event
- Women in particular, are at risk of psychological distress for months and perhaps years after the incident
- The relationship with the baby's father may also be affected, although previous studies are conflicting
- Little is known about women's long-term mental health after stillbirth, and long-term quality of life has to our knowledge not been investigated previously
- Several sociodemographic, obstetric and care-related factors are associated with short-term psychological distress after stillbirth, but their role in the longer term remains uncertain
- Some researchers dispute the potential benefit of current guidelines encouraging mothers to see and hold their stillborn baby
- The subsequent pregnancy after stillbirth is a vulnerable period, often associated with anxiety, depression and post-traumatic stress symptoms
- There is a lack of knowledge regarding women's healthcare utilisation in the subsequent pregnancy after stillbirth
- Preterm delivery, induced labour and caesarean section is more prevalent among women pregnant after stillbirth, and the frequency of interventions may not be accounted for by pregnancy complications or medical risks
- Anxiety and dread of childbirth may be potential mediators for increased healthcare utilisation and elective caesarean section in the pregnancy after stillbirth

6 Aims

The overall aims of this thesis were to study the long-term quality of life and mental health of women with a previous stillbirth, and to investigate the impact of stillbirth on the subsequent pregnancy. More specifically, the main aims were to:

Paper

- I
 - Measure long-term quality of life, well-being and depression symptoms in women with a history of stillbirth
 - Study the influence of sociodemographic, obstetric and health-related variables on quality of life, well-being and depression
- II
 - Measure long-term post-traumatic stress symptoms related to stillbirth and estimate the proportion above a clinical case-level and PTSD case-level
 - Describe women's long-term memories related to the stillbirth, and identify possible risk factors for long-term post-traumatic stress symptoms
- III
 - Estimate the frequency of case-level anxiety, case-level depression and dissatisfaction with partner relationship in the pregnancy after stillbirth and after a subsequent delivery
 - Assess the duration of the inter-pregnancy interval and gestational age at stillbirth as potential risk factors for anxiety and depression in the subsequent pregnancy
- IV
 - Investigate women's use of healthcare services and frequency of induced labour and caesarean section in the pregnancy after stillbirth
 - Assess anxiety and dread of childbirth as mediators for the frequency of antenatal visits and elective caesarean section

7 Materials and methods

This thesis presents results from two large observational studies.

The first part of the thesis (Papers I and II) is based on a retrospective study on women with a previous IUFD and a control group of women with only live births. This study is part of the hospital-based Venous Thromboembolism in Pregnancy (VIP) study, registered as a clinical observational study at www.clinicaltrials.gov (registration number NCT00856076). Previous theses from the VIP study have investigated epidemiology and risk factors for pregnancy-related venous thrombosis (217, 218), long-term consequences of pregnancy-related venous thrombosis (219) and classification and risk factors for IUFD (220). I was recruited to the project in January 2010, as a student on the Medical Student Research Program at the University of Oslo. Thus, I was not involved in the planning of the study or the data collection.

The second part of the thesis (Papers III and IV) is based on a prospective study on women pregnant after stillbirth, women pregnant after a live birth and pregnant women that were previously nulliparous. This study is a substudy to the Norwegian Mother and Child Cohort study (MoBa) and includes additional information from the Medical Birth Registry of Norway (MBRN), a national health registry containing compulsory notifications of all pregnancies ending after 12 gestational weeks (≥ 16 gestational weeks until 1999) (221). MoBa is a large population-based pregnancy cohort study conducted by the Norwegian Institute of Public Health (222). I conducted the main work in planning this substudy, which is based on version VIII of the quality-assured data files released for research on 14th of February 2014. Detailed information about MoBa and all relevant questionnaires are available at www.fhi.no/en/studies/moba/.

7.1 Study populations

7.1.1 First study (papers I and II)

Cases

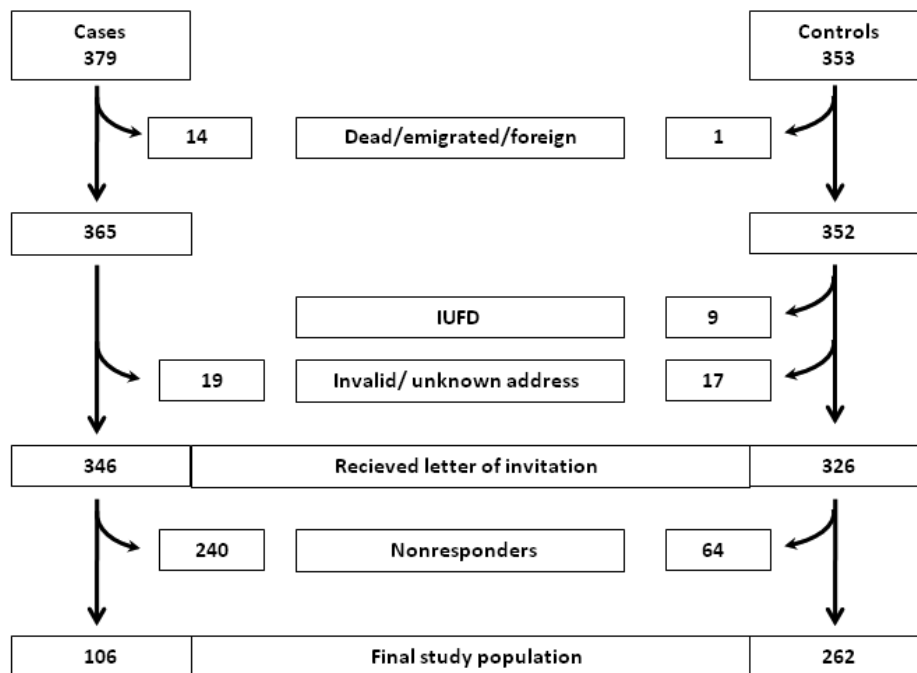
Women with IUFD between 1990 and 2003 at Oslo university hospital, Ullevål and Akershus university hospital were identified through the hospital administration systems by searching for the following ICD-codes: 656.4 – “intrauterine death affecting management of mother” (ICD-9) and O36.4 – “maternal care for intrauterine death” (ICD-10), and 434 possible cases were identified. Medical records were then extracted and IUFD was verified by the following definition: fetal death in a singleton or duplex pregnancy at ≥ 23 completed gestational weeks or birth weight ≥ 500 g. After excluding eight cases with non-retrievable records and 49 with incorrect diagnosis, 377 cases had a verified diagnosis of IUFD. Additionally, two women with a previous IUFD that fulfilled the inclusion criteria, but were not previously identified, contacted the study after having heard of it through the Norwegian Sudden Infant Death and Stillbirth Society. Women who had died, emigrated or did not have a valid Norwegian address were excluded. A total of 346 cases were eligible for participation and were approached by an invitation letter in 2008 outlining the purpose of the study. Those who were interested contacted our group by telephone or e-mail to schedule an appointment to answer the study questionnaire and donate a blood sample (used in a previous part of the study). After two reminders, 106 (31%) women with a history of IUFD consented to participate (Figure 2).

Controls

The control group for the VIP study ($n = 1229$) consisted of women naïve of venous thromboembolism, with a singleton or twin birth at Oslo University hospital between 1990 and 2003 (223). Four women with a singleton or twin birth at the same time as one woman with a pregnancy-related venous thrombosis were selected using data from the MBRN. The two women first listed were prioritised as controls, but if their medical records were not retrievable, they were replaced by the third and/or fourth woman. After the exclusion of women who were dead, foreign, had emigrated or did not have a valid Norwegian address, 1092 eligible controls received an invitation letter outlining the purpose of the study. Those who were interested contacted the study group by telephone or e-mail to schedule an appointment to answer the study questionnaire and donate a blood sample in 2006. A total of 353 women (32.3%) consented to participate in the first part of the VIP study (224). These women also consented to receive a new invitation letter for the second part of the VIP study concerning IUFD. However, in 2008, it turned out that nine controls had a history of IUFD and 18 had died, emigrated or did not have a valid Norwegian address. Thus, a remaining total of 326 women were eligible for participation in this part of the study and were sent an

invitation letter and the study questionnaire. After two reminders, 262 women had consented to participate and returned the questionnaire (Figure 2).

Figure 2. Flowchart for the selection of the study population in the first study (modified from LB Helgadottir (220) with permission)



7.1.2 Second study (papers III and IV)

The participants in MoBa are women who were pregnant between 1999 and 2008 that were recruited from all over Norway. The women were sent a postal invitation together with their routine ultrasound appointment card and consented to participate in 40.6% of invited pregnancies. The MoBa cohort now includes more than 100 000 pregnancies, 95 000 mothers, 75 000 fathers and 114 000 children (225).

This substudy included selected data from MoBa for:

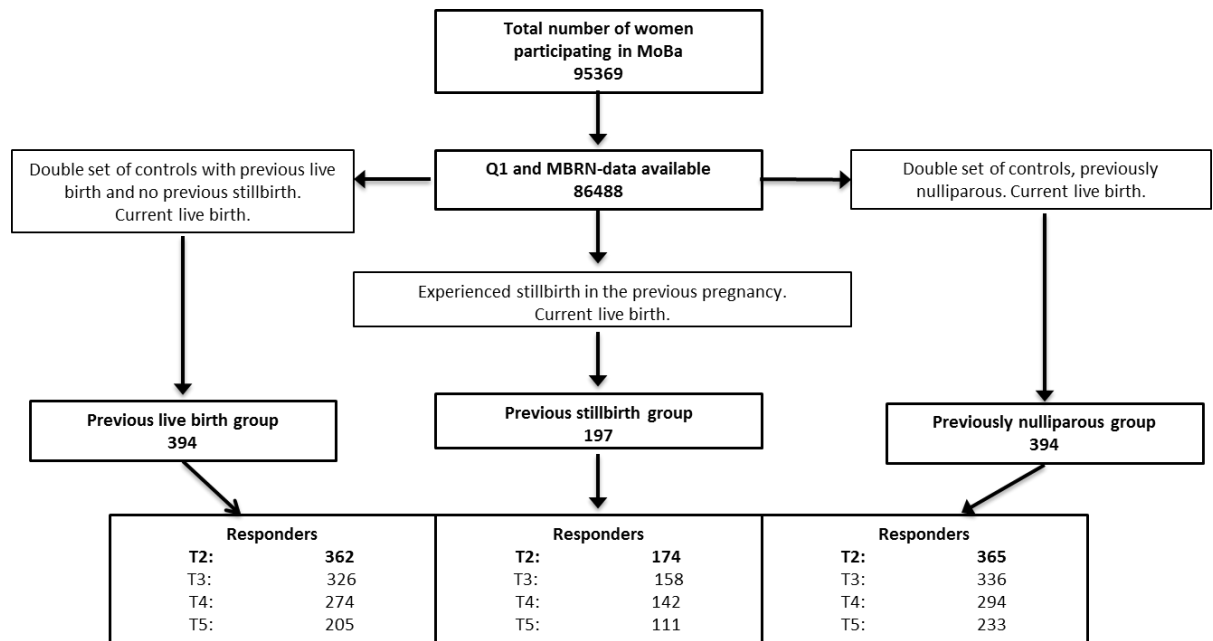
1. Women pregnant again following a stillbirth (stillbirth group) and two reference groups:
2. Women pregnant subsequent to at least one live birth and no previous stillbirth (live birth group)
3. Pregnant women who were previously nulliparous (nulliparous group)

Selection criteria for all three groups were:

1. Responded to the first MoBa questionnaire and available data in the MBRN
2. Singleton or twin pregnancy in MoBa and in the pregnancy prior to MoBa (previous stillbirth or live birth group)
3. The pregnancy in MoBa resulted in a live birth
4. Women who participated in with more than one pregnancy was only selected once

Identification and selection of the substudy population was performed by the MoBa administration following our instructions. Details regarding previous pregnancies were obtained from the first MoBa questionnaire, and the information was verified using data from the MBRN. Stillbirth was defined according to WHO's ICD-10 as fetal death at ≥ 22 completed weeks of gestation or fetal weight ≥ 500 grams (11). A total of 197 women with a stillbirth in their previous pregnancy were identified. Due to the use of previous MBRN data for identification of the study population, the Regional Ethical Committee only allowed us to include a limited number of reference women instead of using the entire MoBa population as a reference. Aside from the previously stated selection criteria, the two reference groups were randomly selected from the entire MoBa cohort. Each reference group included 394 women. At the second assessment (30 gestational weeks), 174 women with a previous stillbirth, 362 with a previous live birth and 365 nulliparous women completed the questionnaire. Only 99 women in the stillbirth group, 189 women in the live birth group and 218 women in the nulliparous group answered all five questionnaires. A flowchart for the selection of the substudy population is provided (Figure 3).

Figure 3. Flowchart for the selection of the study population in the second study



MoBa: The Norwegian Mother and Child Cohort Study
 MBRN: Medical Birth Registry of Norway
 T2: Responders at 30 gestational weeks
 T3: Responders at 30 gestational weeks and 6 months postpartum
 T4: Responders at 30 gestational weeks and 18 months postpartum
 T5: Responders at 30 gestational weeks and 36 months postpartum

7.2 Measures

Questionnaires are the main source of data on which this thesis is based. Additionally, we had access to information from medical records at the time of the index pregnancy (Papers I and II) or from the MBRN (Papers III and IV).

7.2.1 First study (papers I and II)

The data were collected in 2008–2009, accordingly 5-18 years after the stillbirth. The first part of the study questionnaire was administered to both cases and controls and included information on current sociodemographic factors, obstetrical history, general health and three scales measuring QOL, well-being and symptoms of depression. The second part of the questionnaire was exclusively given to women with a previous stillbirth and was answered by the majority of cases (101/106). This part of the questionnaire was designed to investigate the women's experiences at the hospital around the time of the stillbirth, in close collaboration with Professor Ingela Rådestad who has extensive experience in this field. A scale measuring post-traumatic stress symptoms related to the experience of stillbirth was also included. Prior to the study, this part of the questionnaire was tested in a pilot sample of women with a previous stillbirth (N = 20). The candidates were instructed to report any misconceptions and the questionnaire was revised accordingly. The questionnaire was considered to be understandable and of good quality. The completed questionnaires were optically scanned and transferred electronically to the project database. Consistency analyses were run to check for scanning errors and invalid data entries were corrected.

Outcome variables

Quality of life

For the evaluation of long-term QOL, the generic Ferrans and Powers QOL Index (QLI) version II (110) was chosen. The QLI is used worldwide and provides a holistic, multidimensional construct of QOL in accordance with existing literature and the WHO-QOL group's definition (108, 226). It emphasises the subjective nature of QOL as a concept by measuring both satisfaction with various aspects of life as well as individual subjective importance rating of the same aspects (227). In addition to measuring overall QOL the global scale has a factor structure that can be subclassified into four subdomains: 1) health/functioning (14 items), 2) psychological/spiritual (seven items), 3) socioeconomic (nine items), and 4) family (four items) (227). The scale has been translated into Norwegian and validated (228) and has shown a high degree of validity and reliability in various other studies (110, 229-231).

We used standard scoring algorithms for the QLI available at www.uic.edu/orgs/qli. (Current scoring algorithms presented on the website are applicable for the QLI version III). The 34 items are rated by a response ranging from 1 (low satisfaction/low importance) to 6 (high satisfaction/high importance). The item scores are then calculated on a Likert scale ranging from 0 to 5, weighing the scores on the satisfaction ratings by the importance ratings on the corresponding items. This yields a score range of 0-30 for the global scale, with high values denoting high QOL. Combinations of high satisfaction and high importance responses produce the highest scores, while the lowest scores are produced by low satisfaction and high importance responses. The total score was not calculated if more than five items were missing among either the satisfaction responses or the importance responses (227). If less than five items were missing, the individual's mean score on the non-missing items were imputed. In our study, the Cronbach's alpha of internal consistency ranged from 0.70 to 0.91 for the four subdomains of the QLI and 0.94 for the global scale.

Well-being

Subjective well-being was measured by Goldberg's General Health Questionnaire (GHQ) (232). The GHQ was originally developed as a screening tool to detect individuals with or at risk of having a non-psychotic psychiatric illness (i.e. anxiety or depression) in the general population (233), but has frequently been used as an assessment of psychological well-being (232, 234-236). The 20-item version (GHQ-20) has been translated into Norwegian and shown satisfactory validity and reliability (236, 237). It reflects both positive and negative aspects of psychological health and functioning, and comprises both emotional and cognitive judgments. Each item is rated on a 4-point Likert scale; 1) less than usual, 2) no more than usual, 3) rather more than usual or 4) much more than usual). Positively phrased items were scored in reverse so that high scores on any question were consistent with lower well-being or conversely, more psychological distress, giving a total range of 0-60. The total score was not calculated if more than half of the items were missing ('half-item rule') (238). If less than half of the items were missing, the individual's mean score on the non-missing items were imputed. The Cronbach's alpha was 0.88.

Depression

To measure symptoms of depression the Center for Epidemiological Studies Depression Scale (CES-D) was used (239). The scale was developed to identify the presence of depression symptoms in the general population and individuals with a high risk of clinical depression. The CES-D consists of questions regarding the frequency and duration of depression symptoms experienced within the most recent week, and covers major components of depression, including depressed mood and feelings of worthlessness as well as physiological

components such as loss of appetite and sleeping problems. The scale is applicable across various demographic groups and settings and is demonstrated to have high validity and reliability in clinical as well as pregnant and postpartum samples (239-243). The CES-D comprises 20 items rated on a 4-point Likert-scale ranging from 0 (“rarely”) to 3 (“all the time”) and the range of the total score range is 0–60. A global score of 16 or more indicates a (possible) case-level for depression symptoms (239, 241). According to its factor structure, the CES-D can be subdivided into four subdomains: 1) depressed affect (seven items), 2) positive affect (four items), 3) somatic affect (seven items), and 4) interpersonal domain (two items). If more than four items were missing on the entire scale, the scores were not calculated (239). If four or less items were missing, the individual’s mean score on the non-missing items were imputed. The Cronbach’s alpha ranged from 0.69 to 0.83 for the four subscales and 0.87 for the global score.

Experiences at the hospital before, during and after the stillbirth

The cases were asked about experiences in relation to the diagnosis of IUFD, the delivery, approaching the baby postpartum, their stay at the hospital and follow-up in the aftermath. We were especially interested in the women’s long-term evaluation of the care they received from healthcare professionals. The most central questions about the time before, during and after the delivery were:

- Did you suspect that something was wrong with the baby before a doctor or midwife told you? If so, did you contact healthcare services about your suspicion? Were further investigations conducted?
- Did you know that your baby was dead before the delivery started? If so, for how long did you know?
- Who informed you about the baby’s death? To what degree are you satisfied with the way this information was conveyed?
- Where did you deliver your baby? How did the delivery start? If any, what kind of medication did you receive during the delivery?
- Did you have the baby’s father, a close relative or friend with you during the delivery?
- Where did you stay after the delivery?
- Were you asked for permission to perform an autopsy of the baby? If so, how did you feel about this request? Was an autopsy performed?
- Did you receive an explanation for your baby’s death? How important do you consider such an explanation?

- Did you receive any short-term follow up? If so, what kind?

The following questions were included to investigate to what degree and under what circumstances the women had contact with their stillborn baby:

- Did you wish to see/hold the baby?
- Did you see/hold the baby? If so, under what circumstances?
- How did you experience seeing/holding the baby?
- How much time did you spend with the baby during the hospital stay? Did you spend as much time as you wanted with your baby after the delivery?
- If you did not see/hold your baby after the delivery, what was the reason? Do you regret this decision in retrospect?
- Have you kept any pictures or tokens of remembrance from the baby?
- Was the baby given a name?
- Was a memorial or funeral held for the baby?

The women were also asked whether they agreed on various statements about the experience of the delivery, how the healthcare professionals approached the baby and the role of healthcare professionals in supporting the parents after the delivery. Most questions had several response alternatives for the women to tick the best fitted. If none of the alternatives fitted, they could write the answer in an open text box. Also included in the questionnaire were some open questions with fields to describe experiences in the women's own words.

Post-traumatic stress symptoms

To measure post-traumatic stress symptoms the widely used Impact of Event Scale (IES) (244) was used. The IES is a frequently used instrument with good psychometric properties to measure the degree of subjective psychological distress after a traumatic event and screen for PTSD in various populations (245-247). The IES has been widely used in the general population after trauma exposure (248) and has also been assessed to measure short-term post-traumatic stress symptoms among women with a late miscarriage/stillbirth or termination of pregnancy do to fetal anomaly (147). The scale consists of 15 questions, seven items that measures intrusion symptoms and eight items that measure avoidance symptoms. Each item is scored on a six-point Likert-scale with response alternatives from 0 = 'never' to 5 = 'a high degree'. The range of the total scale is 0-75 and higher scores indicate more post-traumatic stress symptoms. In accordance with several previous studies, we regarded a total IES score of ≥ 20 as a high level of symptoms and a score of ≥ 35 as severe symptoms with a high probability of a PTSD diagnosis (245, 249-251). The cases in our study were instructed to

answer the IES questions relating to their prior stillbirth as the index event. If only one item was missing in each of the two subscales, the item was replaced with the mean score of the remaining seven/eight items for that respondent. Three of the 101 cases had more than one missing item in each subscale and were excluded, resulting in $n = 98$ in the IES analyses. The Cronbach's alpha of internal consistency was 0.94 for the intrusion subscale, 0.90 for the avoidance subscale and 0.94 for the total IES score.

Other independent variables and covariates

As outlined in the introduction section, sociodemographic and obstetrical factors are associated with mental health outcomes after stillbirth (158, 168, 180). Additionally, we considered BMI and health-related factors to be relevant as descriptive variables and potential covariates for the assessment of QOL and mental health. The majority of these variables were derived from the study questionnaire and included age at follow-up (years), country of birth (Norway vs. other), marital status, educational level, occupational status, household income, BMI, smoking, alcohol consumption, parity, number of liveborn children, miscarriages, terminations of pregnancy, comorbidity, sick leave, prevalence of pain, overall subjective assessment of own health and physical/mental exhaustion from work. Information about gestational age at the time of stillbirth (completed weeks), time since the index pregnancy (years) and maternal age at the time of stillbirth (years) was derived from medical records. For cases with multiple stillbirths in the study period, the index pregnancy was defined as the pregnancy in which the first stillbirth occurred. Further details regarding all covariates and how they were categorised are described in Papers I and II.

Information from medical records at the time of the index pregnancy included demographic and clinical factors, results from the post-mortem examination of the baby, histopathological examination of the placenta and laboratory data. This information was mainly addressed in a previous thesis by Linda Björk Helgadóttir on risk factors and classification of IUFD (220). For evaluation of potential selection bias, responders and non-responders were compared according to demographic and clinical factors at the time of the index pregnancy (Table 4).

7.2.2 Second study (papers III and IV)

In this substudy, we assessed data from the questionnaires answered at approximately 17 and 30 weeks of gestation in the MoBa pregnancy (Q1 and Q2) and 6, 18 and 36 months after the delivery of a subsequent live born baby (Q3-Q5). Background variables from the MBRN for the MoBa pregnancy and the previous pregnancy (previous stillbirth or live birth group) were also assessed.

Outcome variables

Anxiety and depression

Anxiety and depression symptoms in the recent fortnight were measured using the eight-item version of the Hopkins Symptoms Checklist (SCL-8). The SCL-25 is widely used as a screening tool to detect symptoms of anxiety and depression in various populations and shows a high concordance with clinical assessments of symptom-based psychiatric illness (252). Short versions of the SCL are shown to correlate highly with the original SCL-25 scale and to have good psychometric properties with high validity and reliability (253-255). Similar to the SCL-25, the SCL-8 can be subdivided into two subscales consisting of four items measuring depression (SCL-4d) and four items measuring anxiety (SCL-4a) (255, 256). The correlation between SCL-8 and SCL-25 is 0.94 for the total score, 0.92 for the depression subscale and 0.90 for the anxiety subscale (255). Thus, for most scientific purposes the SCL-8 can replace the SCL-25 as a screening tool for anxiety and depression (255). We hypothesised that women pregnant after a stillbirth would display higher levels of anxiety than depression, and these outcomes were therefore treated separately in our study. Different cut-offs have been applied to indicate possible case-levels or clinically significant symptom levels. A mean score of 1.75 or more (≥ 1.75) is the conventional cut-off for SCL-25, whereas a score of 2.0 or more is shown to be more correct for short versions of the SCL (253, 255). Accordingly, we defined a mean score of ≥ 2.0 as the presence of case-level anxiety and/or depression symptoms in our study. To reduce potential sample distortion caused by missing values, the Estimation-Maximization procedure in SPSS was used to impute missing values on SCL-4a and SCL-4d if at least two items were present. In the current substudy, Cronbach's alpha of internal consistency was 0.69-0.80 for the anxiety subscale and 0.77-0.81 for the depression subscale.

Relationship satisfaction

We used a five-item version of the Relationship Satisfaction Scale (RS) to measure perceived maternal relationship satisfaction among married/cohabiting women (131). Constructed for MoBa, the RS consists of 10 typical items from previously developed scales covering marital

satisfaction and relationship quality (257-260). The RS has good psychometric properties with high reliability and validity (131), correlates 0.92 with the Quality of Marriage index (261) and is highly predictive of future relationship dissolution and life satisfaction (131, 262, 263). The abbreviated five-item version (RS5) correlates 0.97 with the full 10-item version (131). Each item is rated on a 6-point Likert scale ranging from 1) “strongly agree” to 6) “strongly disagree,” and the total score is computed as the average score of all items. A total score below 4.0 implies a relatively high probability of future relationship dissolution (11-15%) and was defined as a cut-off for relationship dissatisfaction (131). The Estimation-Maximization procedure was used to impute missing values on RS5 if at least three items were present. Cronbach’s alpha for RS-5 ranged from 0.87 to 0.90 in our study.

Healthcare utilisation

Questions about healthcare utilisation in pregnancy were included in the questionnaire answered by the participants at 30 weeks of gestation (Q2). The women were asked where they had their antenatal visits (multiple responses) with the following response alternatives; 1) family healthcare centre, 2) physician’s office and 3) hospital outpatient clinic. They were also asked about the number of antenatal visits at each place and the total number of visits was summarised. Further, they were asked if they had had any unscheduled contacts with midwife and/or physician, the number of ultrasound scans (abdominal/vaginal) they had went through and whether or not they had been admitted to hospital during the pregnancy.

Induced labour and caesarean section

Information about induction of labour and caesarean section in the MoBa pregnancy was derived from the MBRN. Onset of labour was classified as spontaneous, induced or CS. Mode of delivery was classified as vaginal birth or CS. Vaginal birth was subclassified as spontaneous or instrumental (vacuum-assisted or forceps-assisted). CS was subclassified as elective or emergency. Elective CS included those planned >8 hours before the delivery, while emergency CS included all other CS.

Other independent variables and covariates

Sociodemographic factors, comorbidity and obstetrical factors are associated with antenatal healthcare utilisation and mode of delivery (210, 211, 264), and were therefore considered to be relevant covariates. Sociodemographic variables were obtained from the questionnaire administered to women in gestational week 17 (Q1), and included marital status, native language (Norwegian vs. other), pre-pregnancy daily smoking, pre-pregnancy BMI, educational level and maternal income. Other variables obtained from Q1 were parity

(verified with information from the MBRN), previous miscarriage(s) and termination(s) of pregnancy. For all three groups, information from the MRBN regarding the MoBa pregnancy was retrieved and included maternal age at the time of delivery (years), pre-pregnancy comorbidity, complications in current pregnancy (bleedings, hypertensive disorder, diabetes, twin gestation and SGA), gestational age at the time of delivery (days), macrosomia (birthweight >4.5 kg) and dystocia (dystocia, feto-pelvic disproportion, abnormal labour and augmentation of labour). For the stillbirth and live birth groups, information from the MBRN regarding the previous pregnancy was obtained and included gestational age (days), inter-pregnancy interval (months between the date of stillbirth and the subsequent conception), complications in previous pregnancy (hypertensive disorder and diabetes), previous instrumental vaginal delivery (forceps or vacuum-assisted) or previous caesarean section (all previous pregnancies). Further details regarding these covariates and how they were categorised are described in Papers III and IV.

Stressful life events

In addition to sociodemographic and obstetrical factors, the occurrence of recent stressful life events is associated with psychological distress in pregnancy (265) and was considered a relevant covariate for the association between previous stillbirth and anxiety/depression in the subsequent pregnancy. The item was obtained from Q2 (30 gestational weeks). Occurrence of a stressful life event was defined as experiencing at least one of the following during the last 12 months: 1) Problems at work or study place, 2) financial problems, 3) divorce/separation/relationship break-up, 4) conflicts with family or friends, 5) serious injury or illness to the woman herself or a loved one, or 6) involvement in a serious accident, fire or robbery. For the purpose of this substudy, the “loss of a loved one” was not included as a stressful life event as it could include the experience of stillbirth.

Dread of childbirth

Dread of childbirth was considered a potential mediator for the association between previous stillbirth and elective caesarean section in the subsequent pregnancy. This was obtained from the MoBa questionnaire answered in gestational week 30 (Q2). The participants were instructed to respond to the statement “I am really dreading giving birth” with one of six response alternatives: 1) “I agree completely”, 2) “I agree”, 3) “I agree somewhat”, 4) “I disagree somewhat”, 5) “I disagree” and 6) “I disagree completely”. The answers were dichotomised, defining score 1 and 2 as “dread of childbirth” and 3-6 as “no dread of childbirth”.

7.3 Statistical procedure

All statistical analyses were performed using the Statistical Package for the Social Sciences version 15.0, 18.0 or 22.0 (IBM SPSS Inc., Chicago, Illinois, USA). Findings with two-sided P values <0.05 were considered statistically significant. Descriptive statistics were used to present the characteristics of the study population in both studies. Categorical data were presented as counts and percentages, while continuous variables were presented as mean or median with standard deviation (SD), range, 95% confidence intervals (CI) or interquartile range (IQR). The two-sided Pearson's chi-square test was used to compare categorical variables according to group. The Student's t-test was used to compare continuous variables between groups if the distributions were close to normal; otherwise, the non-parametric Mann-Whitney U test was applied. In order to investigate the association between a previous stillbirth and the various outcomes, bivariate and multivariate linear and logistic regression models were used. Covariates thought to influence the association between the main exposure variable (previous stillbirth) and the various outcomes were selected on the basis of existing literature and pre-analytical assumptions. Results from the linear and logistic regression models are presented as betas (B) and adjusted betas (aB) or odds ratios (OR) and adjusted odds ratios (aOR), respectively, with 95% confidence intervals (95% CI). Interactions between the exposure variable (stillbirth) and covariates that remained significant in the final models were tested separately, one term at the time. Details of the differing statistical procedures in each paper are outlined in the following sections.

Paper 1

Main aim: To assess long-term QOL, depression and well-being after stillbirth

Details of the statistical procedure: For the multivariate analyses of the global QLI score, the GHQ-20 score and the global CES-D score, the following variables were regarded as potential covariates: age, education, household income, BMI, daily smoking, alcohol consumption, comorbidity, pain, sick leave within the past 12 months, physical/mental exhaustion from work, subjective assessment of own health and previous miscarriage. In the multivariate analyses of global QLI and GHQ-20, linear regression models were applied. The global CES-D score was dichotomised at the predefined cutoff ≥ 16 indicating case-level depression, and a logistic regression model was applied. Covariates that were unevenly distributed between cases and controls ($p < 0.2$), associated with the outcome variable ($p < 0.2$) were included in the multivariate models. In order to limit the number of variables in the final models, forward variable selection (Wald) was used. Age and previous stillbirth was included as covariates in all final models.

Paper II

Main aim: To describe women's experiences related to the prior stillbirth, assess long-term PTSS and investigate potential risk factors for this outcome

Details of the statistical procedure: The global IES score was dichotomised at the pre-defined cut-off ≥ 20 indicating clinically significant PTSS. To identify risk factors for long-term PTSS ≥ 20 , bivariate and multivariate logistic regression models were used. As outlined in the introduction section, maternal contact with the baby and other factors related to the stillbirth can in addition to sociodemographic and obstetrical factors associated with psychological distress (5, 148, 158, 160, 180). Thus, the following covariates were considered as potential predictors for PTSS after stillbirth; age at the time of stillbirth, marital status, relationship dissolution after stillbirth, country of birth, household income, education, occupational status, parity at the time of stillbirth, gestational age at stillbirth, time (years) since stillbirth, previous miscarriage, termination of pregnancy prior to stillbirth, live birth after stillbirth, time from diagnosis to delivery, having the baby's father or a close relative/friend present during the delivery, having held the baby, amount of time spent with the baby, autopsy conduction, having arranged a memorial ceremony for the baby, postpartum consultation with the obstetrician and additional follow-up. Variables that were associated with IES ≥ 20 ($p < 0.2$) were included in a multivariate logistic regression model, using forward variable selection (Wald).

Paper III

Main aim: To assess case-level anxiety, depression and relationship dissatisfaction in the pregnancy after stillbirth and after the subsequent delivery.

Details of the statistical procedure: The McNemar's test was used to analyse the over-time variability in the frequency of case-level anxiety, depression and relationship satisfaction in each of the three groups. Bivariate and multivariate logistic regression models were used to investigate the association between previous stillbirth and case-level anxiety and depression in the subsequent pregnancy. The following variables were regarded as potential covariates; age, marital status, native language other than Norwegian, pre-pregnancy daily smoking, BMI, education, maternal income, previous miscarriage, previous termination of pregnancy and stressful life events. Covariates that were unevenly distributed between the groups ($p < 0.1$) and associated with the outcome variable ($p < 0.1$) were included in the multivariate analyses. Age was included as a covariate in all the multivariate models. For the stillbirth group, separate bivariate regression models were used to investigate if gestational age at the time of stillbirth or duration of the interval between pregnancies were significant risk factors

for anxiety or depression in the subsequent pregnancy. To preserve power and reduce the number of comparisons, we combined anxiety and depression for these subgroup analyses.

Paper IV:

Main aim: To assess healthcare utilisation, induced labour and caesarean section in the pregnancy after stillbirth and assess anxiety and dread of childbirth as mediators for the frequency of antenatal visits and elective caesarean section.

Details of the statistical procedure: Bivariate and multivariate linear regression models were used to investigate the association between previous stillbirth and healthcare utilisation (frequency of antenatal visits), while logistic regression models were used to assess the association between stillbirth and induced labour, caesarean section (all) and elective caesarean section. The following variables were regarded as potential covariates; age, marital status, pre-pregnancy daily smoking, pre-pregnancy comorbidity, hypertensive disorder in previous pregnancy (stillbirth vs. live birth group), bleedings in pregnancy, hypertensive disorder in pregnancy, diabetes in pregnancy, SGA and twin gestation. Covariates that were only relevant when comparing the previous stillbirth group with the previous live birth group were: parity, hypertensive disorder in previous pregnancy, previous instrumental vaginal delivery, previous caesarean section and inter-pregnancy interval. For the association between previous stillbirth and induced labour or caesarean section, additional delivery factors were included; macrosomia, preterm birth and delivery after 41 gestational weeks. Induction of labour was considered as a covariate for the association between previous stillbirth and CS. Covariates that were unevenly distributed between the groups ($p < 0.1$) and associated with the outcome variable ($p < 0.1$) were included in the multivariate analyses. Age was included as covariate in each multivariate model.

To limit the number of comparisons, testing for mediators was restricted to the multivariate models comparing women with a previous stillbirth to women with a previous live birth.

Anxiety was tested for bivariate association with frequency of antenatal visits and elective caesarean section, while dread of childbirth was tested for bivariate association with elective caesarean section. If associated with the outcome variable ($p < 0.1$) the potential mediators were included in the multivariate models. Mediation analyses were conducted using the procedure described by Baron and Kenny (266). Since the mediator variables (anxiety and dread of childbirth) and one of the outcome variables (elective caesarean section) were dichotomous, the regression coefficients were standardised to make them comparable before testing the significance of the mediating effect using the Sobel test (267, 268).

7.4 Power analyses

First study (VIP): This study was originally designed to investigate the epidemiology of pregnancy-related venous thrombosis and IUFD. Although far from ideal, a post-hoc analysis was conducted to assess the power of our study to detect differences in global QOL. We considered a minimum difference of 2 (50% of SD) units on the global QLI as a moderate effect size and a clinically relevant difference (269). The SD for global QLI was 4.0 among the controls in our study and this is consistent with previous studies in the Norwegian and Swedish female population (270, 271). When performing an independent samples t-test with a 5% type I error and a sample size of 106 cases and 262 controls (SD = 4.0), our study would have >95% power to detect such a difference.

Second study (MoBa): When planning this substudy, we conducted a power analysis to estimate the necessary sample size for assessments of the main outcomes, i.e. the frequency of case-level anxiety and depression in the pregnancy after stillbirth. The analysis was based on findings from a previous study that reported high levels of depression symptoms among 28% of women pregnant after stillbirth compared with 8% of controls (6). Assuming a prevalence of 25% for case-level depression or anxiety symptoms in the subsequent pregnancy after a stillbirth and 10% for reference women, a sample size of N = 100 in each group yields 80% power for detecting differences of this magnitude using a 5% significance level. However, since we aimed to investigate multiple outcomes as well as to perform subgroup analyses, we applied for permission to include all women in MoBa with the most recent pregnancy ending in stillbirth and twice as many participants in each reference groups.

7.5 Ethical aspects

First study (VIP): The regional Committee for Medical Research Ethics, Region East, Norway, approved the study. Authorisation for the use of information from medical records for research purposes was obtained from the Norwegian Ministry of Health and Social Affairs. The Norwegian Data Inspectorate approved the use of data comprising sensitive personal health information. The study was approved by the Data Protection Official at Oslo University Hospital.

Second study (MoBa): The MoBa study was approved by the Regional Committee for Medical Research Ethics and the Norwegian Data Inspectorate. Additionally, this substudy received specific approval by The Regional Committee for Medical Research Ethics in South-Eastern Norway. The MoBa group Norwegian extracted the relevant data for this substudy and no personal data were sent to our research group.

All participants in both studies provided written informed consent approving the use of the information provided for research purposes. The participants in the MoBa cohort specifically approved the linking of questionnaire data with data from the MBRN upon recruitment. The studies were purely observational and did not include any interventions. Although participants are shown to report high levels of satisfaction and no increase in anxiety when participating in stillbirth research (272), we assumed that participation in research could be strainful for women with a previous stillbirth. In the first study, which was conducted by our group, healthcare professionals were available for support when the women met to fill out the questionnaires.

8 Summary of results

8.1 Paper I

Long-term impact of intrauterine fetal death on quality of life and depression: a case-control study. Gravensteen IK, Helgadóttir LB, Jacobsen EM, Sandset PM, Ekeberg O. *BMC pregnancy and childbirth*. 2012;12:43.

In this paper we compared cases and controls on sociodemographic, obstetrical and health-related variables and assessed the level of global QOL, well-being and depression symptoms in the long-term (after 5-18 years).

Mean follow-up after stillbirth was 10.7 years (SD 4.0). The cases had more often lower education (23.6% vs. 11.1%, $p = 0.001$) and lower household income (52.9% vs. 38.5%, $p = 0.012$), more were overweight (46.7% vs. 32.2%, $p = 0.009$) and daily smokers (16.3% vs. 8.4%, $p = 0.027$), and fewer consumed alcohol more often than once a week (21.9% vs. 46.7%, $p < 0.001$) compared with controls. While the mean number of liveborn children or proportions having experienced miscarriage or termination of pregnancy did not differ between groups, fewer cases felt they had obtained the number of children that they wished for (61.0% vs. 78.6%, $p < 0.001$). Cases reported higher mean comorbidity (1.6 vs. 1.2, $p = 0.012$) and more frequently pain (21.8% vs. 12.8%, $p = 0.035$), exhaustion from work and poor overall health (12.4% vs. 3.8%, $p = 0.002$).

The cases scored slightly lower on the QLI health and functioning subscale (mean 22.3 vs. 23.5, $p = 0.023$) and higher on the CES-D depressed affect subscale (median 2.0 vs 1.0, $p = 0.004$) and the CES-D global score (median 7.0 vs. 5.0, $p = 0.017$). The estimated proportion with case-level depression (CES-D ≥ 16) and subjective well-being did not differ between groups. In the multivariate analyses, previous stillbirth was not associated with global QOL (B 0.2, $p = 0.674$), well-being or case-level depression (aOR 0.8, $p = 0.465$).

8.2 Paper II

Women's experiences in relation to stillbirth and risk factors for long-term post-traumatic stress symptoms: a retrospective study. Gravensteen IK, Helgadottir LB, Jacobsen EM, Radestad I, Sandset PM, Ekeberg O. *BMJ open*. 2013;3(10):e003323.

In this paper, we quantitatively described the women's memories of experiences related to the prior stillbirth and the care they received from healthcare professionals. Additionally, we measured their level of long-term post-traumatic stress symptoms and assessed risk factors for this outcome.

About half (52%) reported that they were given none or a very uncertain explanation for the stillbirth, but the majority (71%) rated an explanation to be very important. Most (94%) wished to see and hold (84%) their baby, and all but two saw and 82% held the baby. The majority stated that they were to a large degree supported in seeing (97%) and holding (88%), and in making their own decisions about seeing/holding (79% / 76%). All but one of the 16 women who did not wish to hold the baby stated they were supported in this decision, whereas the women who did not wish to see the baby reported a varying degree of support and pressure. None stated that the staff tried to persuade or pressure them to hold the baby against their wishes. Almost all the women kept a photograph of the baby (97%) and at least one other token of remembrance (99%). Most (91%) reported that they had received short-term follow-up by invitation from the hospital or on own initiative.

The mean IES scores were 15.8 for the total score, 10.2 on the intrusion subscale and 5.6 on the avoidance subscale, and distributions were skewed with a tail to the right. One in three (31.6%) scored above the clinical case-level (≥ 20) and 13.3% above the (possible) PTSD level (≥ 35). Younger age (≤ 27 years), having given birth prior to stillbirth and prior termination of pregnancy was associated with higher odds of a high PTSS level. Having held the baby was associated with lower odds of a high PTSS level. Time since stillbirth was not associated with PTSS. There was a significant interaction between age and parity at the time of stillbirth. A prior birth among those aged >27 years was associated higher odds of IES ≥ 20 , but this association was not seen among those aged ≤ 27 years.

8.3 Paper III

Anxiety, depression and relationship dissatisfaction in the pregnancy following stillbirth and after the birth of a liveborn baby: A prospective study. Gravensteen IK, Jacobsen EM, Sandset PM, Helgadottir LB, Rådestad I, Sandvik L, Ekeberg Ø.

Submitted.

In this paper we estimated the prevalence of anxiety and depression in the pregnancy after stillbirth and the course of anxiety, depression and relationship dissatisfaction up to 36 months after the birth of a liveborn baby. We also assessed gestational age at stillbirth and duration of the inter-pregnancy interval as risk factors for anxiety and depression in the subsequent pregnancy.

Case-level anxiety (22.5%) and depression (19.7%) was more prevalent in the third trimester in the pregnancy after stillbirth compared with women with a previous live birth (4.4% and 10.3% respectively) and previously nulliparous women (5.5% and 9.9% respectively). The aOR for anxiety was 5.5 compared with the live birth group (95% CI 2.9-10.3, $p < 0.001$) and 5.0 compared with the nulliparous group (95% CI 2.7-9.2, $p < 0.001$). The aOR for depression was 1.9 compared with the live birth group (95% CI 1.1-3.3, $p = 0.019$) and 1.9 compared with the nulliparous group (95% CI 1.1-3.4, $p = 0.026$). The proportion with both anxiety and depression was 12.7% in the stillbirth group compared with 3.6% in each reference group ($p < 0.001$ for both comparisons). Inter-pregnancy interval <12 months and gestational age at stillbirth >30 weeks was not significantly associated with anxiety and/or depression in the third trimester of the subsequent pregnancy.

The frequencies of case-level anxiety and depression decreased from the first assessment to six months postpartum in the stillbirth group, and did not differ between groups by six and 18 months postpartum, respectively. From six to 36 months postpartum, the frequencies increased significantly in the stillbirth group, and 36 months postpartum the frequencies of case-level anxiety and depression were higher in the stillbirth group compared with the live birth group, but not compared with the nulliparous group. The frequency of relationship dissatisfaction among married/cohabiting women increased slightly in all three groups from the third trimester to 36 months postpartum, but did not differ between the stillbirth group and the reference groups at any time point.

8.4 Paper IV

Healthcare utilisation induced labour and caesarean section in the pregnancy after stillbirth – a prospective study. Gravensteen IK, Jacobsen EM, Sandset PM, Helgadottir LB, Rådestad I, Sandvik L, Ekeberg Ø. Submitted.

In this paper we investigated women's healthcare utilisation and the frequency of induced labour and caesarean section in the pregnancy after stillbirth. Additionally, we assessed anxiety and dread of childbirth as possible mediators for frequency of antenatal visits and elective caesarean section.

Women with a previous stillbirth had significantly more antenatal visits (mean 10.0) compared with women with a previous live birth (mean 6.0, $p < 0.001$) and previously nulliparous women (mean 6.3, $p < 0.001$). Induced labour, caesarean section (all) and elective caesarean section was more prevalent in the stillbirth group (42%, 32% and 14% respectively) compared with the live birth group (9%, 11% and 6% respectively) and the nulliparous group (18%, 16% and 4% respectively).

In the multivariate regression models, stillbirth was significantly associated with more frequent antenatal visits (aB 3.9 and 3.6) and higher odds of induced labour (aOR 9.5, and 4.3), caesarean section (aOR 4.8 and 2.5) and elective caesarean section (aOR 2.5 and 3.7). Anxiety had a minor influence on the association between stillbirth and frequency of antenatal visits (aB reduced from 3.9 to 3.7, 95% CI 3.1-4.2), but the mediating effect only accounted for 7.1% of the total effect ($p = 0.037$). There was a significant interaction between anxiety and previous stillbirth. Anxiety was associated with more frequent antenatal visits among women with a previous stillbirth (aB 1.7, p -value 0.021), but not among women with a previous live birth (aB -0.4, p -value 0.472). Dread of childbirth had a minor influence on the association between previous stillbirth and elective caesarean section (aOR reduced from 2.5 to 2.1, 95% CI 1.1-4.3), but the mediating effect was not significant ($p = 0.088$).

9 Discussion

9.1 Main findings

Paper I: On group level, women with a previous stillbirth had characteristics associated with lower socioeconomic status and did not rate their health as good as women with a previous live birth. When adjusted for sociodemographic variables, obstetrical history and health-related factors, the level of long-term QOL, well-being and global depression did not differ between groups.

Paper II: The majority of women with a previous stillbirth saw and held their baby and was satisfied with the support they received from healthcare professionals. One in three presented with a clinically significant level of PTSS 5-18 years after the stillbirth and 13% scored above a (possible) PTSD level. Having held the baby appeared to be protective, whereas a prior termination of pregnancy was associated with more PTSS.

Paper III: Women with a previous stillbirth were at significantly greater risk of case-level anxiety and depression in the subsequent pregnancy compared with women with a previous live birth and previously nulliparous women. Gestational age at stillbirth (> 30 weeks) and inter-pregnancy interval < 12 months were not associated with case-level depression and/or anxiety. The proportions with case-level anxiety and depression were similar to the reference groups six to 18 months after the birth of a live born baby, but increased slightly at 36 months postpartum. Relationship dissatisfaction did not differ between groups at any time point.

Paper IV: Women pregnant after stillbirth were more ample users of healthcare services, induced labour and caesarean section in the subsequent pregnancy compared with women with a previous live birth and previously nulliparous women. Anxiety was a minor mediator for the association between stillbirth and frequency of antenatal visits while dread of childbirth was not a mediator for elective caesarean section.

9.2 Methodological considerations

9.2.1 Strengths and limitations

This research field is generally limited by studies on small samples that are often self-selected through web-based recruitment or support groups. Response-rates are often not given and many studies lack a reference population or have made comparisons with one control group consisting of either women with previous live births or primi-gravidae. Multivariate models are scarcely used.

The first study (VIP) gathered data from two university hospitals covering a substantial proportion of women giving birth in the south-eastern part of Norway. The second study (MoBa) is a large National cohort and the prospective design limited reporting bias and allowed for long-term follow-up. The use of healthy reference groups enabled us to compare women with a previous stillbirth to assumed “baseline” populations. Using two reference groups is a unique strength to our second study. The psychometric instruments are generally acknowledged and well validated and our data include sociodemographic, obstetrical and health-related factors likely to impact our outcomes.

As far as we know, QOL and various predictors for PTSS have not previously been studied in a large group of non-pregnant women several years after the occurrence of stillbirth. Although symptom levels have been studied previously, this is the first study that has contemporaneously estimated the proportion with case-level anxiety and depression as well as relationship dissatisfaction during and after the pregnancy following stillbirth. We are also the first to assess anxiety and dread of childbirth as possible mediators for increased healthcare utilisation and elective caesarean section in this group.

Our studies have a number of limitations. The main limitation of the studies is the lack of ability to make conclusions about causality based on the association between a history of stillbirth and QOL and mental health. Even though the study samples are large compared to previous studies, some subgroups were small and the statistical power to detect differences between these groups may be limited. Further, the risk of selection bias is potentially high, the risk of recall bias and residual confounding cannot be excluded, and some of the instruments may not be optimal with regards to validity and reliability. These potential limitations will be discussed in further detail in this chapter.

9.2.2 Definition of stillbirth

In the first study, stillbirth was defined as 23 or more completed gestational weeks or fetal weight ≥ 500 grams. In the second study, we defined stillbirth according to the WHO definition; i.e. 22 or more completed weeks of gestation or fetal weight ≥ 500 grams (273). Since definitions of stillbirth vary greatly between countries, we applied this standard international definition in order to increase comparability to other studies in the field. A few more stillbirths ($n = 6$) were included in the second cohort study, i.e. with gestational age ≥ 22 , but < 23 weeks and birth weight < 500 grams. We find it unlikely that this affects the comparability of the two studies to a substantial degree.

9.2.3 Study populations, selection bias and generalisability

Selection bias can occur due to systematic error in the selection of the study sample, resulting in systematic differences between the sample and the source population (274). Selection bias may compromise the external validity which reflects the degree to which the results can be generalised from the study sample to a target population (274).

First study (VIP)

Due to inaccurate coding, it is possible that some cases were not detected by searching for ICD-codes in the hospitals administrative systems. However, since each case was verified by reviewing the medical records, those with erroneous diagnoses were excluded.

The control populations were originally selected for the first part of the VIP study, and included women without a known venous thrombosis or previous stillbirth. Due to practical considerations, they were selected from only one of the study hospitals, Ullevål. Potential women giving birth at AHUS were slightly younger and more often smokers than women giving birth at Ullevål. Ideally the controls should also have been selected from both study hospitals in order to reflect the entire source population. The selection of controls without a history of venous thrombosis and only from Ullevål hospital may have contributed to the observed differences in socioeconomic status and health-related variables between cases and controls. However, for the main part, the differences between the cases and controls are probably true, as low socioeconomic status and various maternal medical conditions are well-known risk factors for IUFD (38, 39, 47). In any case, we find it unlikely that the selection of the control population introduced bias affecting our main conclusion that QOL, depression and well-being did not differ between groups after having adjusted for other factors.

As for most studies based on questionnaires, the response rate for cases (31%) and controls (26%) was low and introduces a risk of selection bias. The inconvenience of having to present at the hospital may have contributed to the low response rate. Available information from

medical records for all eligible participants allowed us to compare participants with non-participants on a number of factors. Among controls, the participating women were slightly older, with lower parity, more often married or cohabiting, and had more often preeclampsia/eclampsia compared with non-participants (Table 4). Other factors were evenly distributed between groups. Among cases, there were no significant differences in sociodemographic and clinical factors at the time of the index pregnancy. This indicates that the participation rate among cases was not a source of serious selection bias. However, we cannot rule out that more women with negative long-term outcomes after stillbirth declined to participate in the study. Conversely, those having adequately coped with the loss may also have found it less interesting to participate since the research issue was not salient in their lives at the current time (275). Women with lower income and education were probably also overrepresented among the non-responders, (275), but this presumably accounts for both groups. Accordingly, a higher response rate would highlight the socioeconomic differences even more, but the conclusion that a history of stillbirth did not significantly impact long-term QOL, well-being or depression, would probably have remained the same.

With regards to PTSS, a larger proportion of cases with a high level of avoidance symptoms may have declined participation in the study. In that case this could have resulted in an underestimation of the mean score for the IES avoidance subscale, but should not have affected our main result, i.e. that the frequency of overall PTSS was evident among women with a previous stillbirth. Thus, our opinion is that our main findings, with some consideration, can be generalised to other (Norwegian) women having experienced stillbirth, perhaps with the exception of those within the lowest income groups.

Table 4. Characteristics at the time of the index delivery among participant and non-participants (modified from LB Helgadottir (220) with permission).

Variables	Cases participating N = 106	Cases not participating N = 273	p	Controls participating N = 262	Controls not participating N = 953	p
	%	%		%	%	
Delivery hospital						
UUS	62.9	61.3		100	100	
AHUS	37.1	38.7	n.s.	0	0	n.s.
Year of the index delivery						
1990-1999	60.3	59.5		62.3	57.9	
2000-2003	39.7	40.5	n.s.	37.7	42.1	n.s.
Maternal age						
<35	80.2	76.9		68.3	77.9	
≥35	19.8	23.1	n.s.	31.7	22.1	0.001
Parity						
0	51.9	51.3		50.4	48.1	n.s.
1	34.0	30.8		39.3	31.6	Ref
≥2	14.2	17.9	n.s.	10.3	20.4	<0.001
Civil status						
Married or cohabiting	89.6	85.0		96.6	90.7	0.001
Not married/cohabiting	10.4	15.0	n.s.	3.4	9.3	n.s.
Multiple pregnancy	3.8	6.6	n.s.	2.7	2.0	n.s.
Hypertensive disorders						
Preeclampsia/eclampsia	5.7	7.7		7.3	4.4	0.035
Hypertension	4.7	9.9	n.s.	4.6	4.1	n.s.
Diabetes						
Diabetes type 1 or 2	1.0	2.2		0.0	0.5	
Gestational diabetes	0.0	2.2		0.4	1.3	
All diabetes	1.0	4.4	n.s.	0.4	1.8	n.s.
Placental abruption	8.5	12.8	n.s.	0.8	0.9	n.s.
Placenta previa	1.9	1.1	n.s.	0.8	0.6	n.s.
Smoking						
Non-smoker	70.8	61.5		91.6	85.1	
Smoker	29.2	38.5	n.s.	8.4	14.9	n.s.
SGA	35.2	35.8	n.s.	1.5	2.1	n.s.

n.s.; not significant; SGA, UUS; Ullevål University Hospital, AHUS; Akershus University Hospital, SGA; Small for gestational age

Second study (MoBa)

Two independent sources of information were used for the selection of the study population, namely Q1 and the MBRN. This increases the accuracy of the exposure variable, i.e. previous stillbirth, live birth or no previous births. Notifications of stillbirths and live births in the MBRN are reported to be good (276). However, some women participating in MoBa in the pregnancy after stillbirth may not have been identified due to missing or erroneous data in Q1 and/or missing data in the MBRN. Aside from the selection criteria, the reference women were selected randomly from the entire MoBa cohort, assuring that the distribution of exposures reflected that of the source population. The representativeness of the reference groups is demonstrated by the prevalence of case-level anxiety and depression being similar to a larger group of women in MoBa without epilepsy (277).

In MoBa, the response rate is 41% which is relatively low, but as expected for population-based studies (278). Some groups were under-represented such as those living alone, of young age, of high parity or with previous stillbirths (279). Women participating in MoBa may also be somewhat more educated than the overall Norwegian population (280). Nevertheless, self-selection in MoBa is demonstrated to be of little concern in studies of exposure-outcome associations (279). This indicates that the risk of serious selection bias affecting the generalizability of our results is relatively low. Thus, the prevalence estimates of case-level anxiety and depression in the subsequent pregnancy after stillbirth may be affected by the response rate, but the relative differences between women with a previous stillbirth and the reference groups is probably generalisable to the Norwegian obstetrical population.

However, selection bias may have been the result of the considerable rate of loss to follow-up although comparable to previous studies on perinatal depression (281). Only 111 (52%) in the stillbirth group, 205 (53%) in the live birth group and 233 (59%) in the nulliparous group responded at 36 months. Thus, estimates of case-level anxiety, depression and relationship satisfaction from six to 36 months postpartum should be considered with caution. In an attempt to address potential selection bias due to attrition, characteristics were compared between participants completing all five questionnaires and participants who dropped out at any point after 30 gestational weeks (Table 5).

Table 5. Characteristics among participants completing all five questionnaires compared with drop-outs at any point after 30 gestational weeks

	Stillbirth group			Live birth group			Nulliparous group		
	Responders Q1-Q5 N = 99	Drop-outs N = 75	P-value	Responders Q1-Q5 N = 189	Drop-outs N = 173	P-value	Responders Q1-Q5 N = 218	Drop-outs N = 147	P-value
	%	%		%	%		%	%	
Maternal age (mean yrs)*	31.7	30.5	n.s.	31.5	31.1	n.s.	29.2	28.0	n.s.
Married/cohabiting	98.0	97.3	n.s.	98.9	97.7	n.s.	95.4	94.6	n.s.
Native language other than Norwegian	6.1	2.7	n.s.	4.8	4.2	n.s.	6.4	6.3	n.s.
Pre-pregnancy daily smoking	13.1	26.0	0.032	10.7	16.5	n.s.	16.5	23.4	n.s.
BMI ≥ 25	46.9	43.8	n.s.	31.9	39.6	n.s.	27.4	29.7	n.s.
Low education ^a	38.8	39.2	n.s.	25.7	23.4	n.s.	23.4	34.8	0.019
Low income ^b	29.2	30.6	n.s.	33.3	36.3	n.s.	23.5	30.7	n.s.
Parity ≥ 2	43.4	56.0	n.s.	28.6	33.5	n.s.			
Previous miscarriage	15.2	22.7	n.s.	13.2	17.3	n.s.	13.8	15.0	n.s.
Previous termination of pregnancy	10.1	9.3	n.s.	8.5	11.0	n.s.	8.7	8.8	n.s.
Comorbidity*	13.1	17.3	n.s.	12.7	11.0	n.s.	14.2	10.9	n.s.
Stressful life-events	57.6	60.0	n.s.	46.0	50.3	n.s.	50.0	55.1	n.s.
Inter-pregnancy interval <= 12 months*	67.7	74.3	n.s.	14.9	9.2	n.s.			
Gestational age at the time of stillbirth >30 weeks*	67.4	68.9	n.s.						
Case-level anxiety (Q2)	15.2	32.4	0.007	4.2	4.7	n.s.	4.6	6.8	n.s.
Case-level depression (Q2)	12.1	29.7	0.004	9.7	12.8	n.s.	9.7	10.2	n.s.
Relationship dissatisfaction (Q2)	5.1	5.5	n.s.	7.0	5.9	n.s.	3.3	3.4	n.s.

*Data from the Norwegian Medical Birth Registry of Norway

^aHighschool or less

^bMaternal income < 200 000 Norwegian kroner per year

n.s.; not significant, Q1; follow-up at 17 gestational weeks, Q2; follow-up at 30 gestational weeks, Q3; follow-up at six months postpartum, Q4; follow-up at 18 months postpartum, Q5; follow-up at 36 months postpartum

In the stillbirth group, drop-outs were more often smokers and had case-level anxiety and depression in the third trimester. In the nulliparous group, drop-outs were less educated and were younger compared with those completing all five questionnaires. Remaining characteristics did not differ significantly between groups. Accordingly, the frequency of case-level anxiety and depression at follow-up may be probably somewhat underestimated in the stillbirth group.

9.2.4 Information bias

Information bias can occur due to measurement inaccuracies and is an inevitable risk in all studies based on questionnaires (274). This may result in spurious correlations between self-reported covariates and outcomes. In Paper I-III, we used questionnaire data to assess both the main outcomes and most of the covariates and these may be subject to information bias. In the first study, the retrospective design and long follow-up period introduces a risk of recall bias concerning descriptive variables, particularly regarding experiences at the time of stillbirth (Paper II). However, the recollection of potentially traumatic events is shown to be more accurate than for other life events (282). Thus, accounts of core events such as whether or not the women held the baby, is probably of high reliability. In Paper IV, information about healthcare utilisation was obtained by the questionnaire given to women in gestational week 30 and may also have been subject to recall bias, although the questions were related to the current pregnancy. This information could preferably have been validated with information from medical records.

Information about outcomes related to onset of delivery and mode of delivery (induced labour and caesarean section) in Paper IV was obtained from the MBRN, and measured prospectively. The data in the MBRN is based on information provided by a birth attendant, usually a midwife, and the register is quality-assessed (221). The risk of misclassifications and missing information cannot be excluded, but several studies have confirmed that data from the MBRN is generally of good quality (283-286). As previously mentioned the main exposure variable, i.e. previous stillbirth, was validated with information from medical records or the MBRN and thus, considered accurate.

9.2.5 Covariates and confounding factors

A confounding factor is a variable associated with both the outcome and the exposure that is not a consequence of the exposure (274). Residual confounding, i.e. lack of adjustments for confounders that were not considered or available, could potentially lead to distortion of the estimates (274).

Regarding paper I, subjective measures such as assessment of overall health and physical/mental exhaustion from work can be considered as outcomes of stillbirth rather than confounding factors. However, even if these variables were excluded from the multivariate analyses, a history of stillbirth was not associated with long-term global QOL, subjective well-being or global depression. We cannot exclude the possibility that other covariates measured at follow-up such as income and comorbidity may actually be causally affected by a previous stillbirth.

Regarding paper II, we cannot exclude that the association between holding the baby after stillbirth and a lower risk of long-term PTSS could be due to confounding factors such as maternal personality traits.

Regarding paper III, we did not have access to data on the women's mental health prior to stillbirth. Thus, it is possible that the higher prevalence of case-level anxiety and depression in the pregnancy after stillbirth reflect baseline psychological distress that could have been elevated even before the occurrence of stillbirth.

Regarding paper IV, it would be optimal to have access to medical records in order to ensure the quality of the covariates retrieved from the MBRN. Additionally, due to small numbers, some variables were not considered as covariates for healthcare utilisation and mode of delivery, such as previous placental abruption. This may have inflated our estimates.

9.2.6 Validity and reliability of the psychometric scales

Our estimates on quality of life and psychological distress after stillbirth relied on self-reporting using validated screening tools. Although psychiatric symptoms may be more correctly reported in an anonymous questionnaire than in a clinical interview (287), it is important to highlight that self-report measures are not created to make formal diagnoses.

Measurement of quality of life, well-being and depression (Paper I)

The QLI is a generic QOL assessment and also includes overall questions regarding QOL. As QOL incorporates different things for different people, an important advantage of the QLI is the assessment of subjective importance of various aspects of life in addition to the satisfaction with these aspects. The SF-36 is the most widely accepted measure of health-related quality of life and has existing population norm data (288). However, the SF-36 does not measure generic quality of life which was the focus in this study.

The GHQ incorporates a wide range of items focusing on both positive and negative aspects of mental health. We considered it to add potentially valuable information concerning psychological well-being, but it can also be considered to be a screening tool for psychiatric illness or psychological distress (233).

The CES-D is widely used as a screening tool for identification of subjects with depression or at high risk of depression, and has been specifically validated in samples of postpartum women (242). Using a score of 16 as cut-off, a recent systematic review reported a sensitivity of 0.87 (95% CI: 0.82–0.92) and a specificity of 0.70 (95% CI: 0.65–0.75) to detect major depression in the general population (289). However, worldwide, the Beck Depression Inventory is the most widely used self-rating scale for depression (290).

As outlined in the Methods section, the QLI, the GHQ-20, the CES-D, have been translated to Norwegian and are demonstrated to be of high validity and reliability. The validity of the three scales was supported by their significant correlation with each other. However, they only overlapped to a moderate degree, indicating that they reflect different domains of mental well-being, functioning and quality of life. The Cronbach's alpha values were >0.8 for all three global scales (Table 6) reflecting high internal reliability.

Measurement of post-traumatic stress symptoms (Paper II)

The IES is one of the most widely used tools for measurement of post-traumatic stress symptoms and has high validity and reliability (147, 245-248). The Cronbach's alpha of 0.94 reflected high internal reliability. The frequency with PTSS above the predefined clinical cut-off (≥ 20) was reasonably high among cases in our study (31%) even though the group level QOL was fairly good. Since screening tools that measure symptom levels may overestimate the frequency of a disorder (291, 292), the more conservative cut-off (≥ 35) is probably more accurate for indication of when treatment is needed. Furthermore, the IES does not assess for criterion A (severe traumatic event) and does not measure symptoms of hyper-arousal that are required for a PTSD diagnosis according to the ICD-10 or DSM-V systems. We therefore find it likely that the proportion of cases with an IES above a clinical or PTSD level is somewhat overestimated in our study. Preferably, this could have been verified with a clinical interview.

Measurements of anxiety, depression and relationship satisfaction (Papers III and IV)

As for many population-based studies, MoBa uses several short-form versions of psychometric scales. This is mainly due to practical advantages such as limiting the length of

the questionnaires and reducing the burden for the respondents. Even though short-form versions affect the measurement precision, it often remains sufficient for epidemiological purposes (255).

Anxiety and depression symptoms were measured with short-form subscales that correlate highly with the original anxiety (10 items) and depression (13 items) subscales of the 25-item Hopkins symptom checklist (255). Thus, to the extent that the subscales of the SCL-25 tap symptoms of anxiety and depression, the 4-item subscales of the SCL-8 also tap symptoms of anxiety and depression. An advantage of our short-form subscales is that they do not include items relating to faintness and sleeping problems, as these symptoms may just as well reflect normal states in pregnancy and the postpartum period.

The distribution of the SCL and its subscales are often skewed as they also were in our study. Dichotomizing the scale at a pre-validated cut-off allowed us to estimate the proportion at risk of having an anxiety or depression disorder or with sub-diagnostic symptom levels requiring clinical attention (253, 254). A recent Swedish population-based study demonstrated the SCL-25 subscales to be well-suited for the detection of anxiety and depressive disorders otherwise diagnosed by a clinical interview (293). Using the conventional cut-off (≥ 1.75), the sensitivity and specificity was 63.2% and 83.8% for the anxiety subscale and 79.8% and 70.3% for the depression subscale. However, a previous Norwegian study found the ability of the SCL-25 to discriminate anxiety from depression to be less than optimal, partly due to high intercorrelation between symptoms (294). It should also be noted that the anxiety and depression subscales of the SCL-8 (SCL-4a and SCL-4d) have not been specifically assessed for their concordance with diagnostic procedures.

To measure perceived relationship satisfaction, we used the 5-item version of the Relationship Satisfaction Scale (RS5), correlating 0.97 with the full 10-item version which was developed for the MoBa study based on previous well-known instruments (131). Although, not extensively investigated, the scale has shown generally high structural validity (131). The validity of the 5-items version depends entirely on the validity of the 10-items version. To ease comparisons with the SCL-8 anxiety and depression subscale and due to skewed distributions, we chose to dichotomise the RS5 at a predefined cut-off (< 4.0), shown to be predictive of future relationship dissolution (131). However, treating the scale as a continuous outcome yielded similar results, namely no significant differences between the stillbirth group and the reference groups at any time point.

As we hypothesised that the frequency of particularly case-level anxiety, but also case-level depression, would be higher in the pregnancy after stillbirth compared with the reference groups, our results indicate acceptable sensitivity and construct validity for the SCL-4a and SCL4-d. Further, the Cronbach's alpha values were acceptable for the SCL-4a and SCL-4d and for the RS5 (Table 6), reflecting adequate internal reliability even though the scales consist of few items. Test-retest correlations from 30 gestational weeks to six months postpartum were 0.39 for SCL-4a, 0.45 for SCL-4d and 0.68 for RS5. Test-retest correlations from six to 36 months postpartum were 0.43 SCL-4a, 0.44 for SCL-4d and 0.58 for RS5. As outlined by Tambs and Røysamb, the test-retest correlations probably underestimates the reliability of the scales, reflecting long follow-up periods and true changes in anxiety, depression and relationship satisfaction (255).

Dread of childbirth

The variable “dread of childbirth” was derived from the women’s response to the statement “I am really dreading giving birth.” We categorised the variable according to a previous substudy in MoBa that regarded this item as synonymous to “fear of childbirth (295).” However, for women with a history of stillbirth, “dread” of the subsequent childbirth may incorporate other aspects than merely fear of going through labour (personal correspondence with Ingela Rådestad). In addition to potential fear of pain or lack of control related to the upcoming delivery, the fear of losing another baby grows stronger as the delivery approaches. We therefore named the item “dread of childbirth” reflecting the wording in the questionnaire. The validity and reliability of this construct has not been tested. Preferably, we would have included a validated psychometric scale specifically designed to measure fear of childbirth such as the Wiljma Delivery Expectancy/Experience Questionnaire (296).

Table 6. Reliability analyses (internal consistency) of the psychometric scales used in the two studies, measured by Cronbach’s alpha

Instrument	Items	Cronbachs alpha
QLI (quality of life) - 4 subscales	34 4-14	0.94 0.70-0.91 (range)
GHQ-20 (well-being)	20	0.88
CES-D (depression) - 4 subscales	20 2-7	0.87 0.69-0.83 (range)
IES (posttraumatic stress symptoms) - Intrusion - Avoidance	15 7 8	0.94 0.94 0.90
SCL-8 - SCL-4a (anxiety) - SCL-4d (depression)	8 4 4	0.86-0.92 (range) 0.69-0.80 (range) 0.77-0.81 (range)
RS5 (relationship satisfaction)	5	0.87-0.90 (range)

9.2.7 Missing data

First study (VIP): The proportion of missing values ranged from 0% to 5.7% on descriptive variables and was highest for health-related variables such as physical/mental exhaustion from work and sick leave. For the QLI, up to five missing values were imputed in 68 (64%) of the cases and 143 (54.5%) of controls, resulting in 0% and 0.7% missing. For the GHQ-20, up to ten missing values were imputed in 11 (10.3%) of cases and 36 (13.7%) of controls, resulting in 1.8% and 0% missing. For the CES-D, up to four missing values were imputed in 8 (7.5%) of cases and 9 (3.4%) of controls, resulting in no missing. For the IES, one missing item was imputed for one or both subscales in 4 (3.9%) of cases, resulting in 2.9% missing. For some variables regarding experiences before, during and after stillbirth, up to 10% of the values were missing. The questionnaire may have been too extensive, some response-categories could have been perceived as unclear or some women may have skipped questions they did not find relevant instead of answering “no”. For the variables that were considered potential predictors for PTSS, there were up to 4% missing.

Second study (MoBa): The proportion of missing values ranged from 0% to 2.6% on descriptive variables. At the third trimester assessment, up to two missing values on the SCL-4a, SCL-4d and RS5 were imputed in 46 (5.1%), 48 (5.3%) and 16 (1.8%) of the women, resulting in 0.4%, 0.4% and 1.8% missing, respectively. At six months postpartum, imputation of values resulted in 0.5% missing on the SCL-4a and SCL-4d and 3.1% missing on RS5. At 18 months postpartum, imputation of values resulted in 1.5% missing on SCL-4a, 1.6% missing on SCL-4d and 3.5% missing on RS5. At 36 months postpartum, imputation of values resulted in 2.3% missing on the SCL-4a and SCL-4d and 6.7% missing on RS5.

In summary, we obtained good data quality with relatively low levels of missing data on important variables. The risk of bias due to missing data is considered to be low.

9.2.8 Statistical considerations

The power calculations show that the sample sizes are adequate for assessment of the main outcomes, i.e the association between a history of stillbirth and long-term quality of life and the frequency of case-level anxiety and depression in the subsequent pregnancy. However, the power to detect within group differences, i.e. results from subgroup analyses, may not be satisfactory. For example, the non-significant associations between gestational age at stillbirth or inter-pregnancy interval and case-level anxiety and/or depression in the subsequent pregnancy, may be due to sample size limitations. Additionally, non-significant estimates for some covariates and potential predictors in the regression models could be due to small

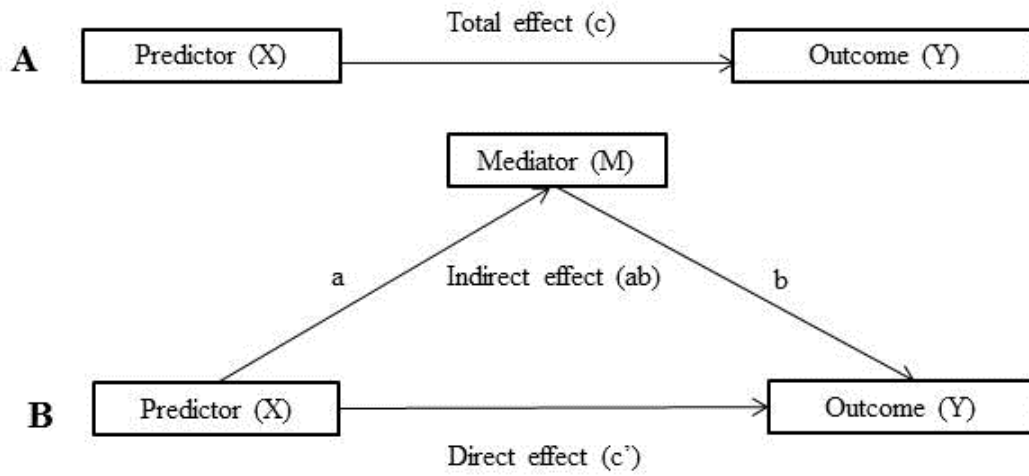
numbers, and wide confidence intervals limit the precision of the multivariate regression analyses in Papers II, III and IV. Adjustments for multiple comparisons were not performed, in order to preserve power and limit the risk of type II errors. Thus, findings with p-values ≥ 0.01 should be interpreted with some caution.

Testing for mediators (paper IV)

A variable could be considered a mediator if it accounts for the effect of the predictor on the outcome (266). A moderator on the other hand, is a variable that affects the direction or strength of the relation between the predictor and the outcome. Whereas moderators specify under what conditions an effect will hold (depending on e.g. gender, age), mediators explain how an effect occurs. Anxiety was considered as a potential mediator for the number of antenatal visits in the pregnancy after stillbirth, whereas anxiety and dread of childbirth were considered as potential mediators for elective caesarean section. Based on existing literature and the study's prospective design, we assumed that the association between previous stillbirth and anxiety or fear of childbirth at least to some degree represents a causal relationship, although this cannot be verified. Similarly, we cannot verify that the association between the mediators and the outcomes represents causal relationships.

A general test for mediation effect is to examine the association between the predictor and the outcome, the association between the predictor and the mediator variable and the association between the mediator and the outcome variable (Figure 4). If all these associations are significant, mediation is present in statistical terms (266). If the association between the predictor and the outcome variable is reduced to zero after adjusting for the mediator variable, full mediation is present. If the association is reduced, but not to zero, partial mediation is present. According to these criteria, anxiety was a partial, although a minor, mediator for the association between previous stillbirth and frequency of antenatal visits. Similarly, dread of childbirth was a minor mediator for the association between previous stillbirth and elective caesarean section. However, the latter effect did not prove to be significant according to the Sobel test, and this could be due to sample size limitations.

Figure 4. Traditional mediation



Panel A illustrates the total effect of the predictor on the outcome (path c).

Panel B illustrates a mediation design.

The direct effect of the predictor on the outcome after adjustment for the mediator is depicted as path c' .

The indirect effect (ab) is the effect of the predictor on the outcome that is mediated through a third variable (mediator) and is defined as the product of path a and path b .

The proportion of effect mediated (PM) is the indirect effect (ab) divided by the total effect (c).

9.3 Interpretation of main findings

9.3.1 Long-term quality of life, well-being and depression after stillbirth

The women in our study scored somewhat better on the QLI global score and the QLI subscales compared with women in the general Swedish population (270), showing that their quality of life is good. The QLI scores were comparable to those obtained among healthy women in a previous Norwegian case-control study (297). The women with a previous stillbirth scored slightly lower on the QLI health and functioning subscale and slightly higher on the CES-D depressed affect subscale and global depression. However, the differences were too small to represent a moderate effect size according to Cohens index (139), and considered unlikely to be of clinical significance. There were no significant differences in global QOL, well-being and global depression when adjusting for socioeconomic and health-related factors.

Our findings suggest that 5-18 years after stillbirth, the QOL, well-being and depression is comparable to other women. Previous studies have found negative associations between previous stillbirth and mental health (5, 149), but within shorter observation periods (three years). It is probable that the longer time since stillbirth in our study has allowed for coping and adaption that contributed to the positive outcomes. Similar to our findings, Turton et al. found not difference in case-level depression 6-8 years after the next birth in women with a history of stillbirth (156). However, as previously discussed, we cannot exclude that our findings are partly subject to selection bias.

9.3.2 Women's experiences in relation to stillbirth

Similar to the findings by Rådestad et al. in 1994 (165, 175), the women in our study reported a high degree of satisfaction with the care they received at the time of stillbirth and how healthcare professionals approached them and their baby. Most of the women reported that they wished to, and were encouraged by healthcare professionals to see and hold their stillborn baby, while women not wishing to see their child reported a varying degree of support and pressure from healthcare professionals regarding this. The great majority of the women saw and held their baby, named the child, took photographs and kept other tokens of remembrance and arranged a memorial or funeral. This is consistent with previous studies showing that encouraging women to confront their stillborn baby has become procedure in many high-income countries, and this is in line with most, but not all women's wishes (165, 166, 169, 174). Similar to a Swedish qualitative study (2), the majority of the women felt good about seeing and holding the baby, and more than half of those who did not hold their baby regretted this decision in retrospect.

Most women (91.1%) reported having received short-term follow-up, confirming that the psychological impact of a stillbirth is acknowledged by the Norwegian healthcare system. In line with previous studies (175, 177), the majority of the women in our study felt it was important to have an explanation for the baby's death. However, about half reported that they were given none or a very unlikely explanation. This does not add up with the finding by Helgadottir et al. that in about 20% of cases the cause was unknown (28) and may reflect a need for improvement in healthcare professionals communication with parents in the aftermath of stillbirth.

9.3.3 Frequency and predictors for long-term PTSS after stillbirth

Long-term post-traumatic stress-symptoms were evident in women 5-18 years after stillbirth. About one third scored above the clinically relevant symptom level (≥ 20) and 13% above the pre-defined (possible) PTSD level (≥ 35). Generally, post-traumatic stress symptoms develop more frequently after exposure to violence than after sudden medical emergencies (97, 98). However, the sudden death of a baby before birth may be harder for parents to accept as "natural" compared to other medical events and the potential for stress reactions may be higher. The mean intrusion and avoidance scores in our study were similar to those obtained at one year follow-up in a sample of 29 women with a stillbirth or late miscarriage (147). The total IES score was a little higher than in a group of women having experienced preterm birth 18 months previously (298).

Even though a high level of PTSS was associated with lower scores on global QOL, the group level QOL and depression were similar to the controls. This indicates that although a subgroup of women seems to have substantial symptoms of PTSS, quality of life and daily functioning is not impaired for the majority of cases. Alternatively, the proportion of cases with a clinically relevant symptom level is overestimated in this study. It is also possible that participating in the study reactivated memories about the stillbirth that influenced the women's responses. As the IES relates to a past trauma, we did not have the opportunity to compare these results with the control group. We cannot exclude that the experience of birth itself could have been a trigger for post-traumatic stress reactions in some women, although a previous Norwegian hospital-based study found low IES scores in women five years after the birth of a healthy child (299). In a previous study, Turton et al. found no difference in PTSD between stillbirth cases and controls 6–8 years after the birth of a subsequent child (156).

Independent predictors for PTSS were young age, high parity at the time of stillbirth and prior induced abortion. Having held the baby appeared to be protective. Young age and high parity

have previously been shown to be predictors for anxiety- and depression symptoms after stillbirth (158, 180) and young age is associated with PTSD in general (99). In contrast to a previous study with a shorter observational period (2.3 years) (183), we found no significant association with time since stillbirth and PTSS and other determinants may be more important for persisting PTSS after five years. Induced abortion prior to stillbirth remained a strong predictor for a high PTSS level in our study. This is a new finding that should be confirmed and explored in future studies. The fact that high parity and induced abortion predicted a high symptom level may indicate that previous obstetrical experiences enhance the development of PTSS after stillbirth. Alternatively, higher parity and previous terminations of pregnancy could be markers for socioeconomic status.

Our finding that holding the stillborn baby seems to protect against PTSS in the long term supports the general opinion that contact with the baby is beneficial (5, 158), even though this effect may be temporarily reversed during a subsequent pregnancy (158, 160). None of the women in our study were pregnant at follow-up. However, as described in the introduction sections, some studies report negative effects. The study by Hughes et al. reporting that seeing and holding the stillborn baby increases psychological morbidity (160), have been criticised by several researchers, mostly because of a self-selected study group of women being interviewed just before the due date of their next baby (300). However, a more recent study from the UK (n = 468) also found that holding the stillborn baby was associated with anxiety and relationship difficulties after nine months, although not significant for non-pregnant women (301). Both Rådestad's studies and the current are from Scandinavia (Sweden and Norway), whilst the two studies that claim that contact is harmful are both from the UK. The discrepancy may thus reflect different management strategies and attitudes of healthcare professionals that may influence the outcomes. A recent phenomenological study from Switzerland emphasised that preparation before contact with the baby and professional support is crucial in prevention of maternal health problems (179). Accordingly, Rådestad and Christoffersen suggested that a reason for the findings by Hughes et al. could be that the women were not sufficiently prepared or supported by healthcare professionals (302). Gestational age at stillbirth may also explain different findings. The majority of the stillbirths in Hughes' study occurred at 18-27 gestational weeks (62%), while in Rådestad's study all the stillbirths occurred ≥ 28 weeks. Time since the loss can also be a relevant factor, since the follow-up period in studies reporting negative effects are generally shorter than those reporting positive effects.

Regardless of our findings, we cannot exclude that a high degree of pressure and persuasion into seeing and holding the baby is potentially traumatic if the woman does not want this

contact (303). Our sample is too small to make assumptions about this, as very few ($n = 4$) saw and held ($n = 6$) the baby despite not wanting to. However, the balance between care that promotes confrontation and acknowledgment of the loss versus the facilitation of unhealthy attachment is difficult to establish and probably highly individual. Further, a number of characteristics are shown to predict whether a woman ends up holding her stillborn, such as gestational age, years since loss, ethnicity and educational level (158, 301). Undetected factors such as personality traits may also be relevant. Thus, the effects of contact with the stillborn baby could, at least in part, be confounded by systematic differences between women who sees/holds and those who don't.

9.3.4 Anxiety, depression and relationship satisfaction in the subsequent pregnancy

Case-level anxiety and depression was prevalent in the pregnancy after stillbirth, while six to 18 months after the subsequent delivery the frequencies were similar to those of the reference groups. This is in accordance with previous findings Hughes et al. that women pregnant after stillbirth had significantly higher levels of depression and state anxiety during pregnancy compared with primi-gravidae and no significant differences six weeks and 12 months postpartum (6). Armstrong et al. similarly reported that in women pregnant after perinatal death, levels of depressive and anxiety symptoms decreased three months after the birth of a subsequently healthy infant and remained so at eight months postpartum (194). However, as the follow-up period in our study extends further, at 36 months postpartum the frequency of case-level anxiety and depression seemed to increase somewhat, particularly in the stillbirth group. Possibly, the birth of a liveborn baby is only temporarily relieving for some women, but attrition limits our study's abilities to conclude about this finding. Blackmore et al. reported that depression and anxiety did not significantly fluctuate up to 33 months after a subsequent birth, although according to the figure present in the paper there was a drop in symptoms shortly after the delivery (195). However, since the latter study included mainly early miscarriages with no specification of whether the pregnancy under study was directly subsequent to the loss, it is not comparable to ours.

Relationship dissatisfaction was not more prevalent in pregnancy or postpartum among women with a previous stillbirth. Although some previous studies have found a negative impact of stillbirth on the partner relationship (156, 170), such effects may be moderated when the parents are expecting and delivering another baby. Alternatively, the women in our study represent those whose partner relationship was not negatively affected by the stillbirth. Losing a child can potentially affect the parent's relationship in various ways, and while some struggle, others become closer (304).

In our study, an inter-pregnancy interval ≤ 12 months was not significantly associated with case-level anxiety and/or depression in the subsequent pregnancy, contrary to the findings by Hughes et al (6). The studies are possibly not quite comparable due to different study populations (no response rate given for Hughes et al.'s study), setting (UK vs. Norway) and time lapse (Hughes et al.'s study was published in 1999). Also, since the majority (>70%) in our study conceived within a year after the loss, the power to detect smaller differences between the groups may be too low. As pointed out by Hughes et al., different characteristics such as more trait anxiety among those who conceive quickly may also explain their findings. In any case, other considerations may be more important when planning the subsequent pregnancy. Data regarding medical risks by duration of the inter-pregnancy interval after stillbirth is scarce. Both short (<15-24 months) and long (>4 years) inter-pregnancy intervals is associated with increased risk of subsequent adverse perinatal outcomes (69, 305). Taking maternal age and medical considerations into account, the best advice may in many cases be that the mother should wait until she, herself, feels ready (306).

Having experienced an early (22-30 weeks) compared to a late stillbirth (>30 weeks) was not significantly associated with case-level anxiety and/or depression in the third trimester of the subsequent pregnancy. However, the p-value was just slightly above the significance level. Thus, as reported by Janssen et al., the duration of the pregnancy could be relevant for the risk of psychological distress after miscarriage or stillbirth (187). However, the impact of relative gestational age at the time of fetal death may be of diminishing importance in pregnancies that have advanced beyond 22 completed gestational weeks.

9.3.5 Healthcare utilisation in the subsequent pregnancy

Consistent with findings by Huttu et al. including a sample of women with mainly miscarriages (7) and a recent international survey (197), we found substantially increased healthcare utilisation in the pregnancy after stillbirth. Similar to the results of Huttu et al., anxiety was associated with the frequency of antenatal visits among women with a previous stillbirth. However, anxiety was only a minor mediator in terms of explaining why women with a previous stillbirth had more antenatal visits than women with a previous live births. One reason for this may be that women with a previous stillbirth are provided with more antenatal care visits than other women, regardless of their anxiety levels. Furthermore, pregnancy specific anxiety could potentially be a stronger mediator for this association. Unfortunately, our study did not have the ability to assess that.

There is a lack of quantitative studies addressing how psychological distress, such as anxiety and depression is addressed and managed during the subsequent pregnancy after stillbirth. While assessments and surveillance probably represent the main aspects of the extra care provided for this group, emotional and psychological aspects may be overlooked (197). Qualitative research implies that more frequent antenatal care visits and dialogue with healthcare professionals increase emotional well-being and reduce anxiety and depression symptoms (198, 307). However, while some studies have found that diagnostic procedures such as ultrasound scans may relieve stress (198), this may not apply to all women. Phipps reported that while mothers with a history of previous neonatal death had more questions and made more requests for assessments in the subsequent pregnancy, they did not experience the relief they anticipated (205). Further, O'Leary found that ultrasound examinations might trigger flashbacks and PTSD symptoms that require additional interventions by healthcare professionals in the pregnancy after a loss (308).

9.3.6 Induced labour and caesarean section in the subsequent pregnancy

Our findings of greater frequency of induced labour and caesarean section in pregnancies subsequent to stillbirths are consistent with findings from previous studies (65, 66, 70). The ORs were somewhat higher in our study, particularly for induced labour. This might be explained by that our study includes women regardless of parity with stillbirths regardless of cause and thus represents a population with increased risk of complications. Further, in this study deliveries by elective caesarean section were excluded when estimating aORs for induced labour. Differing practices in obstetrical management between countries may also be an explanatory factor.

Fear of childbirth has previously been demonstrated to be associated with maternal requests for caesarean section (209, 210) and women bereaved by stillbirth often opt for the possibility of a caesarean delivery in their subsequent pregnancy (198). However, in our study, anxiety was not a mediator for elective caesarean section and dread of childbirth did not have a statistically significant mediating effect. Larger studies are needed to conclude about this effect. Our findings indicate that even though dread of childbirth was associated with elective caesarean section, it is not a substantial factor in explaining the increased frequency in women pregnant after stillbirth compared with women pregnant after a live birth.

Several other mechanisms are likely to explain the association between a previous stillbirth and mode of delivery in the subsequent pregnancy. Unfortunately, we did not have information on the causes of stillbirth for the participants in this study, as this could have

provided opportunities for meaningful stratifications of the outcomes. Studies have shown increased risk of complications and recurrent stillbirth among women with previous stillbirths (63, 64, 66, 68-70), although dependent on the cause of the prior stillbirth (309). Thus, a higher level of fear and anxiety can be expected. Further, these feelings may influence the obstetrician, causing a lower margin for interventions, particularly in the case of other complicating factors. According to Robson et al., altered management strategies not necessarily dependent on pregnancy complications may in part account for earlier deliveries and more frequent caesarean sections in the pregnancy after stillbirth (310). As the risk of stillbirth increases in late pregnancy (57, 59, 61), obstetricians may grant early delivery by induced labour or caesarean section for preventive reasons. However, while the stillbirth recurrence risk is potentially reduced by earlier delivery, the overall cost-benefit effects of interventions remain uncertain (67, 311). Our study was not suited to evaluate the risks and benefits regarding interventions in the pregnancy after stillbirth.

10 Clinical implications

Long-term QOL, well-being and depression were on group level similar in women with a history of stillbirth compared with controls. This is important knowledge for healthcare professionals who provide care and guidance to parents, and may be a reassuring message to convey. However, one third of the women in our study reported significant PTSS and a subgroup (13%) presented with symptoms above a possible PTSD level. These proportions are probably somewhat overestimated, but it remains clear that a stillbirth is a major traumatic event and that memories could be easily reactivated even after many years. Screening procedures for PTSS may facilitate appropriate long-term follow-up for those with the highest symptom levels.

The great majority of the women in our study saw and held their baby after the stillbirth and felt that the health care professionals were supportive and showed respect. Having held the stillborn baby was associated with less long-term PTSS in our study, implicating that healthcare professionals should continue to provide the opportunity and encourage women to see and hold their baby after stillbirth. However, since the beneficial effects are not clearly established, we suggest that the few women who express that they don't want this contact should be met with empathy, information and understanding, rather than being pressured or persuaded into holding their baby. The opportunity to see or hold the baby at a later time, during the hospital stay, should be available.

In our study, case-level anxiety and depression was prevalent in the pregnancy after stillbirth. The frequencies declined after the birth of a healthy baby and were indistinguishable from the reference groups by six to 18 months postpartum, while at 36 months postpartum there was an increase. Timing of the subsequent pregnancy was not significantly associated with case-level anxiety and/or depression in the third trimester and neither was gestational age at the time of stillbirth. Having experienced a stillbirth was not associated with partner relationship dissatisfaction in the subsequent pregnancy or after the birth of a live born baby. Based on these findings, we suggest that healthcare professionals in prenatal care services routinely screen for symptoms of depression and anxiety among women pregnant after stillbirth. Instead of providing definitive advice about the timing of the subsequent pregnancy after stillbirth, guidance should be adapted to the individual woman's needs and overall risk assessments.

11 Future work

Future studies in this field should estimate the long-term prevalence of PTSD in women with a history of stillbirth, and preferably controls, using a clinical interview. In order to establish certainties about the effects of contact with the stillborn baby, systematic studies are needed that incorporate relevant influential factors such as personality traits, care and attitudes of healthcare professionals.

As anxiety and depression is common in the pregnancy after stillbirth, future research should assess the current management for this group and investigate the effects of interventions aiming to reduce mental distress. With regard to factors that may influence the rate of early delivery by induced labour or caesarean section in the pregnancy after stillbirth, this field could benefit from studies assessing aspect such as post-traumatic stress symptoms, pregnancy related anxiety and attitudes of birth attendants.

Knowledge about other outcomes after stillbirth, such as women's risk of mortality and infertility and father's long-term mental health, is limited. These outcomes should also be assessed in prospective cohort studies, but this would require large samples followed over many years.

12 Conclusions

In this thesis, which was based on two observational studies, the following main findings were noted:

- Having experienced a stillbirth was not associated with long-term QOL, well-being or depression after 5-18 years after adjustments for sociodemographic and health-related factors.
- There was a substantial risk of long-term post-traumatic stress symptoms in women with a history of stillbirth.
- Having held the baby appeared to be protective of long-term post-traumatic stress symptoms.
- Case-level anxiety in particular, but also depression was prevalent in the pregnancy after stillbirth when compared with other multi- and primi-parous women without such history.
- The frequencies of case-level anxiety and depression declined after the birth of a healthy baby and were not significantly different from the reference groups by six to 18 months postpartum, while at 36 months postpartum, there seemed to be an increase.
- Relationship satisfaction during and after the subsequent pregnancy did not differ between women with a previous stillbirth, women with a previous livebirth and previously nulliparous women.
- The frequency of antenatal visits, induced labour and caesarean section, both elective and emergency, was substantially higher in the pregnancy after stillbirth.
- Anxiety was a minor mediator for the association between previous stillbirth and frequency of antenatal visits, whereas fear of childbirth was not a significant mediator for the association between previous stillbirth and elective caesarean section.

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Appendix

- 1) Questionnaires administered to participants in the first study (VIP)
- 2) Items included in the short versions of the Hopkins Symptoms Checklist and the Relationship Satisfaction Scale
- 3) Medical Birth Registry Form 1999 to present

The extensive questionnaires used in the MoBa study are easily accessible at the following web-adress:

<https://www.fhi.no/en/studies/moba/for-forskere-artikler/questionnaires-from-moba/>



Spørreskjema – FRIQ studien

Endret regnr

1. Fødselsår:

2. Ditt fødeland:

Skriv inn

Fødeland mor:

Skriv inn

Fødeland far:

Skriv inn

3. Sosiale forhold:

Gift/samboende

Lever i partnerskap

Bor alene

Hvis du er gift/samboende – når flyttet dere sammen?

Måned

År

Har du vært samboer eller gift tidligere? Regn ikke med nåværende ektefelle/samboer!

Ja - fortsett med neste spørsmål

Nei – gå til spørsmål 4

Vi ønsker å tidfeste alle tidligere samboerforhold og ekteskap du har levd i. Begynn med den første gangen du ble samboer/giftet deg?

Vi ble samboere

Vi giftet oss

Vi flyttet fra hverandre

Eksempel
Måned År

Måned År

Måned År

Forhold 1
Måned År

Forhold 1
Måned År

Forhold 1
Måned År

Forhold 2
Måned År

Forhold 2
Måned År

Forhold 2
Måned År

Forhold 3
Måned År

Forhold 3
Måned År

Forhold 3
Måned År

Forhold 4
Måned År

Forhold 4
Måned År

Forhold 4
Måned År

Forhold 5
Måned År

Forhold 5
Måned År

Forhold 5
Måned År

Forhold 6
Måned År

Forhold 6
Måned År

Forhold 6
Måned År

4. Hva er din høyeste avsluttede utdanning?

- ≤ gymnas/videregående skole
- 1-2 år etter gymnas/videregående skole
- 3-5 år etter gymnas/videregående skole
- > 5 år etter gymnas/videregående skole (for eks. embetseksamen)

5. Hvor mange års skolegang/yrkesutdannelse har du i alt, ta med barne- og ungdomsskole

--	--

Antall år skole totalt

6. Yrke/Arbeider som:	
------------------------------	--

7. Arbeidssituasjon

- | | | |
|---|--|--|
| <input type="checkbox"/> 90-100% i arbeid | <input type="checkbox"/> Husmor | <input type="checkbox"/> Under attføring |
| <input type="checkbox"/> 50-89% | <input type="checkbox"/> Under utdanning | <input type="checkbox"/> Uføretrygdet |
| <input type="checkbox"/> 20-49% | <input type="checkbox"/> Arbeidsledig | <input type="checkbox"/> Sykmeldt |
| <input type="checkbox"/> <20% | <input type="checkbox"/> Pensjonist | <input type="checkbox"/> Svangerskapspermisjon |

Skriv inn yrkestittel i feltet

Ikke skriv i feltene, kodes senere

8. Hvor høy er bruttoinntekten totalt i husholdningen

- | | |
|---|--|
| <input type="checkbox"/> under 150 000 kr | <input type="checkbox"/> 450-599 000 kr |
| <input type="checkbox"/> 150-299 000 kr | <input type="checkbox"/> 600-749 000 kr |
| <input type="checkbox"/> 300-449 000 kr | <input type="checkbox"/> 750 000 kr eller høyere |

9. Hvordan vurderer du de økonomiske forholdene i husholdningen

- meget gode
 gode
 dårlige
 meget dårlige

10. Har det i løpet av det siste året hendt at husholdningen har hatt vansker med å klare de løpende utgiftene til mat, strøm, transport, bolig eller lignende?

- Ja, ofte
 Ja, av og til
 Ja, en sjelden gang
 Nei, aldri

11. Mottar du for tiden noen av de følgende offentlige ytelser?

Husk å sette kryss på ALLE spørsmålene!

- | | Ja | Nei | | Ja | Nei |
|---|--------------------------|--------------------------|--|--------------------------|--------------------------|
| 1. Sykepenger/rehabiliteringspenger | <input type="checkbox"/> | <input type="checkbox"/> | 6. Sosialstøtte..... | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Ytelser under yrkesrettet attføring..... | <input type="checkbox"/> | <input type="checkbox"/> | 7. Arbeidsløshetsstrygd..... | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Uførepensjon | <input type="checkbox"/> | <input type="checkbox"/> | 8. Overgangsstønad..... | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Alderspensjon..... | <input type="checkbox"/> | <input type="checkbox"/> | 9. Etterlattepensjon..... | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Avtalefestet pensjon AFP | <input type="checkbox"/> | <input type="checkbox"/> | 10. Annen offentlig ytelse (Hvilken? ↓)..... | <input type="checkbox"/> | <input type="checkbox"/> |

Annen offentlig ytelse: **Skriv STORE TYDELIGE BLOKKBOKSTAVER, og bare ett tegn i hvert felt**

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

12. Høyde og vekt

Hvor høy er du (hele cm) cm

Hva veier du i dag (hele kg) kg

Hva veide du for 10 år siden (hele kg) kg

13. Graviditeter/barn

Er du gravid nå? Ja Nei

Hvor mange ganger har du vært gravid? (0=ingen)

Hvor mange barn har du født? (0=ingen)

Vi ønsker å få informasjon om alle dine svangerskap – hvilket år de er avsluttet, type svangerskap, om du ble spontant gravid, eller ble gravid etter behandling. Se eksempelet nedenfor:

Type svangerskap: 1) Fødsel 2) Dødfødsel 3) Svangerskap utenfor livmor
4) Spontan abort 5) Fremkalt abort

Eksempel: Fødte tvillinger i 1993, ble spontant gravid:

Eks.	År	Type svangerskap	Antall fostre	Spontant gravid		Gravid etter behandling	
				ja	nei	ja	nei
	1 9 9 3	1	2	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
1.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.				<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14. Har du under noen av svangerskapene opplevd sykdom eller noen av følgende tilstander:

Svangerskap nr.	1	2	3	4	5	6	7	Aldri
Høyt blodtrykk.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blodpropp i svangerskapet.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brukt blodfortynnende medisin.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Svangerskapsforgiftning.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behandlingstrengende kvalme..... (kun hvis innlagt sykehus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Løsning av morkake.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For tidlig fødsel (før uke 37).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Født barn med for lav fødselsvekt i forhold til svangerskapets lengde.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behandlet for diabetes i svangerskapet.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Var du sengeliggende i svangerskapet mer enn en uke?.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18d: Krever arbeidet så mye konsentrasjon og oppmerksomhet at du ofte føler deg utslitt etter en arbeidsdag?
NB: Regn også med hjemmearbeid.

- Aldri eller nesten aldri
 Ganske sjelden
 Ganske ofte
 Alltid eller nesten alltid
 Ikke aktuelt

19. Generell helse og livskvalitet

Selvopplevd helse: Hvordan vurderer du din egen helse?

- meget god god dårlig meget dårlig

20. Livskvalitet

Hvor fornøyd er du med følgende forhold?

	Svært mis- fornøyd	Noe mis- fornøyd	Litt mis- fornøyd	Litt fornøyd	Noe fornøyd	Svært fornøyd
1. Din helse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Helseomsorgen du får/har fått i det siste	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Mengden av smerte du har	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Din energi i hverdagen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Din fysiske uavhengighet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Graden av kontroll over eget liv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Utsiktene til å få et langt liv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Familiens helse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Dine barn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Familiens lykke/trivsel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Forholdet til ektefelle/annen betydningsfull person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Ditt seksualliv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Dine venner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Den følelsesmessige støtten du får fra andre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Din evne til å mestre familieforpliktelser	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Din evne til å være til hjelp for andre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Mengden av stress og bekymringer i livet ditt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Hjemmet ditt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Nabolaget/nærmiljøet ditt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Din levestandard	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Jobben din	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Å ikke ha jobb	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Din utdanning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Din økonomiske uavhengighet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Dine fritidsaktiviteter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Mulighetene til å kunne reise i feriene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Svært mis- fornøyd	Noe mis- fornøyd	Litt mis- fornøyd	Litt fornøyd	Noe fornøyd	Svært fornøyd
27. Utsiktene til en lykkelig alderdom/pensjonisttilværelse .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Din sinnsro	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Din gudstro.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Din evne til å nå personlige mål	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Din følelse av lykke generelt.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Ditt liv i sin alminnelighet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Ditt eget utseende.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Deg selv i sin alminnelighet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor <u>viktige</u> er følgende forhold for deg?	Svært lite viktig	Nokså lite viktig	Litt lite viktig	Litt viktig	Noe viktig	Svært viktig
1. Din helse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Helseomsorg.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Smertefrihet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Å ha nok energi i hverdagen.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Fysisk uavhengighet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Kontroll over eget liv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Å leve lenge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Familiens helse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Dine barn	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Familiens lykke/trivsel.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Forholdet til ektefelle/annen betydningsfull person	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Ditt seksualliv	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Dine venner.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Den følelsesmessige støtten du får fra andre.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Å mestre familieforpliktelser.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Å være til hjelp for andre.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Å ha en overkommelig mengde stress og bekymringer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Hjemmet ditt.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Nabolaget/nærmiljøet ditt.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. En god levestandard	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Jobben din	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Å ha en jobb.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Din utdannelse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Økonomisk uavhengighet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Fritidsaktiviteter.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Mulighetene til å kunne reise i feriene	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Utsiktene til en lykkelig alderdom/pensjonisttilværelse .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Hvor <u>viktige</u> er følgende forhold for deg?	Svært lite viktig	Nokså lite viktig	Litt lite viktig	Litt viktig	Noe viktig	Svært viktig
28. Sinnsro.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Din gudstro.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Å nå dine personlige mål.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Din følelse av lykke generelt.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Å være tilfreds med livet.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Ditt eget utseende.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Hvor viktig er du for deg selv.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21. Hvordan opplever du helsen din i hverdagslivet?

Har du i løpet av den siste tiden.....

1...vært i stand til å konsentrere deg (fullt ut) om alt du har gjort?	Bedre enn vanlig <input type="checkbox"/> ₁	Mindre enn vanlig..... <input type="checkbox"/> ₃
	Samme som vanlig <input type="checkbox"/> ₂	Mye mindre enn vanlig..... <input type="checkbox"/> ₄
2...ligget våken på grunn av bekymringer?	Ikke i det hele tatt <input type="checkbox"/> ₁	Heller mer enn vanlig..... <input type="checkbox"/> ₃
	Ikke mer enn vanlig <input type="checkbox"/> ₂	Mye mer enn vanlig..... <input type="checkbox"/> ₄
3...vært i stand til å holde deg engasjert og i virksomhet	Mer enn vanlig <input type="checkbox"/> ₁	Mindre enn vanlig..... <input type="checkbox"/> ₃
	Samme som vanlig..... <input type="checkbox"/> ₂	Mye mindre enn vanlig..... <input type="checkbox"/> ₄
4...vært ute blant andre så mye som du pleier?	Mer enn vanlig <input type="checkbox"/> ₁	Mindre enn vanlig..... <input type="checkbox"/> ₃
	Samme som vanlig... .. <input type="checkbox"/> ₂	Mye mindre enn vanlig..... <input type="checkbox"/> ₄
5...følt at du i det store og hele har greid deg bra?	Bedre enn vanlig <input type="checkbox"/> ₁	Mindre bra enn vanlig..... <input type="checkbox"/> ₃
	Omtrent som før..... <input type="checkbox"/> ₂	Mye mindre bra..... <input type="checkbox"/> ₄
6...vært fornøyd med måten du fungerer på?	Mer fornøyd enn vanlig <input type="checkbox"/> ₁	Mindre fornøyd..... <input type="checkbox"/> ₃
	Omtrent som vanlig..... <input type="checkbox"/> ₂	Mye mindre fornøyd..... <input type="checkbox"/> ₄
7...følt at du tar del i ting på en nyttig måte?	Mer enn vanlig <input type="checkbox"/> ₁	Mindre nyttig enn vanlig... <input type="checkbox"/> ₃
	Samme som vanlig..... <input type="checkbox"/> ₂	Mye mindre enn vanlig.... <input type="checkbox"/> ₄
8...følt at du er i stand til å ta bestemmelser?	Bedre enn vanlig <input type="checkbox"/> ₁	Mindre enn vanlig..... <input type="checkbox"/> ₃
	Samme som vanlig..... <input type="checkbox"/> ₂	Mye mindre enn vanlig..... <input type="checkbox"/> ₄
9...følt deg stadig under press?	Ikke i det hele tatt <input type="checkbox"/> ₁	Heller mer enn vanlig..... <input type="checkbox"/> ₃
	Ikke mer enn vanlig..... <input type="checkbox"/> ₂	Mye mer enn vanlig..... <input type="checkbox"/> ₄
10...følt deg ute av stand til å mestre dine vanskeligheter?	Ikke i det hele tatt <input type="checkbox"/> ₁	Heller mer enn vanlig..... <input type="checkbox"/> ₃
	Ikke mer enn vanlig..... <input type="checkbox"/> ₂	Mye mer enn vanlig..... <input type="checkbox"/> ₄
11...vært i stand til å glede deg over daglige gjøremål?	Mer enn vanlig <input type="checkbox"/> ₁	Mindre enn vanlig.. .. <input type="checkbox"/> ₃
	Samme som vanlig... .. <input type="checkbox"/> ₂	Mye mindre enn vanlig..... <input type="checkbox"/> ₄
12...tatt tingene tungt?	Ikke i det hele tatt <input type="checkbox"/> ₁	Heller mer enn vanlig..... <input type="checkbox"/> ₃
	Ikke mer enn vanlig.... <input type="checkbox"/> ₂	Mye mer enn vanlig..... <input type="checkbox"/> ₄
13...vært i stand til å møte dine problemer?	Mer enn vanlig <input type="checkbox"/> ₁	Mindre enn vanlig..... <input type="checkbox"/> ₃
	Samme som vanlig..... <input type="checkbox"/> ₂	Mye mindre enn vanlig..... <input type="checkbox"/> ₄
14...syntes at alt har vokst over hodet på deg?	Ikke i det hele tatt <input type="checkbox"/> ₁	Heller mer enn vanlig..... <input type="checkbox"/> ₃
	Ikke mer enn vanlig <input type="checkbox"/> ₂	Mye mer enn vanlig..... <input type="checkbox"/> ₄

Har du i løpet av den siste tiden.....

- 15...følt deg ulykkelig og nedtrykt? Ikke i det hele tatt ₁ Heller mer enn vanlig..... ₃
Ikke mer enn vanlig ₂ Mye mer enn vanlig..... ₄
- 16...mistet selvtilliten? Ikke i det hele tatt ₁ Heller mer enn vanlig..... ₃
Ikke mer enn vanlig ₂ Mye mer enn vanlig..... ₄
- 17...tenkt på deg selv som en verdiløs person? Ikke i det hele tatt ₁ Heller mer enn vanlig..... ₃
Ikke mer enn vanlig ₂ Mye mer enn vanlig..... ₄
- 18...stort sett følt deg tilfreds, alt tatt i betraktning? Mer enn vanlig ₁ Mindre enn vanlig..... ₃
Omtrent som vanlig..... ₂ Mye mindre enn vanlig..... ₄
- 19...stadig følt deg nervøs og anspent/oppjaget? Ikke i det hele tatt ₁ Heller mer enn vanlig..... ₃
Ikke mer enn vanlig ₂ Mye mer enn vanlig..... ₄
- 20...følt at du til tider ikke var i stand til å gjøre det minste fordi nervene dine var i ulage? Ikke i det hele tatt ₁ Heller mer enn vanlig..... ₃
Ikke mer enn vanlig ₂ Mye mer enn vanlig..... ₄

22 Kjenner du din blodtype?

Blodgruppe: Gr. A Gr. B Gr. AB Gr. 0 Vet ikke

23 Blodpropp

23a Har du noen gang fått diagnosen/behandling for blodpropp i beina, lungene, overarmene, store vener ellers i kroppen eller i hjernen ?

	Blodpropp i beina	Blodpropp i lungene	Blodpropp i overarmene	Blodpropp annet sted
	Ja Nei	Ja Nei	Ja Nei	Ja Nei
Jeg har hatt.....	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

23b Hvis "ja" på ett eller flere spørsmål, hvilket år var første gangen?

--	--	--	--

23c Hvor mange ganger har du hatt blodpropp?.....

--	--	--

23d Har du hatt blodpropp i forbindelse med bruk av p-piller?

Ja Nei

28 Mosjon (f.eks. aktiv trening, treningsstudio, turer, ski, svømmer osv.)

- 28a Hvor ofte driver du mosjon:
- | | |
|-----------------------------------|--------------------------|
| Aldri | <input type="checkbox"/> |
| Sjeldnere enn en gang i uka | <input type="checkbox"/> |
| En gang i uka | <input type="checkbox"/> |
| 2-3 ganger i uka | <input type="checkbox"/> |
| Daglig | <input type="checkbox"/> |

28b Dersom du driver mosjon så ofte som en eller flere ganger i uka: hvor hardt mosjonerer du?

- | | |
|---|--------------------------|
| Tar det rolig uten å bli andpusten og svett | <input type="checkbox"/> |
| Tar det så hardt at jeg blir andpusten og svett | <input type="checkbox"/> |
| Tar meg nesten helt ut..... | <input type="checkbox"/> |

28c Hvor lenge holder du på hver gang?

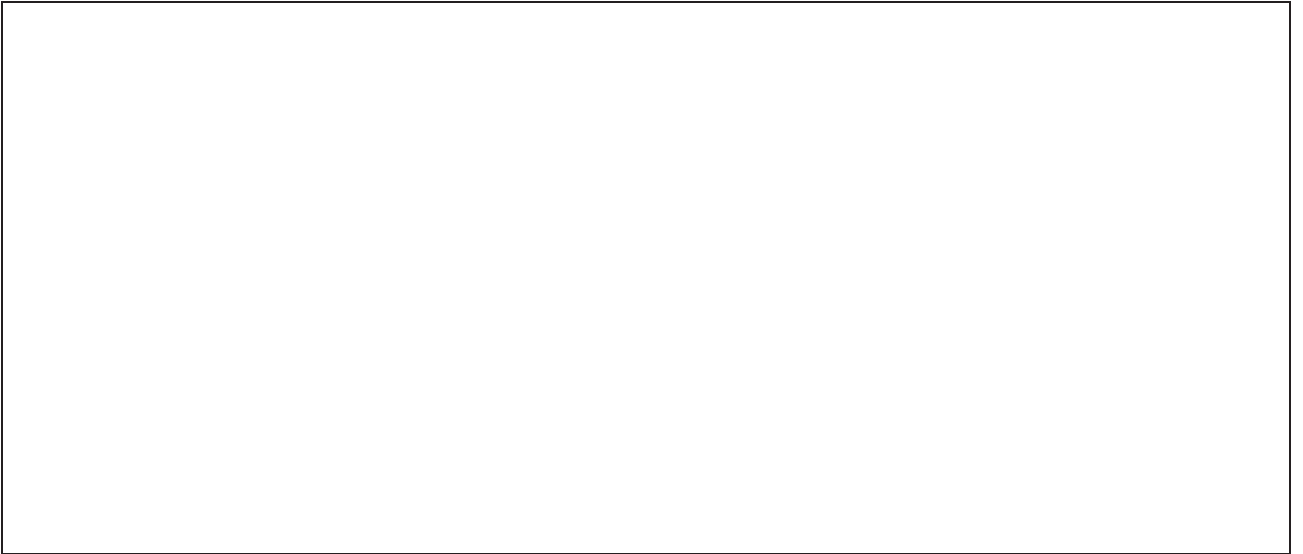
- | | |
|-----------------------------|--------------------------|
| Mindre enn 15 minutter..... | <input type="checkbox"/> |
| 15-30 minutter..... | <input type="checkbox"/> |
| 30-59 minutter..... | <input type="checkbox"/> |
| 60 minutter og mer | <input type="checkbox"/> |

29. Under finner du en rekke utsagn som beskriver hvordan du kan ha følt deg i det siste.

Kryss av for hvor ofte du har følt det på denne måten i løpet av den siste uka.

	Aldri eller nesten aldri	Litt av tiden	En del av tiden	Hele eller nesten hele tiden
1. Jeg var plaget av ting som vanligvis ikke plager meg	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Jeg hadde dårlig appetitt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Jeg var nedstemt og kunne ikke riste det av meg, til tross for støtte fra familie og venner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Jeg følte meg like mye verdt som andre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Jeg hadde problemer med å konsentrere meg om det jeg holdt på med.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Jeg følte meg deprimert	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Jeg følte at alt var et ork.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Jeg så lyst på framtiden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Jeg tenkte at livet mitt hadde vært mislykket.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Jeg følte meg engstelig.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Jeg sov urolig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Jeg følte meg lykkelig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Jeg var mer taus enn vanlig.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Jeg følte meg ensom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Folk var uvennlige.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Jeg satte pris på livet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Jeg følte meg trist.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Jeg gråt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Jeg følte at folk mislikte meg.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Jeg var initiativløs.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Kommentarer:

A large, empty rectangular box with a thin black border, intended for providing comments or feedback. It occupies the upper half of the page.

Spørreskjema til kvinner som har mistet et barn før fødselen

Nedenfor finner du en del setninger som folk som har vært utsatt for store påkjenninger bruker for å beskrive hvordan de har det.

Les hver setning og sett kryss for det tallet fra 0 til 5 som tilsvarer hvordan du har hatt det **i de siste 7 dagene**. Med "hendelsen" mener vi her det tapet du opplevde da barnet ditt døde.

Det finnes ikke riktige eller uriktige svar.

	I høy grad 5	Ganske mye 4	Middels 3	Noe 2	Litt 1	Aldri 0
1) Jeg har hatt perioder med sterke følelser omkring hendelsen.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) Ting jeg har sett og hørt minnet meg plutselig om hendelsen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) Tanker om hendelsen har trengt seg på også når jeg ikke har villet.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) Bilder fra hendelsen har plutselig dukket opp i tankene mine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) Enhver påminnelse har gjenoppvekket følelser knyttet til hendelsen.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) Jeg har hatt vanskelig for å sove på grunn av tanker og bilder om hendelsen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) Jeg har hatt vonde drømmer om hendelsen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) Jeg vet at mange uforløste følelser om hendelsen er der, men jeg har skjøvet dem bort	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) Jeg har ikke tillatt meg å bli følelsesmessig berørt når jeg tenker på hendelsen eller blir minnet på den.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) Jeg har ønsket å bli kvitt minner om hendelsen.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) Jeg har forsøkt å bli kvitt minner om hendelsen.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) Jeg har opplevd det som uvirkelig, som om hendelsen ikke har hendt eller vært virkelig.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) Jeg har holdt meg unna ting eller situasjoner som kan minne meg om hendelsen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14) Mine følelser om hendelsen er nærmest lammet.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15) Jeg har ikke tillatt meg selv tanker om hendelsen.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1. Har du fått en forklaring på hvorfor barnet døde?

- Ja, en helt sikker forklaring
- Ja, en sannsynlig forklaring
- Ja, men en svært usikker forklaring
- Nei, ingen forklaring

2. Synes du det er viktig å få en forklaring på hvorfor barnet døde?

- Svært viktig
- Viktig
- Noe viktig
- Nei, ikke viktig

3. Hvordan startet fødselen?

- Spontant, av seg selv (rier eller vannavgang)
- Den ble satt i gang med legemiddel (drypp, tabletter, gel eller annet)
- Planlagt keisersnitt

4. Visste du før fødselen startet at barnet ikke var i live?

- Ja
- Nei - Gå videre til spørsmål 9.

5. Hvis du visste at barnet ikke levde før fødselen startet, hvor lang tid før fødselen startet fikk du vite det?

- Kortere tid enn 6 timer før fødselen startet
- 6 til 24 timer før
- 1 – 2 døgn før
- Mer enn to døgn før

Hvis du kan, angi gjerne hvor lenge du visste at barnet ditt var dødt?

6a. Hvem fortalte deg at barnet ikke var i live?

- Jordmor
- Fastlegen
- Fødselslegen

6b. I hvilken grad er du tilferds med måten informasjonen om at barnet ikke levde ble formidlet?

- Meget fornøyd
- Ganske fornøyd
- Ganske misfornøyd
- Meget misfornøyd

Kan du beskrive hva som var "godt" og hva som var "dårlig" med måten informasjonen ble formidlet?

7. Fikk du noen informasjon om det praktiske rundt fødselen/ igangsetting av fødselen?

- Ja, skriftlig informasjon om dødfødsel/igangsetting av fødsel
- Ja, skriftlig informasjon om hva man bør ha med på sykehuset
- Ja, muntlig informasjon om dødfødsel/igangsetting av fødsel
- Ja, muntlig informasjon om hva man bør ha med på sykehuset

8a. Etter at du fikk vite at barnet ikke var i live, hvor var du i ventetiden til fødselen skulle settes i gang:

- Reiste hjem fram til fødselen skulle settes i gang
 Var på sykehuset hele tiden mens jeg ventet på at fødselen skulle settes i gang
 En kort tur hjem, før ventetiden fortsatte på sykehuset
 Annet, var

- Hadde ingen ventetid, fødselen ble satt i gang med en gang (innen 4 timer)

8b. Hva gjorde du i tiden etter du fikk vite om at barnet ikke var i live og til fødselen ble satt i gang?

8c. Hvis du visste at barnet ikke var i live mer enn to døgn før fødselen startet, hva var årsaken til at fødselen ikke ble satt i gang tidligere?

- Jeg ble anbefalt å vente
 Jeg ville selv vente
 Det gikk ikke tidligere av praktiske grunner
 Annet, hva?

9. Hadde du selv noen anelse eller mistanke om at det var noe galt med barnet før du fikk beskjed av lege eller jordmor om det.

- Ja Nei – Gå til spørsmål 11.

Hvis du svarte "ja", hvorfor mistenkte du at det var noe galt med barnet ?

10a. Hvis du hadde mistanke om at det var noe galt med barnet, søkte du hjelp for å undersøke hvordan barnet hadde det?

- Ja, jeg kontaktet sykehuset/fødeavdelingen
 Ja, jeg kontaktet jordmoren min
 Ja, jeg kontaktet fastlegen / gynekologen min
 Nei - Gå videre til spørsmål 11.
 Jeg ventet til jeg skulle på neste kontroll

10b. Hvis du søkte hjelp, ble det gjort nærmere undersøkelser?

- Nei, ingen foreslo at det skulle gjøres undersøkelser
 Nei, han/hun/de jeg kontaktet sa at undersøkelse ikke var nødvendig
 Ja, jeg fikk komme til en kontroll, men ble sendt hjem igjen
 Ja, jeg ble undersøkt og lagt inn
 Annet, hva?

11a. Hvor fødte du barnet?

- På fødeavdelingen Gynekologisk avd. På vei til sykehuset Hjemme
 Annet, hvor?

11b. Hadde du noen nærstående med deg under fødselen (barnefaren eller nær slektning/venn)?

- Ja, hele tiden Ja, i perioder Nei

12a. Hvor var du innlagt etter fødselen?

- På fødeavdelingen Barsel avd. Gynekologisk avd. Sykehotell
 Observasjonspost for gravide

12b. Hvilke type sengeplass hadde du?

- Enerom To-sengs rom Tre-fire sengs rom

12c. Hadde du noen nærstående med deg under oppholdet etter fødselen ?:

- Ja, hele tiden Ja, i perioder Hvis "ja" – gå til spørsmål 13
 nei – gå til spørsmål 12d.

12d. Hvis du ikke hadde noen med deg under oppholdet etter selve fødselen, hvorfor ikke?

- Jeg ønsket ikke det
 Ikke mulig av praktiske årsaker i avdelingen
 Annet

13. Fikk du noen av disse smertestillende midlene under fødselen?

- | | Ja | Nei | Vet ikke |
|--|--------------------------|--------------------------|--------------------------|
| Epidural (bedøvelse satt i ryggen) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Bedøvelse av bekkenbunnen (Pudendal bedøvelse, PDB) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Bedøvelse av livmorhalsen (Paracervikal bedøvelse, PCB) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Petidin eller Morfin (smertestillende sprøyte) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Lystgass | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Beroligende middel..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Akupunktur | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Annet, hva?

- Jeg fikk ingen bedøvelse eller smertestillende
 Jeg husker ikke om jeg fikk noen bedøvelse eller smertestillende

14. Nedenfor finner du noen påstander om tiden rundt fødselen. Kryss av for hvordan påstandene passer med det du føler om det som skjedde.

	Helt uenig	Litt uenig	Litt enig	Helt enig
Fødselen var/er et godt minne.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fødselen var/er et ubehagelig minne	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg var for sløvet/hadde fått for mye medikamenter under fødselen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg ønsker at jeg hadde sovet/vært i narkose under forløsningen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg hadde for mye smerte under fødselen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg fikk for lite bedøvelse da jeg fødte barnet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg fikk tilstrekkelig med smertelindring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personalet var en god støtte da jeg fødte barnet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personalet viste respekt for barnet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personalet viste ømhet overfor barnet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personalet viste redsel overfor barnet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personalet tok avstand fra barnet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15a. Ønsket du å se barnet etter fødselen?

- Nei, helt sikkert ikke
- Nei, men usikker
- Ja, men usikker
- Ja, helt sikkert

Hvis du ikke ønsket å se barnet

I hvilken grad fikk du støtte fra personalet til ikke å se barnet?

- I meget høy grad
- I ganske høy grad
- I ganske liten grad
- Ikke i det hele tatt

Hvis du ikke ønsket å se barnet

I hvilken grad ble du forsøkt overtalt/presset av personalet til å se barnet?

- I meget høy grad
- I ganske høy grad
- I ganske liten grad
- Ikke i det hele tatt

15a. Ønsket du å holde barnet etter fødselen?

- Nei, helt sikkert ikke
- Nei, men usikker
- Ja, men usikker
- Ja, helt sikkert

Hvis du ikke ønsket å holde barnet

I hvilken grad fikk du støtte fra personalet til ikke å holde barnet?

- I meget høy grad
- I ganske høy grad
- I ganske liten grad
- Ikke i det hele tatt

Hvis du ikke ønsket å holde barnet

I hvilken grad ble du forsøkt overtalt/presset av personalet til å holde barnet?

- I meget høy grad
- I ganske høy grad
- I ganske liten grad
- Ikke i det hele tatt

16a. Så du barnet etter fødselen? Ja Nei - **Gå videre til spørsmål 20**

16b. På hvilken måte ble barnet presentert for deg etter fødselen?

- Personalet viste meg/ga meg barnet uten å spørre
- Jeg ble spurt om jeg ville se barnet
- Jeg spurte selv om jeg kunne få se barnet
- Jeg ble oppfordret av personalet til å se barnet

16c. Hvordan opplevdes det å se barnet?

	Helt uenig	Litt uenig	Litt enig	Helt enig
Det var ubehagelig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det var opprørende	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det var trist.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det følte godt.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det følte beroligende	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det følte helt naturlig.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17a. Holdt du barnet etter fødselen? Ja Nei - **Gå til spørsmål 18**

17b. Under hvilke omstendigheter holdt du barnet?

- Personalet ga meg barnet uten å spørre
- Jeg tok selv opp barnet
- Jeg ble spurt om jeg ville holde barnet
- Jeg spurte selv om jeg kunne holde barnet
- Jeg ble oppfordret av personalet til å holde barnet

17c. Hvordan opplevdes det å holde barnet?

	Helt uenig	Litt uenig	Litt enig	Helt enig
Det var ubehagelig	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det var opprørende	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det var trist.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det følte godt.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det følte beroligende	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Det følte helt naturlig.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Har du svart på spørsmålene 17a, 17b og 17c - gå til spørsmål 19

18a. Hvis du ikke holdt barnet etter fødselen – hva var grunnen?

	Helt uenig	Litt uenig	Litt enig	Helt enig
Jeg ville ikke holde det	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg turte ikke holde det	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg fikk ikke tilbud om å holde det	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg var for sløv av medikamenter.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ikke aktuelt, jeg så ikke barnet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18b. Hvis du ikke holdt barnet etter fødselen, hadde du i dag ønsket at du gjorde det?

- Ja, helt sikkert
- Ja, ganske sikkert
- Nei, ganske sikkert ikke
- Nei, ikke i det hele tatt
- Vet ikke

19a. Hvordan var samværet med barnet etter fødselen?

- Jeg hadde barnet hos meg under hele sykehusoppholdet
- Jeg hadde barnet hos meg 2 – 4 ganger om dagen under sykehusoppholdet
- Jeg hadde barnet hos meg 1 gang om dagen
- Jeg hadde bare barnet hos meg like etter fødselen

Totalt summeres dette til: minutter timer dager

19b. Var du sammen med barnet så lenge som du selv ønsket etter fødselen?

- Ja, passelig med tid
- Nei, det var for kort tid
- Nei, det var for lang tid

Hvis tiden du var sammen med barnet var for kort eller lang, hvorfor ble det slik?

20a. Hvis du ikke så barnet etter fødselen – hvordan stemmer påstandene nedenfor ?

	Helt uenig	Litt uenig	Litt enig	Helt enig
Jeg ville ikke se det	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg fikk ikke tilbud om å se det.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg ble anbefalt av personalet å ikke se barnet.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg sov/hadde fått narkose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg var for sløv av medikamenter.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20b. Hvis du ikke så barnet etter fødselen, hadde du i dag ønsket at du gjorde det?

- Ja, helt sikkert
- Ja, ganske sikkert
- Nei, ganske sikkert ikke
- Nei, ikke i det hele tatt
- Vet ikke

21. Hvordan stemmer påstandene nedenfor med hva du føler nå?

	Helt uenig	Litt uenig	Litt enig	Helt enig
Jeg fikk støtte fra personalet til å se barnet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg fikk støtte fra personalet til å holde barnet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg fikk støtte fra personalet til å velge om jeg ville se barnet.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Jeg fikk støtte fra personalet til å velge om jeg ville holde barnet.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personalet skulle vært mer aktive til å foreslå ting jeg kunne ha gjort med barnet.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personalet skulle vært mer tilbakeholden, latt meg bestemme mer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22a. Er du i dag takknemlig for noe som personalet gjorde i forbindelse med fødselen og i tiden etterpå?

22b. Er det noe du ønsker at personalet hadde gjort annerledes i forbindelse med fødselen og i tiden etterpå?

22c. Er du i dag lei deg, sint eller såret over noe personalet gjorde i forbindelse med fødselen eller i tiden etterpå?

23. Var du forberedt på at barnet kunne ha synlige kroppslige forandringer?

- Ja Nei Vet ikke

Hadde barnet noen kroppslige forandringer?

- Nei, ingen forandringer
 Ja, mindre forandringer; kan du beskrive:

- Ja, store forandringer; kan du beskrive:

- Vet ikke

24a. Ble du spurt om tillatelse til obduksjon?

- Ja
 Nei - **Gå til 24c**
 Husker ikke – Gå til 24e

24b. Hvis du ble spurt, hvordan opplevde du det?

- Helt greit
 Litt ubehagelig
 Veldig ubehagelig

- Annet

24c. Ble barnet obdusert?

- Ja
 Nei - **Gå videre til 24e**
 Husker ikke – Gå til 24e

24d. Hvis barnet ble obdusert, hva syntes du om det?

- Jeg syntes det var viktig for å undersøke mulig årsak til at barnet døde
 Jeg syntes det var ubehagelig, men skjønte det var nødvendig
 Jeg syntes det var ubehagelig og ønsket at det ikke ble gjort

24e. Hvis barnet ikke ble obdusert, hva var grunnen til det?

- Jeg/vi ville ikke at barnet skulle obduseres
 Var ikke mulig av praktiske grunner
 Vet ikke
 Annet

25. Hvor mange dager var du innlagt på sykehuset fra fødselen startet eller ble satt i gang til du kom hjem for godt?

26a. Fikk du noen oppfølging i tiden etter sykehusoppholdet?

- Ja - **Gå videre til 26b** Nei – **Gå videre til 26f**

26b. Fikk du etterkontroll ved sykehuset du fødte?

- Nei
 Ja, av fødselslegen – vi hadde en generell samtale
 Ja, av fødselslegen – vi gikk gjennom prøvesvar og aktuelle funn
 Ja, av andre leger ved sykehuset – vi gikk gjennom prøvesvar og funn

26c. Hvis du hadde etterkontroll ved sykehuset – hvor fornøyd var du med informasjonen du fikk?

- veldig fornøyd
 littfornøyd
 litt misfornøyd
 veldig misfornøyd

26d. Synes du etterkontrollen ved sykehuset kom på riktig tidspunkt?

- Riktig tidspunkt
 For tidlig
 For sent
 Vanskelig å vurdere

26e. Hadde du oppfølging av andre etter sykehusoppholdet?

- Jeg fikk samtale med psykolog/ psykiater ordnet av sykehuset ... Ja Nei
Jeg ordnet selv samtale med psykolog/psykiater Ja Nei
Jeg deltok i en sorggruppe Ja Nei
Jeg fikk samtale med jordmor Ja Nei
Jeg fikk oppfølging av fastlegen/min faste gynekolog Ja Nei
Jeg fikk samtale med prest eller annen sjelesørger Ja Nei

- Annet, hva?

26f. Hvis du ikke fikk noen oppfølging, hva synes du om det?

Jeg følte ikke behov for det..... Ja Nei

Jeg skulle gjerne hatt det..... Ja Nei

27a. Har du et bilde av barnet?

Ja, ett eller flere bilder tatt av meg selv, barnefaren, en annen pårørende eller sykehuspersonalet.

Ja, ett eller flere bilder tatt av en fotograf.

Nei - **Gå til spørsmål 28**

27b. Hvis du har noe bilde av barnet, er du fornøyd med bildet?

Ja, veldig fornøyd

Ja, ganske fornøyd

Ja, litt fornøyd

Nei, ikke fornøyd

27c. Hvis du ikke er fornøyd med bildet, kan du gi en eller flere grunner/hva skyldes det?

Tekniske årsaker, for eksempel dårlig bildekvalitet

Hvordan bildet er tatt

Bildet er tatt for lang tid etter barnets fødsel

Annen årsak, hva?

27d. Hvis du har bilde(r) av barnet, hvordan bruker/oppbevarer du de(t) nå? Kryss av for de alternativene som passer.

Det står/henger framme så alle kan se det

Det ligger i en skuff, et album eller lignende

Jeg tar det sjelden fram

Jeg tar det ofte fram for meg selv

Jeg tar det ofte fram for å vise det til andre

Et eller flere bilder av barnet er lagt ut på Internett

Jeg viser de(t) ikke fram til andre

28. Hvis du ikke har et bilde av barnet, ønsker du at du hadde hatt det?

Ja, skulle veldig gjerne hatt det

Ja, skulle gjerne hatt det

Ja, men det er ikke så viktig

Nei, jeg føler ikke noe for det

29a. Har du noen gjenstand(er) som minner deg om barnet?

Hårlokk..... Ja Nei

Fot- og/eller håndavtrykk Ja Nei

Navnebånd..... Ja Nei

Ultralydbilde Ja Nei

Klær barnet har hatt på seg eller skulle hatt på seg Ja Nei

Leker eller kosedyr som barnet skulle hatt..... Ja Nei

Smykker barnet bar eller skulle ha båret Ja Nei

Journaler/papirer fra sykehuset Ja Nei

Brev eller hilsener fra slekt/venner i tiden etterpå Ja Nei

Annet, hva?

29b. Er det noen gjenstand eller annet minne som du savner og gjerne skulle hatt?

30. Har du et spesielt sted eller plass hjemme for gjenstander som minner om barnet?

- Ja, et skap hvor jeg oppbevarer minner
 Ja, et bord eller en hylle hvor minnene står framme
 Annet, hva?
 Nei

31. Fikk barnet et navn?

- Ja
 Nei

32. Hadde du noen navneseremoni for barnet?

- Ja, vi hadde en seremoni der prest deltok
 Ja, vi hadde en egen navneseremoni uten prest tilstede
 Nei

33a. Hadde du en minnestund for barnet

- Ja Nei

33b. Hadde du en begravelse for barnet?

- Ja
 Nei

34. Hvor er barnet begravd?

- En egen gravplass
 En familiegrav
 En minnelund
 Asken spredt over hav eller land
 Jeg vet ikke hvor barnet er lagt ned
 Annet, hva?

35. Hvor ofte besøker du graven til barnet?

- Hver uke
 Hver måned
 3 eller flere ganger i året
 1-2 ganger i året
 Ikke besøkt gravplassen siste året
 Ikke aktuelt, barnet har ingen gravplass

36. Er det noe du vil formidle som du ikke synes har blitt tatt opp i dette spørreskjemaet:

Takk for den tiden og arbeidet som du har lagt ned for å besvare spørreskjemaet.

Ønsker du å skrive noe om hvordan du opplevde det å besvare spørsmålene i denne undersøkelsen, er vi svært takknemlige for tilbakemelding.

Hopkins Symptom Checklist (SCL)

“Have you been bothered with any of the following during the last two weeks?”

(Not bothered – a little bothered – quite bothered – very bothered)

Items included in the anxiety subscale (SCL-4a)

- 1) *Feeling fearful*
- 2) *Nervousness or shaking inside*
- 3) *Feeling tense or keyed up “*
- 4) *Suddenly scared for no reason*

Items included in the depression subscale (SCL-4d)

- 5) *Feeling hopeless about the future*
- 6) *Feeling blue*
- 7) *Worrying too much about things*
- 8) *Feeling everything is an effort*

The Relationship Satisfaction Scale (RS)

“How well do these statements describe your relationship?”

(Strongly agree – agree – slightly agree – slightly disagree – disagree – strongly disagree)

Items included in the 5-items version (RS5)

- 1) *My partner and I have problems in our relationship*
- 2) *I am very happy with our relationship*
- 3) *My partner is generally understanding*
- 4) *I am satisfied with my relationship with my partner*
- 5) *We agree on how children should be raised*



Melding om avsluttet svangerskap etter 12. uke – Fødsel, dødfødsel, spontanabort

Se utfyllingsinstruks for blanketten på baksiden

A – Sivile opplysninger	Institusjonsnr: <input type="text"/>	Institusjonsnavn: <input type="text"/>	Fødsel utenfor institusjon: <input type="checkbox"/> Hjemme, planlagt <input type="checkbox"/> Hjemme, ikke planlagt <input type="checkbox"/> Under transport <input type="checkbox"/> Annet sted	Mors fulle navn og adresse: <input type="text"/>
	Mors sivilstatus: <input type="checkbox"/> Gift <input type="checkbox"/> Ugift/enslig <input type="checkbox"/> Annet <input type="checkbox"/> Samboer <input type="checkbox"/> Skilt/separert/enke	Slektskap mellom barnets foreldre? <input type="checkbox"/> Nei <input type="checkbox"/> Ja Hvis ja, hvorledes: <input type="text"/>	Mors bokommune: <input type="text"/>	Pikenavn (etternavn): <input type="text"/>
	Fars fødselsdato: <input type="text"/>	Fars fulle navn: <input type="text"/>	Mors fødselsnr.: <input type="text"/>	

B – Om svangerskap og mors helse	Siste menstr. 1. blodn.dag: <input type="text"/>	<input type="checkbox"/> Sikker <input type="checkbox"/> Usikker	Mors tidligere svangerskap/født: <input type="text"/>	Levende-født: <input type="text"/>	Dødfødt (24. uke og over): <input type="text"/>	Spontanabort/Dødfødt (12.–23. uke): <input type="text"/>	Spontanaborter (under 12. uke): <input type="text"/>	
	Ultralyd utført? <input type="checkbox"/> Nei <input type="checkbox"/> Ja	UL termin: <input type="text"/>	Annen prenatal diagnostikk? <input type="checkbox"/> Nei <input type="checkbox"/> Ja, angi type: <input type="text"/>	Patologiske funn ved prenatal diagnostikk? <input type="checkbox"/> Nei <input type="checkbox"/> Ja, hvis bekreftet – spesifiser	Regelmessig kosttilskudd: <input type="checkbox"/> Nei <input type="checkbox"/> Ja Fø sv.sk. I sv.sk. Multivitamin <input type="checkbox"/> <input type="checkbox"/> Folat/Folsyre <input type="checkbox"/> <input type="checkbox"/>			
	Spesielle forhold før svangerskapet: <input type="checkbox"/> Astma <input type="checkbox"/> Allergi <input type="checkbox"/> Tidligere sectio <input type="checkbox"/> Res. urinveisinfeksjon	<input type="checkbox"/> Kronisk nyresykdom <input type="checkbox"/> Kronisk hypertensjon <input type="checkbox"/> Reumatoid artritt <input type="checkbox"/> Hjertesykom	<input type="checkbox"/> Epilepsi <input type="checkbox"/> Diabetes type 1 <input type="checkbox"/> Diabetes type 2 <input type="checkbox"/> Annet, spesifiser i «B»	Spesifikasjon av forhold før eller under svangerskapet: B				
	Spesielle forhold under svangerskapet: <input type="checkbox"/> Blødning < 13 uke <input type="checkbox"/> Blødning 13–28 uke <input type="checkbox"/> Blødning > 28 uke <input type="checkbox"/> Glukosuri <input type="checkbox"/> Svangerskapsdiabetes	<input type="checkbox"/> Hypertensjon alene <input type="checkbox"/> Preeklampsi lett <input type="checkbox"/> Preeklampsi alvorlig <input type="checkbox"/> Preeklampsi før 34. uke <input type="checkbox"/> HELLP syndrom	<input type="checkbox"/> Eklampsi <input type="checkbox"/> Hb < 9.0 g/dl <input type="checkbox"/> Hb > 13.5 g/dl <input type="checkbox"/> Trombose, beh. <input type="checkbox"/> Infeksjon, spes. i «B»	Legemidler i svangerskapet: <input type="checkbox"/> Nei <input type="checkbox"/> Ja – spesifiser i «B»				

C – Om fødselen	Røyking og yrke Forutsetter mors samtykke – se rettleiing på baksiden <input type="checkbox"/> Skriftlig orientering gitt til mor <input type="checkbox"/> Samtykker ikke for røykeoppl.	Røykte mor ved sv.sk. begynnelse? <input type="checkbox"/> Nei <input type="checkbox"/> Av og til	Ant. sig. dagl.: <input type="text"/>	Mors yrke: <input type="checkbox"/> Samtykker ikke for yrkesoppl. <input type="checkbox"/> Ikke yrkesaktiv <input type="checkbox"/> Yrkesaktiv heltid <input type="checkbox"/> Yrkesaktiv deltid	Mors yrke: <input type="text"/>	
	Leie/presentasjon: <input type="checkbox"/> Sete <input type="checkbox"/> Normal bakhode <input type="checkbox"/> Tverrleie <input type="checkbox"/> Avvikende hodefødsel <input type="checkbox"/> Annet, spesifiser i «C»	Fødselstart: <input type="checkbox"/> Spontan <input type="checkbox"/> Indusert <input type="checkbox"/> Sectio	Ev. induksjonsmetode: <input type="checkbox"/> Prostaglandin <input type="checkbox"/> Oxytocin <input type="checkbox"/> Amniotomi <input type="checkbox"/> Annet, spesifiser i «C»	Indikasjon for inngrep og/eller induksjon: <input type="checkbox"/> Komplikasjoner som beskrevet nedenfor <input type="checkbox"/> Fosterermisdannelser <input type="checkbox"/> Overtid <input type="checkbox"/> Annet, spesifiser i «C»		
	Inngrep/tiltak: <input type="checkbox"/> Ingen <input type="checkbox"/> Utskj. tang, hodeleie <input type="checkbox"/> Annen tang, hodeleie <input type="checkbox"/> Vakuume ekstraktor <input type="checkbox"/> Episiotomi	Fremhj. ved setefødsel: <input type="checkbox"/> Vanlig fremhjelp <input type="checkbox"/> Uttrekning <input type="checkbox"/> Tang på etterk. hode	Sectio: <input type="checkbox"/> Sectio <input type="checkbox"/> Var sectio planlagt for fødsel? <input type="checkbox"/> Nei <input type="checkbox"/> Ja <input type="checkbox"/> Utført som elektiv sectio <input type="checkbox"/> Utført som akutt sectio	Spesifikasjon av forhold ved fødselen/andre komplikasjoner: C		
	Komplikasjoner: <input type="checkbox"/> Ingen <input type="checkbox"/> Vannavg. 12–24 timer <input type="checkbox"/> Vannavg. > 24 timer <input type="checkbox"/> Mekaniske misforhold <input type="checkbox"/> Vanskelig skulderforløsning	<input type="checkbox"/> Placenta previa <input type="checkbox"/> Abruptio placentae <input type="checkbox"/> Perinealruptur (grad 1-2) <input type="checkbox"/> Sphincteruptur (gr. 3-4)	<input type="checkbox"/> Blødn. > 1500 ml, transf. <input type="checkbox"/> Blødning 500–1500 ml <input type="checkbox"/> Eklampsi under fødsel <input type="checkbox"/> Navlesnorremfall	<input type="checkbox"/> Truende intrauterin asfyksi <input type="checkbox"/> Risvekkelse, stimulert <input type="checkbox"/> Langsom fremgang <input type="checkbox"/> Uterus atoni <input type="checkbox"/> Annet:		

D – Om barnet	Anestesi/analgesi: <input type="checkbox"/> Ingen <input type="checkbox"/> Lystgass <input type="checkbox"/> Epidural <input type="checkbox"/> Spinal <input type="checkbox"/> Petidin <input type="checkbox"/> Pudendal <input type="checkbox"/> Infiltrasjon	Navlesnor: <input type="checkbox"/> Normal <input type="checkbox"/> Velamentøst feste <input type="checkbox"/> Marginalt feste <input type="checkbox"/> Karanomalier	<input type="checkbox"/> Omslyng rundt hals <input type="checkbox"/> Annet omslyng <input type="checkbox"/> Ekte knute <input type="checkbox"/> Navlesnorlengde: <input type="text"/>	Fostervann: <input type="checkbox"/> Normal <input type="checkbox"/> Polyhydramnion <input type="checkbox"/> Oligohydramnion	<input type="checkbox"/> Misfarget <input type="checkbox"/> Stinkende, infisert <input type="checkbox"/> Blodtilblandet	Komplikasjoner hos mor etter fødsel: <input type="checkbox"/> Intet spesielt <input type="checkbox"/> Mor overflyttet <input type="checkbox"/> Mor intensivbeh. <input type="checkbox"/> Sepsis <input type="checkbox"/> Eklampsi post partum <input type="checkbox"/> Annet, spesifiser				
	Fødselsdato: <input type="text"/>	Klokken: <input type="text"/>	Pluralitet: <input type="checkbox"/> Enkeltfødsel <input type="checkbox"/> Flerfødsel	For flerfødsel: Nr. <input type="text"/>	Av totalt: <input type="text"/>	Kjønn: <input type="checkbox"/> Gutt <input type="checkbox"/> Pike	Barnets vekt: <input type="text"/>	Total lengde: <input type="text"/>	Apgar score: <input type="text"/>	
	Barnet var: <input type="checkbox"/> Levendefødt <input type="checkbox"/> Dødfødt/sp.abort	For dødfødt: <input type="checkbox"/> Død for fødsel <input type="checkbox"/> Død under fødselen <input type="checkbox"/> Ukjent dødstidspunkt	For dødfødt, oppgi også: <input type="checkbox"/> Død for innkomst <input type="checkbox"/> Død etter innkomst	Levendefødt, død innen 24 timer: Livet varte: <input type="text"/>	Timer: <input type="text"/>	Min: <input type="text"/>	Død senere (dato): <input type="text"/>	Klokken: <input type="text"/>	Eventuelt sete-isssmål: <input type="text"/>	5 min: <input type="text"/>
	Overfl. barneavd.: <input type="checkbox"/> Nei <input type="checkbox"/> Ja	Dato: <input type="text"/>	Overfl. til: <input type="text"/>	Indikasjon for overflytting: <input type="checkbox"/> Respirasjonsproblem <input type="checkbox"/> Prematur	<input type="checkbox"/> Medfødte misd. <input type="checkbox"/> Perinatale infeksjoner	<input type="checkbox"/> Annet, spesifiser	Behandlingskoder: <input type="checkbox"/> Icterus behandlet: <input type="checkbox"/> Systemisk antibiotika <input type="checkbox"/> Respiratorbeh. <input type="checkbox"/> CPAP beh.	<input type="checkbox"/> Lysbehandlet <input type="checkbox"/> Utskifting	Årsak: <input type="text"/>	<input type="checkbox"/> ABO uforlik. <input type="checkbox"/> RH immunisering <input type="checkbox"/> Fysiologisk <input type="checkbox"/> Annen årsak

Tegn til medfødte misdannelser: Nei Ja

Spesifikasjon av skader, neonatale diagnoser og medfødte misdannelser – utfylles av lege: **D**

Kryss av hvis skjema er oppfølgingskjema:

Jordmor v/fødsel:

Jordmor v/utskrivning:

Lege:

Lege barse/barneavd.:

Utskrivningsdato:

Mor:

Barn: