BMJ open

Women's experiences in relation to stillbirth and predictors for long-term post-traumatic stress symptoms: a retrospective study

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-003323
Article Type:	Research
Date Submitted by the Author:	30-May-2013
Complete List of Authors:	Gravensteen, Ida Kathrine; Oslo University Hospital, Department of Haematology Helgadóttir, Linda; Oslo University Hospital, Department of Obstetrics and Gynaecology Jacobsen, Eva-Marie; Oslo University Hospital, Department of Haematology; University of Oslo, Insitute of Clinical Medicine Rådestad, Ingela; Sofiahemmet University, Sandset, Per Morten; University of Oslo, Insitute of Clinical Medicine; Oslo University Hospital, Department of Haematology Ekeberg, Oivind; University of Oslo, Department of Behavioral Sciences in Medicine ; Oslo University Hospital, Department of Acute Medicine
Primary Subject Heading:	Obstetrics and gynaecology
Secondary Subject Heading:	Mental health, Epidemiology, Nursing
Keywords:	Maternal medicine < OBSTETRICS, Anxiety disorders < PSYCHIATRY, EPIDEMIOLOGY

Women's experiences in relation to stillbirth and predictors for long-term post-traumatic stress symptoms: a retrospective study

Ida Kathrine Gravensteen, MedStud [1,2,3], Linda Björk Helgadóttir MD, PhD[1,4], Eva-Marie Jacobsen MD, PhD[1,3], Ingela Rådestad, RN, RM, PhD[5], Per Morten Sandset MD, PhD[1,3] and Øivind Ekeberg MD, PhD[2,6]

[1]Departments of Haematology, [4]Obstetrics and Gynaecology, and [6]Acute Medicine, Oslo University Hospital, Oslo, Norway, and

[2]Department of Behavioral Sciences in Medicine and [3]Institute of Clinical Medicine, University of Oslo, Oslo, Norway, and

[5]Sophiahemmet University, Stockholm, Sweden.

Corresponding author:

Eva-Marie Jacobsen

Oslo University Hospital, Department of Hematology

Box 4950 Nydalen, N-0424 Oslo, Norway

Tel. +47 22119240 – fax. +47 22119040

E-mail: e.m.jacobsen@medisin.uio.no

Keywords: stillbirth, fetal death, long-term memories, quality of health care, post-traumatic stress

Word count: 3711

ABSTRACT

Objectives: To investigate the experiences of women with a previous stillbirth and their appraisal of the care they received at the hospital, and to assess the long-term risk and possible predictors of posttraumatic stress symptoms (PTSS).

Design: A retrospective study.

Setting: Two university hospitals.

Participants: The study population comprised 379 women with a verified diagnosis of stillbirth (≥23 gestational weeks or birth weight ≥500 g) in a singleton or duplex pregnancy 5-18 years previously. 101 women completed a comprehensive questionnaire in two parts.

Primary and secondary outcome measures: The women's experiences and appraisal of the care provided by health care professionals before, during and after stillbirth. PTSS assessed using the Impact of Event Scale (IES).

Results: The great majority saw (98%) and held (82%) their baby and felt that they were supported in doing so. Most women felt that health care professionals were supportive during the delivery (85.6%) and showed respect towards their baby (94.9%). The majority (91.1%) had received some form of short-term follow up. One third showed clinically significant long-term PTSS (IES≧20). Independent predictors for PTSS were younger age (OR 6.60, 95% CI 1.99-21.83), induced abortion prior to stillbirth (OR 5.78, 95% CI 1.56-21.38) and higher parity (OR 3.46, 95% CI 1.19-10.07) at the time of stillbirth. Protective of PTSS was having held the baby (OR 0.17, 95% CI 0.05-0.56).

Conclusion: The great majority saw and held their baby and was satisfied with the support from health care professionals. One in three women presented with a clinically significant level of PTSS 5-18 years after stillbirth. Having held the baby was protective, whereas prior induced abortion was a risk factor for a high level of PTSS.

Trial registration: The study was registered at www.clinicaltrials.gov, with registration number NCT 00856076.

ARTICLE SUMMARY

Article focus:

- How do women with a previous stillbirth experience the diagnosis, the delivery and their time at the hospital?
- How do these women appraise, in the long-term, the care they received from health care professionals?
- What is the long-term risk of post-traumatic stress symptoms (PTSS) among these women and what factors predict this outcome?

Key messages:

- Most of the women in our study wanted to see and hold their stillborn baby and were encouraged by health care professionals to do so.
- A clinically significant level of long-term PTSS was present among approximately one in three women. Having held the baby was protective, whereas prior induced abortion was a risk factor.
- The great majority had received some form of short-term follow-up after the stillbirth.

Strengths and limitations of this study:

- We have used an acknowledged validated instrument to measure the level of PTSS. To our knowledge, this is the first study to assess predictors of PTSS, using a multivariate model, in a large group of non-pregnant women many years after stillbirth.
- The risk of selection bias and memory bias cannot be excluded.

INTRODUCTION

Stillbirth is a traumatic event for the mother and represents a significant loss. This causes normal grief reactions, but can also cause traumatic experiences that require processing of psychological sequels.[1-3] Women experiencing a stillbirth have been shown to have more anxiety and depression symptoms in the following months and years compared to women with live births,[4-6] and are also at risk of posttraumatic stress symptoms in the subsequent pregnancy.[7]

Grief involves a separation process and the bond to the person that is lost is central in this process. Throughout the pregnancy an attachment between the mother and the unborn baby develops,[8, 9] which is further enhanced shortly after the birth, possibly mediated by high oxytocin levels in maternal blood.[10] Thus, stillbirth is a major challenge for the mother, having to adjust from the expectation of getting a healthy baby to the realization that her child is dead.

Previously it was common that the mother was not given the opportunity to recognize her dead baby and this still applies in many cultures.[11, 12] In the recent decades it has become procedure in many industrialized countries to encourage the mother and other close relatives to see, hold and dress the stillborn baby. In a Swedish study from 1996 on 314 women with stillbirths, nearly every mother had seen and 80% caressed her baby.[13] The general opinion is that seeing and holding the stillborn baby facilitates healthy mourning and reduces the risk of long-term psychological distress.[14, 15] However, some researchers have called this benefit into question and claim that holding the stillborn infant accounts for more psychological morbidity in the subsequent pregnancy and postpartum year, and an increased risk of posttraumatic stress symptoms (PTSS) in the longer term.[16, 17]

Other factors shown to be predictive of psychological morbidity after stillbirth are: a long time from diagnosis to delivery ($\geq$25 hours),[4] not being with the baby for as long as desired,[4, 18] not possessing any token of remembrance,[4] being unmarried, low education and young age,[14] high parity at the time of loss and no subsequent pregnancy.[18] Social support and counseling from health care professionals and bereavement groups seem to have positive effects on the mourning process.[19]

We have previously shown that there are no substantial differences in long-term quality of life (QOL) and depression between women with a previous stillbirth and women with only live births.[20] This is probably due to the effect of time, and possibly adequate guidelines and short-term interventions. However, there are limited data on how experiences and care given at the time of stillbirth are remembered and affect women in the long-term. Stillbirth has previously been defined as a potent stressor for development of posttraumatic stress reactions. However, studies conducted so far are limited by small numbers and short observation periods (one year), or are restricted to follow-up of women with a subsequent live birth and lack multivariate models.[7, 17, 21]

Health care professionals play an important role in providing care and guidance to parents in the first few days following a stillbirth.[15, 22] Parents want guidance, but there should also be room for their own wishes.[22] Rather than enforcing mourning rituals, health care professionals should be flexible towards the mother's needs.[4] This is a delicate and sometimes difficult balance.

The main objective of this study was to investigate how the women experienced the procedures of the diagnosis of stillbirth, the delivery and the postpartum period, and how they appraise, in the long-term, the care they received at the hospital. Secondly, we wanted to assess the women's level of posttraumatic stress symptoms (PTSS), and identify factors that predict this outcome.

METHODS

Women with a diagnosis of stillbirth at Oslo University Hospital, Ullevål, Oslo, Norway, and Akershus University Hospital, Lørenskog, Norway, from January 1 1990 through December 31 2003, were identified through the hospitals' administrative systems. We searched for relevant World Health Organization (WHO) International Classification of Diseases codes, versions 9 or 10, and identified 439 possible cases of stillbirth, defined as fetal death at ≥23 gestational weeks or birth weight ≥500 g. After reviewing the medical records, we excluded 49 cases wrongly diagnosed, eight with non-retrievable records, and three with triplet pregnancies, leaving 379 women with a verified diagnosis of stillbirth in a singleton or duplex pregnancy. Invalid or unknown address was recognized in 19 cases and thus a total of 346 women received a postal invitation to participate in the study. After two reminders, 106 (31%) agreed to participate. The data were collected in 2008–2009, accordingly 5-18 years after the stillbirth. We have previously published a more detailed description of the selection process.[20]

Of the women who agreed to participate, 101 completed a comprehensive questionnaire in two parts. The first part included information on demographic, pregnancy, and health-related variables.[20] The other part was designed to investigate and quantify the women´s experiences at the hospital before, during and after the delivery, and especially what they thought of the procedures and care conducted by health care professionals. There were also open fields to elaborate the answers or describe positive and negative experiences in own words. The questionnaire comprised four scales measuring PTSS, QOL, symptoms of depression, and well-being. The questionnaire was optically scanned and the data were transferred electronically to the project database. All the extracted data were manually verified for scanning errors.

PTSS were quantified using the Impact of Event Scale (IES).[23] This is a frequently used instrument with good psychometric properties to measure the degree of subjective psychological distress after a traumatic event and screen for a possible post-traumatic stress disorder (PTSD).[24-26] The scale has a total range of 0-75 and two subscales, one with seven items to measure intrusion, the other with eight items to measure avoidance. Each item has six response alternatives from 0 = 'never' to 5 = 'a high degree'. In accordance with previous studies we regarded an

IES score ≥20 as a possible clinical case level and a score ≧35 as a possible PTSD level.[24, 27, 28] One missing item was accepted in each of the subscales and the missing item was replaced with the mean score of the other items for that respondent. Three of 101 women had more than one missing item in a subscale and were excluded, resulting in 98 respondents for the IES analyses. Cronbach´s alpha of internal validity in our study was 0.94 for the intrusion subscale, 0.90 for the avoidance subscales and 0.94 for the total IES score. An acceptable value of Cronbach's alpha is considered to be >0.7.[29]

We had access to information from medical records on demographic and clinical factors for all eligible participants at the time of the index pregnancy. The data included delivery hospital, gestational age, date of index delivery, maternal age, parity, and marital status. These variables were compared between responders and non-responders in order to assess the risk of selection bias.

Statistical analyses

Categorical data are presented as counts and percentages. Continuous variables are presented as mean or median and standard deviation (SD), range, 95% confidence interval (CI) or interquartile range (IQR).

To identify variables independently associated with an IES score above the predefined cut-off value of 20, we used bivariate and multivariate logistic regression. Possible predictors (established and plausible risk factors) were selected among socio-demographic factors, history of pregnancies, events in relation to the stillbirth and contact with the baby, and presented as odds' ratios (OR) and adjusted OR (aOR) with 95% confidence intervals. Variables associated with IES >20 with p <0.2 in the unadjusted analyses were included in a multivariate logistic regression model, using forward Wald variable selection. Variables with <10 subjects in at least one of the categories were not included in the models. Interactions between variables in the final model were tested individually.

Findings with two-sided P values <.05 were considered significant. All data were analyzed using the Statistical Package for the Social Sciences version 18.0 (IBM SPSS Inc, Chicago, Illinois, USA).

Ethics

Authorization for the use of information from medical records for research purposes was obtained from the Norwegian Ministry of Health and Social Affairs. The study was approved by the Data Protection Official at Oslo University Hospital, which serves as an institutional review board, and the Regional Ethics Committee, Region East, Norway. All participants provided written informed consent. The study was registered at www.clinicaltrials.gov, with registration number NCT 00856076.

RESULTS

The mean time from stillbirth to assessment was 10.8 years (range 5-18, SD 4.0). Time since fetal death, socio-demographic and clinical factors did not differ significantly between participants and non-responders (data not shown). Socio-demographic- and pregnancy related characteristics are presented in Table 1. None of the women were pregnant at follow-up.

Table 1: Socio-demographic and pregnancy-related factors at follow up (2008)

	N	Mean (range, SD) n (%)
Age *Age at the time of stillbirth*	101	41.6 (28-54, 5.2) 30.8 (18-43, 4.6)
Country of birth Norway Other	100	 88 (88.0) 12 (12.0)
Civil status Married/cohabitating Living alone *At the time of stillbirth* Married/cohabiting Living alone	101	 86 (85.1) 15 (14.9) 94 (93.1) 7 (6.9)
Education Primary/secondary/high school High school + 1–5 years High school + >5 years	101	 25 (24.8) 58 (57.4) 18 (17.8)
Occupational status Working full time (90–100%) Not working full time	101	 58 (57.4) 43 (42.6)
Household income <750 000 NOK ≥750 000 NOK	97	 52 (53.6) 45 (46.4)
Number of pregnancies, mean (SD)	101	4.2 (1.6)
Number of live-born children, mean (SD)	101	2.2 (1.0)
Experienced spontaneous abortion	101	39 (38.6)
Experienced induced abortion	101	24 (23.8)
Achieved the number of children wished for	96	58 (60.4)

SD, standard deviation; NOK, Norwegian kroner (100 NOK= ~13 euros)

Women´s experiences before, during and after the delivery

Many women (68%) suspected that something was wrong with their unborn baby before they were informed by a health care professional that the fetus had died in utero (Table 2). Most frequently (66%) they had felt less or absence of fetal movements, but some believed this was normal at the end of the pregnancy. The majority (88%) contacted health care services, 63% of these were admitted to the hospital. Most of the women (83%) were aware that the baby was dead before the delivery. They were often (62%) informed of the baby's death by the obstetrician at the hospital and 79% were satisfied with the way the message was conveyed. When describing in their own words what was positive with the way they were informed, synonyms with honesty/clarity (n=19) and empathy/intimacy (n=17) were most frequently reported. On the opposite, lack of eye contact or empathy and hesitations from health care professionals in confirming the baby's death was described as negative experiences.

After giving birth 39 (39%) women were admitted to a standard postnatal ward, but nine women expressed in their own words that they wished they did not have had to stay at the postnatal ward after the delivery. The majority (82%) was asked for permission to perform an autopsy and 25% found the question slightly or very uncomfortable. However, in the case where an autopsy was performed (81%), none of the women stated that they wished it had not been done. In 44% of the cases where an autopsy was not performed, this was because the woman objected to it. Approximately half of the women did not receive any or only a very uncertain explanation for the stillbirth. The majority (71%) meant that such an explanation was very important and only one woman stated this not to be important.

Table 2: The time before, during and after the delivery of a stillborn baby

BEFORE THE DELIVERY	N	n (%)
Did you suspect that something was wrong with the baby?		
Yes	98	67 (68.4)
No		31 (31.6)
Did you contact health care services about your suspicion?		
Yes	66	58 (87.9)

No/waited for the next check-up		8 (12.1)
Was further investigations conducted?		
Examined and admitted to the hospital	57	36 (63.2)
Examined and sent home		12 (21.1)
No		9 (15.8)
Did you know about the baby´s death before the delivery started?		
<24 hours	101	61 (60.4)
24-48 hours		19 (18.8)
>48 hours		4 (4.0)
No		17 (16.8)
Who informed you of the baby´s death?		
Obstetrician	84	52 (61.9)
Midwife		26 (31.0)
General practitioner		6 (7.1)
Are you satisfied with the way the information was passed?		
Very or quite satisfied	82	65 (79.3)
Not satisfied		17 (20.7)
THE DELIVERY		
Where did you deliver your baby?		
Labor ward	101	91 (90.1)
Other/do not remember		10 (9.9)
How did the delivery start?		
Spontaneously	100	24 (24.0)
Induced by medication		70 (70.0)
Caesarian section		6 (6.0)
Did you receive any medication?		
Analgesics or acupuncture	101	77 (76.2)
Narcosis		6 (5.9)
No		11 (10.9)
Do not remember		7 (6.9)
Did you have the baby´s father, a close relative or a friend with you?		
Yes, the whole time	101	84 (83.2)
Yes, at times		8 (7.9)
No		9 (8.9)
AFTER THE DELIVERY		
Where did you stay after the delivery?		
Postnatal department	99	39 (39.4)
Labor ward		25 (25.3)
Observation unit		21 (21.2)
Other/do not remember		14 (14.1)

Were you asked for permission to perform an autopsy?		
Yes	101	83 (82.2)
No/do not remember		18 (17.8)
Was an autopsy performed?		
Yes	101	82 (81.2)
No/do not remember		19 (18.8)
Did you receive an explanation for your baby´s death?		
Yes, a certain or likely explanation	101	49 (48.5)
No or a very uncertain explanation		52 (51.5)

Contact with the baby and appraisal of the delivery and the role of the health care professionals

The majority of the women (94%) wished to see their baby (Table 3). All but two did see the baby and 82% also held their baby. The women were most frequently either shown/given the baby without being asked, encouraged by the health care professionals or asked if they wanted to see/hold the baby. The women felt to a large degree that the health care professionals supported them in having contact with the baby, and to a slightly lesser degree supported them in making their own decisions regarding this. One in four stated that the staff should have been more active in suggesting things to do with the baby, but seven percent stated that the staff should have been more withdrawn and let the women decide more. All but one of the 13 women who did not wish to hold their baby felt that the staff supported them in this decision, whereas the women who did not want to see their child reported a varying degree of support and pressure from health care professionals. None of the women felt that the staff tried to persuade or pressure them into holding the baby against their wishes.

The women expressed mixed emotions about seeing and holding the baby, but a larger proportion expressed more positive than negative emotions (Table 3). The majority stated “it felt good” to see (82%) and to hold (86%) the baby. The majority of the women who saw their baby felt they got to spend as much time with the baby as they wanted. At follow-up, one of the two women who did not see her baby was completely sure she wished she had done so, whereas the other was completely sure of her earlier decision. Eight (62%) of the women who did not hold the baby regretted this in retrospect.

Table 3: The women's contact with the baby and experiences of the delivery and health care professionals

CONTACT WITH THE BABY	**N**	**n (%)**	
Seeing		**Yes**	**No**
Wished to see the baby	101	95 (94.1)	6 (5.9)
Saw the baby		99 (98.0)	2 (2.0)
Circumstances of seeing			
Was showed without being asked	95	29 (30.5)	
Was asked		33 (34.7)	
Asked herself		9 (9.5)	
Was encouraged by the staff		24 (25.3)	
Holding		**Yes**	**No**
Wished to hold the baby	101	85 (84.2)	16 (15.8)
Held the baby		83 (82.2)	18 (17.8)
Circumstances of holding			
Was given the child without being asked	80	18 (22.5)	
Picked up the baby herself		10 (12.5)	
Was asked		35 (43.8)	
Asked herself		4 (5.0)	
Was encouraged by the staff		13 (16.3)	
Time spent with the baby			
<1 hour (or just after the birth)	100	25 (25.0)	
1-11 hours (or 1 time per day)		27 (27.0)	
≥12 hours (or 2-4 times per day)		48 (48.0)	
Sufficient time with the baby	95	74 (77.9)	
Too little time		19 (20.0)	
Too much time		2 (2.1)	
ALLEGATIONS ABOUT THE BIRTH		**Agree**	
I have good memories of the delivery	99	46 (46.5)	
I have unpleasant memories of the delivery	97	60 (61.9)	
I was too jaded/had been given too much medication	95	11 (11.6)	
I wish I was asleep/in narcosis	91	25 (27.5)	
I received too little analgesics	94	26 (27.7)	
ROLE OF HEALTH CARE PROFESSIONALS			
They were a good support when I gave birth	97	83 (85.6)	
They showed respect towards the baby	99	94 (94.9)	
They showed tenderness towards the baby	96	91 (94.8)	
They showed fear towards the baby	97	6 (6.2)	
They distanced themselves from the baby	98	2 (2.0)	

EXPERIENCE OF SEEING / HOLDING THE BABY		
It was unpleasant	86 / 74	36 (41.9) / 24 (32.4)
It was upsetting	88 / 75	57 (64.8) / 49 (65.3)
It was sad	94 / 80	90 (95.7) / 79 (98.8)
It felt good	92 / 79	75 (81.5) / 68 (86.1)
It felt calming	88 / 75	63 (71.6) / 57 (76.0)
It felt completely natural	88 / 77	71 (80.7) / 62 (80.5)
ALLEGATIONS ABOUT THE HEALTH CARE PROFESSIONALS		
They supported me in seeing the baby	94	91 (96.8)
They supported me in holding the baby	91	80 (87.9)
They supported me in choosing whether or not to see the baby	89	70 (78.7)
They supported me in choosing whether or not to hold the baby	90	68 (75.6)
They should have been more active in suggesting things to do with the baby	89	22 (24.7)
They should have been more withdrawn and let me decide more	89	6 (6.7)

Most of the women have one or more photographs of the baby (97%) and at least one other token of remembrance (99%), most often a foot- or handprint (85%). The majority also named their baby (94%), arranged a memorial (83%) and/or a funeral (93%), had their baby buried in a marked grave (90%) and visit the grave at least once a year (83%).

Most of the women (91.1%) received short-term interventions by invitation from the hospital or on own initiative. The majority (75.2%) had a postpartum consultation at the hospital of which 87% were satisfied. In addition 17 (16.8%) had a consultation with a psychologist/psychiatrist, 54 (53.5%) participated in a bereavement group, 58 (57.4%) had a consultation with the midwife, 25 (24.8%) received follow-up from their general practitioner/gynecologist, 34 (33.7%) had a consultation with a priest/religious counselor, and 15 (14.9%) had a consultation with other health care professionals/hospital staff. Only nine women (8.9%) did not receive any follow-up of which three (33.3%) wished they had.

The women expressed mixed emotions about experiencing the delivery, but the majority felt that the staff was supportive and showed respect towards their baby (Table 3).

Posttraumatic stress symptoms and predictors

IES total scores and scores on the subscales are presented in Table 4. The distribution of the IES total score was skewed with a median of 10.0 and a mean of 15.8. One third (31.6%) had IES total score above the predefined clinical case level (≥20) and 13.3% above the PTSD level (≥35).

Table 4: Scores on Impact of Event Scale (IES) (N=98)

IES	Median (IQR)	Mean (SD)	95 % CI of the mean
Intrusion (0-35)	7.5 (16.3)	10.2 (10.3)	8.2–12.3
Avoidance (0-40)	2.5 (7.0)	5.6 (8.3)	3.9–7.3
Total score (0–75)	10.0 (23.0)	15.8 (17.1)	12.4–19.3
	n (%)		
IES score ≥20	31 (31.6)		
IES score ≥35	13 (13.3)		

IQR; interquartile range, SD; standard deviation, CI; confidence interval

Results from the bivariate and multivariate logistic regression analyses of predictors for PTSS are presented in Table 5. Younger age (≤27 years) was the only independent socio-demographic predictor of PTSS (OR 6.60, 95% CI 1.99-21.83). Higher parity at index (OR 3.46, 1.19-10.07) and induced abortion prior to stillbirth (OR 5.78, 95% CI 1.56-21.38) were independent pregnancy history predictors. Having held the baby was strongly protective of PTSS (OR 0.17, 0.05-0.56), but other experiences related to the stillbirth were not significantly associated with PTSS. The variance inflation factor was <5 for all variables in the final model, showing that collinearity does not invalidate the results.

There was a significant interaction between age at index and parity at index (p=0.029). Higher parity (>1) among those aged >27 years at index was associated with a significant higher odds of IES ≥20 (OR 12.61, 95% CI 2.13-74.64, p = 0.005). The association between parity and IES ≥20 was not seen among those aged ≤27 years (OR 1.20, 95% CI 0.19-7.77, p = 0.848).

Table 5: Predictors for IES ≥20

	IES ≥20 (n)	IES <20 (n)	Bivariate			Multivariate		
Socio-demographic variables			OR	95% CI	*P* value	aOR	95% CI	*P* value
*Age at the time of stillbirth**								
>27 years	19	54	1 (ref)			1 (ref)		
≤27 years	12	13	2.62	1.02, 6.74	0.045	6.60	1.99, 21.83	0.002
Civil status								
Married/cohabiting	25	59	1 (ref)					
Living alone	6	8	1.77	0.56, 5.63	0.334			
Divorce/break up after stillbirth								
No	23	56	1 (ref)					
Yes	8	11	1.77	0.63, 4.97	0.278			
Country of birth								
Born in Norway	25	63	1 (ref)					
Not born in Norway	5	4	3.15	0.78, 12.70	0.107			
Household income								
<750 000 NOK	19	31	1 (ref)					
≥750 000 NOK	10	35	0.47	0.19, 1.15	0.099			
Education								
Primary/secondary/high school	11	13	1 (ref)					
High school + 1-5 years	17	40	0.50	0.19, 1.34	0.170			
High school + >5 years	3	14	0.25	0.06, 1.12	0.070			
Occupational status								
Working full time (90-100%)	16	41	1 (ref)					
Not working full time	15	26	1.48	0.63, 3.49	0.372			
Pregnancy history								
*Parity at the time of stillbirth**								
1	11	38	1 (ref)			1 (ref)		
>1	20	29	2.38	0.99, 5.75	0.053	3.46	1.19, 10.07	0.023
Gestational age at stillbirth								
≤30 weeks	12	26	1 (ref)					
>30 weeks	19	39	1.06	0.44, 2.54	0.904			
Time since stillbirth								
≤10 years	18	32	1 (ref)					
11-18 years	13	35	0.66	0.28, 1.56	0.344			
Spontaneous abortion								

No	19	40	1 (ref)					
Yes	12	27	0.94	0.39, 2.24	0.881			
Induced abortion prior to stillbirth								
No	21	60	1 (ref)			1 (ref)		
Yes	10	7	4.08	1.38, 12.09	0.011	5.78	1.56, 21.38	0.009
Live birth after stillbirth								
No	7	6	1 (ref)					
Yes	24	61	0.34	0.10, 1.11	0.073			
Experiences in relation to stillbirth								
Awareness of the baby's death before the delivery								
No	5	11	1 (ref)					
<24 hours	20	39	1.13	0.34, 3.70	0.842			
≥24 hours	6	17	0.78	0.19, 3.18	0.725			
Baby's father/close relative present during the delivery								
No/at times	7	10	1 (ref)					
The whole time	24	57	0.60	0.2, 1.77	0.355			
Held the baby								
No	11	7	1 (ref)			1 (ref)		
Yes	20	60	0.21	0.07, 0.62	0.005	0.17	0.05, 0.56	0.004
Time spent with the baby								
<1 hour (or just after birth)	13	10	1 (ref)					
1-11 hours (or 1 time per day)	8	19	0.32	0.10, 1.04	0.058			
≥12 hours (or ≥2-4 times per day)	9	38	0.18	0.06, 0.55	0.002			
Autopsy								
No	8	9	1 (ref)					
Yes	23	58	0.45	0.15, 1.30	0.138			
Postpartum consultation with the obstetrician								
No	9	10	1 (ref)					
Yes	22	53	0.46	0.17, 1.29	0.140			
Additional follow-up								
No	6	3	1 (ref)					
Yes	25	64	0.20	0.05, 0.84	0.028			
Arranged memorial								
No	8	9	1 (ref)					
Yes	23	54	0.48	0.16, 1.40	0.178			

* Significant interaction between age at index and parity at index in the multivariable model

IES; Impact of Event Scale, OR; odds' ratio, aOR; adjusted odds' ratio, CI; confidence interval

DISCUSSION

The women in this study were to a large degree satisfied with the care they received around the time of stillbirth and how health care professionals approached their baby. The level of PTSS after 5-18 years was noticeably high with approximately one third with a clinically relevant symptom level and 13% above a predefined (possible) PTSD level. Independent predictors of a high symptom level were young age and high parity at the time of stillbirth and prior induced abortion. Having held the baby appeared to be protective.

Most of the women wished and were to a large degree encouraged by health care professionals to see and hold their stillborn baby. The women found honesty, clarity, empathy, availability, information and guidance to be positive elements among health care professionals when informing the women of the baby's death and in the following days at the hospital. Collecting tokens of remembrance was also regarded as positive experience. These findings are consistent with previous studies.[4, 13, 22, 30] Our study also confirmed the finding by Christoffersen that being at the postnatal ward after the delivery and having to confront live-born babies is considered to be emotionally stressful for women with stillbirth.[22]

We have previously reported long-term quality of life and depression among the women with stillbirth and found that they did not differ significantly from controls when adjusted for other factors.[20] This indicates that even though a substantial proportion of the women have IES scores above a possible case level, the daily functioning seems to be rather good. A diagnosis of PTSD or other clinical psychiatric problems cannot be based on a questionnaire alone. Furthermore, the IES scale does not measure symptoms of hyper-arousal that are required to fulfill a PTSD diagnosis according to the ICD-10 or DSM–IV systems. Therefore we find it likely that the number of women with an IES score above a clinical or PTSD level is somewhat overestimated in our study. This point could be studied more thoroughly with a clinical interview in addition to a questionnaire.

Young age and higher parity predicted a higher PTSS level in our study and have previously been shown to increase the risk of long-term anxiety- and depression symptoms.[14, 18] The interaction between parity and age indicates that having a

stillbirth as the second or later birth is associated with a high PTSS level among women aged >27 years, but this was not a predefined end point in our study and must be considered with caution. Prior induced abortion remained the strongest predictor for a high PTSS level. This is a new finding that should be confirmed and explored in future studies. Our finding that holding the stillborn baby is protective for a high PTSS level in the long-term supports the general opinion that contact with the baby is beneficial, even though it has been speculated that this effect may be temporarily reversed during a subsequent pregnancy.[14, 16] Rådestad and Christoffersen have previously suggested that one reason for the findings by Hughes et al, that holding the stillborn baby increases psychological morbidity,[16] could be that the women were not sufficiently prepared for this contact.[31] Even though contact with the baby seems to have a positive effect in our study, it is possible that forced encounter could be potentially traumatic for a subgroup of women who do not want this contact.

Limitations and strengths

As an observational study, there are limitations to consider, which have been discussed to some degree in our previous publication.[20] We consider the low response rate (31%) to be the most critical limitation as this poses a risk of selection bias. The women in our study report similar experiences as have been found in other studies and we therefore argue that our main findings can be generalized to other women who have suffered stillbirth. A higher response rate would presumably not have changed our main conclusions. Since the women were asked about events occurring many years earlier there is a risk of recall bias. However, as a stillbirth usually is considered a substantial event in a woman's life it is reasonable to assume that they have relatively good memory of these critical events. The multivariable analysis of predictors for IES $\geq$20 is limited by small numbers and wide confidence intervals and should therefore be interpreted with some caution.

Strengths of our study are that we have used an acknowledged validated instrument to measure PTSS and, to our knowledge, this is the first time predictors of PTSS have been assessed using a multivariate model in a large group of non-pregnant women many years after stillbirth.

Conclusions

The great majority of the women saw and held their baby after the stillbirth and felt that the health care professionals were supportive. One in three women presented with a clinically significant level of PTSS 5-18 years after stillbirth. Having held the stillborn baby protected against a high level of long-term PTSS implicating that health care professionals should continue to provide the opportunity and encourage women to have contact with their stillborn baby.

Acknowledgements

The authors are grateful to Professor Leiv Sandvik for generous help with the statistical analyses and to all the women who participated in the study.

Contributions to authorship

IKG performed the analyses, interpreted the results and wrote the main draft of the manuscript. LBH designed the original study, collected the data, helped to interpret the results and revised the manuscript. EMJ designed the original study, helped to interpret the results and revised the manuscript. IR helped design the study, helped to interpret the results and revised the manuscript. PMS designed the original study, helped to interpret the results, revised the manuscript and supervised the study. ØE helped design the study, helped with the statistical analyses, helped to interpret the results and revised the manuscript. All authors read and approved the final version of the manuscript.

Competing interests

The authors have no competing interests.

Funding

This work was supported by grants from the South-Eastern Norway Health Authority, the Oslo University Hospital Scientific Trust and the Norwegian Research Council (grant no 160805-V50). The sponsors of the study had no role in the study design; the collection, analysis and interpretation of data; or writing, reviewing or approval of the manuscript. The authors are fully independent of the sponsors.

Data Sharing

Datasets (raw data material) are available for some of the authors.

REFERENCE LIST

[1] LaRoche C, Lalinec-Michaud M, Engelsmann F, et al. Grief reactions to perinatal death--a follow-up study. *Can J Psychiatry* 1984 Feb;**29**:14-9.

[2] Nicol MT, Tompkins JR, Campbell NA, et al. Maternal grieving response after perinatal death. *Med J Aust* 1986;**144**:287-9.

[3] Kelley MC, Trinidad SB. Silent loss and the clinical encounter: Parents' and physicians' experiences of stillbirth-a qualitative analysis. *BMC Pregnancy Childbirth* 2012;**12**:137. doi: 10.1186/1471-2393-12-137

[4] Radestad I, Steineck G, Nordin C, et al. Psychological complications after stillbirth--influence of memories and immediate management: population based study. *BMJ* 1996;**312**:1505-8.

[5] Adeyemi A, Mosaku K, Ajenifuja O, et al. Depressive symptoms in a sample of women following perinatal loss. *J Natl Med Assoc* 2008;**100**:1463-8.

[6] Boyle FM, Vance JC, Najman JM, et al. The mental health impact of stillbirth, neonatal death or SIDS: prevalence and patterns of distress among mothers. *Soc Sci Med* 1996;**43**:1273-82.

[7] Turton P, Hughes P, Evans CD, et al. Incidence, correlates and predictors of post-traumatic stress disorder in the pregnancy after stillbirth. *Br J Psychiatry* 2001;**178**:556-60.

[8] Stainton MC. The fetus: a growing member of the family. *Family Relations* 1985;**34**:321-6.

[9] Lumley JM. Attitudes to the fetus among primigravidae. *Aust Paediatr J* 1982;**18**:106-9.

[10] Nissen E, Lilja G, Widstrom AM, et al. Elevation of oxytocin levels early post partum in women. *Acta Obstet Gynecol Scand* 1995;**74**:530-3.

[11] Froen JF, Cacciatore J, McClure EM, et al. Stillbirths: why they matter. *Lancet* 2011;**377**:1353-66.

[12] Lewis E. The management of stillbirth: coping with an unreality. *Lancet* 1976;**2**:619-20.

[13] Radestad I, Nordin C, Steineck G, et al. Stillbirth is no longer managed as a nonevent: a nationwide study in Sweden. *Birth* 1996;**23**:209-15.

[14] Cacciatore J, Radestad I, Frederik FJ. Effects of contact with stillborn babies on maternal anxiety and depression. *Birth* 2008;**35**:313-20.

[15] Radestad I, Surkan PJ, Steineck G, et al. Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery* 2009;**25**:422-9.

[16] Hughes P, Turton P, Hopper E, et al. Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet* 2002;**360**:114-8.

[17] Turton P, Evans C, Hughes P. Long-term psychosocial sequelae of stillbirth: phase II of a nested case-control cohort study. *Arch Womens Ment Health* 2009;**12**:35-41.

[18] Surkan PJ, Radestad I, Cnattingius S, et al. Events after stillbirth in relation to maternal depressive symptoms: a brief report. *Birth* 2008;**35**:153-7.

[19] Cacciatore J, Schnebly S, Froen JF. The effects of social support on maternal anxiety and depression after stillbirth. *Health Soc Care Community* 2009;**17**:167-76.

[20] Gravensteen IK, Helgadottir LB, Jacobsen EM, et al. Long-term impact of intrauterine fetal death on quality of life and depression: a case-control study. *BMC Pregnancy Childbirth* 2012;**12**:43. doi: 10.1186/1471-2393-12-43

[21] Salvesen KA, Oyen L, Schmidt N, et al. Comparison of long-term psychological responses of women after pregnancy termination due to fetal anomalies and after perinatal loss. *Ultrasound Obstet Gynecol* 1997;**9**:80-5.

[22] Christoffersen L. Helsevesenet ved dødfødsel: Foreldres opplevelse og bruk av det norske helsevesenet før, under og etter en dødfødsel - et pilotprosjekt. (Report in Norwegian) *Oslo School of Management/Landsforeningen Uventet Barnedød*;2008.

[23] Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. *Psychosom Med* 1979;**41**:209-18.

[24] Wohlfarth TD, van den Brink W, Winkel FW, et al. Screening for Posttraumatic Stress Disorder: an evaluation of two self-report scales among crime victims. *Psychol Assess* 2003;**15**:101-9.

[25] Sundin EC, Horowitz MJ. Impact of Event Scale: psychometric properties. *Br J Psychiatry* 2002;**180**:205-9.

[26] Sundin EC, Horowitz MJ. Horowitz's Impact of Event Scale evaluation of 20 years of use. *Psychosom Med* 2003;**65**:870-6.

[27] Neal LA, Busuttil W, Rollins J, et al. Convergent validity of measures of post-traumatic stress disorder in a mixed military and civilian population. *J Trauma Stress* 1994;**7**:447-55.

[28] Johansen VA, Wahl AK, Eilertsen DE, et al. Prevalence and predictors of post-traumatic stress disorder (PTSD) in physically injured victims of non-domestic violence. A longitudinal study. *Soc Psychiatry Psychiatr Epidemiol* 2007;**42**:583-93.

[29] Bland JM, Altman DG. Cronbach's alpha. *BMJ* 1997;**314**:572.

[30] Trulsson O, Radestad I. The silent child--mothers' experiences before, during, and after stillbirth. *Birth* 2004;**31**:189-95.

[31] Rådestad I, Christoffersen L. Helping a woman meet her stillborn baby while it is soft and warm. *British Journal of Midwifery* 2008;**16**:588-91.

STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*

Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any pre-specified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	6
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	Not applicable
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-7
Bias	9	Describe any efforts to address potential sources of bias	7
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	7
		(*b*) Describe any methods used to examine subgroups and interactions	7
		(*c*) Explain how missing data were addressed	7
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	Not applicable

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	6, Table 1-5
		(b) Give reasons for non-participation at each stage	6
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1-3, Table 5
		(b) Indicate number of participants with missing data for each variable of interest	Table 1-5
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	9
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	15
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	6, 15, Table 5
		(*b*) Report category boundaries when continuous variables were categorized	6, Table 5
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	9
Discussion			
Key results	18	Summarise key results with reference to study objectives	19
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	20
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	19-21
Generalisability	21	Discuss the generalisability (external validity) of the study results	20
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	22

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.
Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ open

Women's experiences in relation to stillbirth and risk factors for long-term post-traumatic stress symptoms: a retrospective study

Journal:	*BMJ Open*
Manuscript ID:	bmjopen-2013-003323.R1
Article Type:	Research
Date Submitted by the Author:	09-Aug-2013
Complete List of Authors:	Gravensteen, Ida Kathrine; Oslo University Hospital, Department of Haematology Helgadóttir, Linda; Oslo University Hospital, Department of Obstetrics and Gynaecology Jacobsen, Eva-Marie; Oslo University Hospital, Department of Haematology; University of Oslo, Insitute of Clinical Medicine Rådestad, Ingela; Sofiahemmet University, Sandset, Per Morten; University of Oslo, Insitute of Clinical Medicine; Oslo University Hospital, Department of Haematology Ekeberg, Oivind; University of Oslo, Department of Behavioral Sciences in Medicine ; Oslo University Hospital, Department of Acute Medicine
Primary Subject Heading:	Obstetrics and gynaecology
Secondary Subject Heading:	Mental health, Epidemiology, Nursing
Keywords:	Maternal medicine < OBSTETRICS, Anxiety disorders < PSYCHIATRY, EPIDEMIOLOGY

Women's experiences in relation to stillbirth and risk factors for long-term post-traumatic stress symptoms: a retrospective study

Ida Kathrine Gravensteen, MedStud [1,2,3], Linda Björk Helgadóttir MD, PhD[1,4], Eva-Marie Jacobsen MD, PhD[1,3], Ingela Rådestad, RN, RM, PhD[5], Per Morten Sandset MD, PhD[1,3] and Øivind Ekeberg MD, PhD[2,6]

[1]Departments of Haematology, [4]Obstetrics and Gynaecology, and [6]Acute Medicine, Oslo University Hospital, Oslo, Norway, and

[2]Department of Behavioural Sciences in Medicine and [3]Institute of Clinical Medicine, University of Oslo, Oslo, Norway, and

[5]Sophiahemmet University, Stockholm, Sweden.

Corresponding author:

Eva-Marie Jacobsen

Oslo University Hospital, Department of Haematology

Box 4950 Nydalen, N-0424 Oslo, Norway

Tel. +47 22119240 – fax. +47 22119040

E-mail: e.m.jacobsen@medisin.uio.no

Keywords: stillbirth, fetal death, long-term memories, quality of health care, post-traumatic stress

Word count: 3926

ABSTRACT

Objectives: 1) To investigate the experiences of women with a previous stillbirth and their appraisal of the care they received at the hospital. 2) To assess the long-term level of post-traumatic stress symptoms (PTSS) in this group and identify risk factors for this outcome.

Design: A retrospective study.

Setting: Two university hospitals.

Participants: The study population comprised 379 women with a verified diagnosis of stillbirth (≥23 gestational weeks or birth weight ≥500 g) in a singleton or twin pregnancy 5-18 years previously. 101 women completed a comprehensive questionnaire in two parts.

Primary and secondary outcome measures: The women's experiences and appraisal of the care provided by health care professionals before, during and after stillbirth. PTSS at follow-up was assessed using the Impact of Event Scale (IES).

Results: The great majority saw (98%) and held (82%) their baby. Most women felt that health care professionals were supportive during the delivery (85.6%) and showed respect towards their baby (94.9%). The majority (91.1%) had received some form of short-term follow up. One third showed clinically significant long-term PTSS (IES≧20). Independent risk factors were younger age (OR 6.60, 95% CI 1.99-21.83), induced abortion prior to stillbirth (OR 5.78, 95% CI 1.56-21.38) and higher parity (OR 3.46, 95% CI 1.19-10.07) at the time of stillbirth. Having held the baby (OR 0.17, 95% CI 0.05-0.56) was associated with less PTSS.

Conclusion: The great majority saw and held their baby and was satisfied with the support from health care professionals. One in three women presented with a clinically significant level of PTSS 5-18 years after stillbirth. Having held the baby was protective, whereas prior induced abortion was a risk factor for a high level of PTSS.

Trial registration: The study was registered at www.clinicaltrials.gov, with registration number NCT 00856076.

ARTICLE SUMMARY

Article focus:

- How do women with a previous stillbirth experience the diagnosis, the delivery and their time at the hospital?
- How do these women appraise, in the long-term, the care they received from health care professionals?
- What is the long-term risk of post-traumatic stress symptoms (PTSS) among these women and what factors are associated with this outcome?

Key messages:

- Most of the women in our study wanted to see and hold their stillborn baby and were encouraged by health care professionals to do so.
- A clinically significant level of long-term PTSS was present among approximately one in three women. Having held the baby was protective, whereas prior induced abortion was a risk factor.
- The great majority had received some form of short-term follow-up after the stillbirth.

Strengths and limitations of this study:

- We have used an acknowledged validated instrument to measure the level of PTSS. To our knowledge, this is the first study to assess risk factors for PTSS, using a multivariate model, in a large group of non-pregnant women many years after stillbirth.
- The risk of selection bias and memory bias cannot be excluded.

INTRODUCTION

Stillbirth is a traumatic event for the mother and represents a significant loss. This causes normal grief reactions, but can also cause traumatic experiences that require processing of psychological sequelae.[1-3] Women experiencing a stillbirth have been shown to have more anxiety and depression symptoms in the following months and years compared to women with live births,[4-6] and are also at risk of posttraumatic stress symptoms in the subsequent pregnancy.[7]

Grief involves a separation process and the bond to the person that is lost is central in this process. Throughout the pregnancy an attachment between the mother and the unborn baby develops,[8, 9] which is further enhanced shortly after the birth, possibly mediated by high oxytocin levels in maternal blood.[10] Thus, 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.

Previously it was common that the mother was not given the opportunity to recognise her dead baby and this still applies in many cultures.[11, 12] In the recent decades it has become procedure in many industrialised countries to encourage the mother and other close relatives to see, hold and dress the stillborn baby. In a Swedish study from 1996 on 314 women with stillbirths, nearly every mother had seen and 80% caressed her baby.[13] The general opinion is that seeing and holding the stillborn baby facilitates healthy mourning and reduces the risk of long-term psychological distress.[14, 15] However, some researchers have called this benefit into question and claim that holding the stillborn infant accounts for more psychological morbidity in the subsequent pregnancy and postpartum period, and an increased risk of posttraumatic stress symptoms (PTSS) in the longer term.[16, 17]

Other factors shown to be predictive of psychological morbidity after stillbirth are: a long time from diagnosis to delivery (≥25 hours),[4] not being with the baby for as long as desired,[4, 18] not possessing any token of remembrance,[4], being unmarried, low education and young age,[14] a short time since stillbirth,[7, 14, 19] high parity at the time of loss and no subsequent pregnancy.[18] Sharing memories of the baby, social and professional support is shown to be associated with better mental health following stillbirth.[7,19, 20]

We have previously shown that there are no substantial differences in long-term quality of life (QOL) and depression between women with a previous stillbirth and women with only live births.[21] This is probably due to the effect of time, and possibly adequate guidelines and short-term interventions. However, there are limited data on how experiences and care given at the time of stillbirth are remembered and affect women in the long-term. Stillbirth has previously been defined as a potent stressor for development of posttraumatic stress reactions. However, studies conducted so far are limited by small numbers and short observation periods (one year), or are restricted to follow-up of women with a subsequent live birth and lack multivariate models.[7, 17, 22]

Health care professionals play an important role in providing care and guidance to parents in the first few days following a stillbirth.[15, 23] Parents want guidance, but there should also be room for their own wishes.[23] Rather than enforcing mourning rituals, health care professionals should be flexible towards the mother's needs.[4] This is a delicate and sometimes difficult balance.

The main objective of this study was to investigate how the women experienced the procedures of the diagnosis of stillbirth, the delivery and the postpartum period, and how they appraise, in the long-term, the care they received at the hospital. Secondly, we wanted to assess the women's level of posttraumatic stress symptoms (PTSS), and identify possible risk factors for this outcome.

METHODS

Women with a diagnosis of stillbirth at Oslo University Hospital, Ullevål, Oslo, Norway, and Akershus University Hospital, Lørenskog, Norway, from January 1 1990 through December 31 2003, were identified through the hospitals' administrative systems. We searched for relevant World Health Organization (WHO) International Classification of Diseases codes, versions 9 or 10, and identified 439 possible cases of stillbirth, defined as fetal death at ≥23 gestational weeks or birth weight ≥500 g. After reviewing the medical records, we excluded 49 cases wrongly diagnosed, eight with non-retrievable records, and three with triplet pregnancies, leaving 379 women with a verified diagnosis of stillbirth in a singleton or twin pregnancy. Women who had emigrated, died or had an invalid or foreign address were excluded, thus a total of 346 women received a postal invitation to participate in the study. After two reminders, 106 (31%) agreed to participate. The data were collected in 2008–2009, accordingly 5-18 years after the stillbirth. We have previously published a more detailed description of the selection process.[21]

Of the women who agreed to participate, 101 completed a comprehensive questionnaire in two parts. The first part included information on demographic, pregnancy, and health-related variables.[21] The other part was designed to investigate and quantify the women´s experiences at the hospital before, during and after the delivery, and especially what they thought of the procedures and care conducted by health care professionals. Also included were some open questions with fields to describe positive and negative experiences in own words. The questionnaire comprised four scales measuring PTSS, QOL, symptoms of depression, and well-being. The questionnaire was optically scanned and the data were transferred electronically to the project database. All the extracted data were manually verified for scanning errors.

Current PTSS at follow up (5-18 years after stillbirth) were quantified using the Impact of Event Scale (IES).[24] This is a frequently used instrument with good psychometric properties to measure the degree of subjective psychological distress after a traumatic event and to screen for a possible post-traumatic stress disorder (PTSD).[25-27] The participants were instructed to answer the questions using their prior stillbirth as the reference traumatic event. The scale has a total range of 0-75 and two subscales, one with seven items to measure intrusion, the other with eight

items to measure avoidance. Each item has six response alternatives from 0 = 'never' to 5 = 'a high degree'. In accordance with previous studies we regarded an IES score ≥20 as a possible clinical case level and a score ≧35 as a possible PTSD level.[25, 28, 29] One missing item was accepted in each of the subscales and the missing item was replaced with the mean score of the other items for that respondent. Three of 101 women had more than one missing item in a subscale and were excluded, resulting in 98 respondents for the IES analyses. Cronbach´s alpha of internal validity in our study was 0.94 for the intrusion subscale, 0.90 for the avoidance subscales and 0.94 for the total IES score. An acceptable value of Cronbach's alpha is considered to be >0.7.[30]

We had access to information from medical records on demographic and clinical factors for all eligible participants at the time of the index pregnancy. The data included information on the date of the stillbirth,, maternal age, parity, civil status, birth weight, number of fetuses (single or twins), hypertensive disorders, diabetes, placental abruption and smoking. These variables were compared between responders and non-responders in order to assess the risk of selection bias.

Statistical analyses

Categorical data are presented as counts and percentages. Continuous variables are presented as mean or median and standard deviation (SD), range, 95% confidence interval (CI) or interquartile range (IQR).

To identify variables independently associated with an IES score above the predefined cut-off value of 20, we used bivariate and multivariate logistic regression. Possible predictors (established and plausible risk factors) were selected among socio-demographic factors, history of pregnancies, events in relation to the stillbirth and contact with the baby, and presented as odds' ratios (OR) and adjusted OR (aOR) with 95% confidence intervals. Variables associated with IES >20 with p <0.2 in the unadjusted analyses were included in a multivariate logistic regression model, using forward Wald variable selection. Variables with <10 subjects in at least one of the categories were not included in the models. Interactions between variables in the final model were tested individually.

Findings with two-sided P values <.05 were considered significant. All data were analysed using the Statistical Package for the Social Sciences version 18.0 (IBM SPSS Inc, Chicago, Illinois, USA).

Ethics

Authorisation for the use of information from medical records for research purposes was obtained from the Norwegian Ministry of Health and Social Affairs. The study was approved by the Data Protection Official at Oslo University Hospital, which serves as an institutional review board, and the Regional Ethics Committee, Region East, Norway. All participants provided written informed consent. The study was registered at www.clinicaltrials.gov, with registration number NCT 00856076.

RESULTS

The mean time from stillbirth to assessment was 10.8 years (range 5-18, SD 4.0). Time since fetal death, socio-demographic and clinical factors did not differ significantly between participants and non-responders (data not shown). Socio-demographic- and pregnancy related characteristics are presented in Table 1. None of the women were pregnant at follow-up.

Table 1: Socio-demographic and pregnancy-related factors at follow up (2008)

	N (missing)	Mean (range, SD) n (%)
Age *Age at the time of stillbirth*	101 (0)	41.6 (28-54, 5.2) 30.8 (18-43, 4.6)
Country of birth Norway Other	100 (1)	 88 (88.0) 12 (12.0)
Civil status Married/cohabitating Living alone *At the time of stillbirth* Married/cohabiting Living alone	101 (0)	 86 (85.1) 15 (14.9) 94 (93.1) 7 (6.9)
Education Primary/secondary/high school High school + 1–5 years High school + >5 years	101 (0)	 25 (24.8) 58 (57.4) 18 (17.8)
Occupational status Working full time (90–100%) Not working full time	101 (0)	 58 (57.4) 43 (42.6)
Household income <750 000 NOK ≥750 000 NOK	97 (4)	 52 (53.6) 45 (46.4)
Number of pregnancies, mean (SD)	101 (0)	4.2 (1.6)
Number of live-born children, mean (SD)	101 (0)	2.2 (1.0)
Experienced spontaneous abortion	101 (0)	39 (38.6)
Experienced induced abortion	101 (0)	24 (23.8)
Achieved the number of children wished for	96 (7)	58 (60.4)

SD, standard deviation; NOK, Norwegian kroner (100 NOK= ~13 euros)

Women´s experiences before, during and after the delivery

Many women (68%) suspected that something was wrong with their unborn baby before they were informed by a health care professional that the fetus had died in utero (Table 2). Most frequently (66%) they had felt less or absence of fetal movements, but some believed this was normal at the end of the pregnancy. The majority (88%) contacted health care services, 63% of these were admitted to the hospital. Most of the women (83%) were aware that the baby was dead before the delivery. They were often (62%) informed of the baby's death by the obstetrician at the hospital and 79% were satisfied with the way the message was conveyed. When describing in their own words what was positive with the way they were informed, synonyms with honesty/clarity (n=19) and empathy/intimacy (n=17) were most frequently reported. On the opposite, lack of eye contact or empathy and hesitations from health care professionals in confirming the baby's death was described as negative experiences.

After giving birth 39 (39%) women were admitted to a standard postnatal ward, but nine women expressed in their own words that they wished they did not have had to stay at the postnatal ward after the delivery. The majority (82%) was asked for permission to perform an autopsy and 25% found the question slightly or very uncomfortable. However, in the case where an autopsy was performed (81%), none of the women stated that they wished it had not been done. In 44% of the cases where an autopsy was not performed, this was because the woman objected to it. Approximately half of the women did not receive any or only a very uncertain explanation for the stillbirth. The majority (71%) felt that such an explanation was very important and only one woman stated this not to be important.

Table 2: The time before, during and after the delivery of a stillborn baby

BEFORE THE DELIVERY	**N (missing)**	**n (%)**
Did you suspect that something was wrong with the baby?		
Yes	98 (3)	67 (68.4)
No		31 (31.6)

Did you contact health care services about your suspicion?		
Yes	66 (1)	58 (87.9)
No/waited for the next check-up		8 (12.1)
Was further investigations conducted?		
Examined and admitted to the hospital	57 (1)	36 (63.2)
Examined and sent home		12 (21.1)
No		9 (15.8)
Did you know about the baby´s death before the delivery started?		
<24 hours	101 (0)	61 (60.4)
24-48 hours		19 (18.8)
>48 hours		4 (4.0)
No		17 (16.8)
Who informed you of the baby´s death?		
Obstetrician	84 (0)	52 (61.9)
Midwife		26 (31.0)
General practitioner		6 (7.1)
Are you satisfied with the way the information was passed?		
Very or quite satisfied	82 (2)	65 (79.3)
Not satisfied		17 (20.7)
THE DELIVERY		
Where did you deliver your baby?		
Labor ward	101 (0)	91 (90.1)
Other department		6 (5.9)
Not sure		4 (3.9)
How did the delivery start?		
Spontaneously	100 (1)	24 (24.0)
Induced by medication		70 (70.0)
Caesarian section		6 (6.0)
Did you receive any medication?		
Pain relief, sedatives or acupuncture*	101 (0)	77 (76.2)
General anesthesia		6 (5.9)
No		11 (10.9)
Do not remember		7 (6.9)
Did you have the baby´s father, a close relative or a friend with you?		
Yes, the whole time	101 (0)	84 (83.2)
Yes, at times		8 (7.9)
No		9 (8.9)
AFTER THE DELIVERY		
Where did you stay after the delivery?		
Postnatal department	99 (2)	39 (39.4)

Labor ward		25 (25.3)
Observation unit		21 (21.2)
Other department		10 (9.9)
Not sure		4 (4.0)
Were you asked for permission to perform an autopsy?		
Yes	101 (1)	83 (82.2)
No		7 (6.9)
Do not remember		11 (10.9)
Was an autopsy performed?		
Yes	101 (0)	82 (81.2)
No		18 (17.8)
Do not remember		1 (1.0)
Did you receive an explanation for your baby´s death?		
Yes, a certain or likely explanation	101 (0)	49 (48.5)
No or a very uncertain explanation		52 (51.5)

* Pain relief: Epidural analgesia, spinal analgesia, pudendal block, paracervical block, pethidine/morphine, nitrous oxide, paracetamol

Contact with the baby and appraisal of the delivery and the role of the health care professionals

The majority of the women (94%) wished to see their baby (Table 3). All but two did see the baby and 82% also held their baby. The women were most frequently either shown/given the baby without being asked, encouraged by the health care professionals or asked if they wanted to see/hold the baby. The women felt to a large degree that the health care professionals supported them in having contact with the baby, and to a slightly lesser degree supported them in making their own decisions regarding this. One in four stated that the staff should have been more active in suggesting things to do with the baby, but seven per cent stated that the staff should have been more withdrawn and let the women decide more. All but one of the 16 women who did not wish to hold their baby felt that the staff supported them in this decision, whereas the women who did not want to see their child reported a varying degree of support and pressure from health care professionals. None of the women felt that the staff tried to persuade or pressure them into holding the baby against their wishes.

The women expressed mixed emotions about seeing and holding the baby, but a larger proportion expressed more positive than negative emotions (Table 3). The majority stated "it felt good" to see (82%) and to hold (86%) the baby. The majority of the women who saw their baby felt they got to spend as much time with the baby as they wanted. At follow-up, one of the two women who did not see her baby was completely sure she wished she had done so, whereas the other was completely sure of her earlier decision. Eight (62%) of the women who did not hold the baby regretted this in retrospect.

Table 3: The women's contact with the baby and experiences of the delivery and health care professionals

CONTACT WITH THE BABY	**N (missing)**	**n (%)**	
Seeing		**Yes**	**No**
Wished to see the baby	101 (0)	95 (94.1)	6 (5.9)
Saw the baby		99 (98.0)	2 (2.0)
Circumstances of seeing			
Was showed without being asked	95 (0)	29 (30.5)	
Was asked		33 (34.7)	
Asked herself		9 (9.5)	
Was encouraged by the staff		24 (25.3)	
Holding		**Yes**	**No**
Wished to hold the baby	101 (0)	85 (84.2)	16 (15.8)
Held the baby		83 (82.2)	18 (17.8)
Circumstances of holding			
Was given the child without being asked	80 (3)	18 (22.5)	
Picked up the baby herself		10 (12.5)	
Was asked		35 (43.8)	
Asked herself		4 (5.0)	
Was encouraged by the staff		13 (16.3)	
Time spent with the baby			
<1 hour (or just after the birth)	100 (1)	25 (25.0)	
1-11 hours (or 1 time per day)		27 (27.0)	
≥12 hours (or 2-4 times per day)		48 (48.0)	
Sufficient time with the baby	95 (0)	74 (77.9)	
Too little time		19 (20.0)	
Too much time		2 (2.1)	

STATEMENTS ABOUT THE BIRTH		Agree
I have good memories of the delivery	99 (2)	46 (46.5)
I have unpleasant memories of the delivery	97 (4)	60 (61.9)
I was too sedated/had been given too much medication	95 (6)	11 (11.6)
I wish I was asleep/in general anesthesia	91 (10)	25 (27.5)
I received too little pain relief	94 (7)	26 (27.7)
ROLE OF HEALTH CARE PROFESSIONALS		
They were a good support when I gave birth	97 (4)	83 (85.6)
They showed respect towards the baby	99 (2)	94 (94.9)
They showed tenderness towards the baby	96 (5)	91 (94.8)
They showed fear towards the baby	97 (4)	6 (6.2)
They distanced themselves from the baby	98 (3)	2 (2.0)
EXPERIENCE OF SEEING / HOLDING THE BABY		
It was unpleasant	86 / 74	36 (41.9) / 24 (32.4)
It was upsetting	88 / 75	57 (64.8) / 49 (65.3)
It was sad	94 / 80	90 (95.7) / 79 (98.8)
It felt good	92 / 79	75 (81.5) / 68 (86.1)
It felt calming	88 / 75	63 (71.6) / 57 (76.0)
It felt completely natural	88 / 77	71 (80.7) / 62 (80.5)
STATEMENTS ABOUT THE HEALTH CARE PROFESSIONALS		
They supported me in seeing the baby	94	91 (96.8)
They supported me in holding the baby	91	80 (87.9)
They supported me in choosing whether or not to see the baby	89	70 (78.7)
They supported me in choosing whether or not to hold the baby	90	68 (75.6)
They should have been more active in suggesting things to do with the baby	89	22 (24.7)
They should have been more withdrawn and let me decide more	89	6 (6.7)

Most of the women have one or more photographs of the baby (97%) and at least one other token of remembrance (99%), most often a foot- or handprint (85%). The majority also named their baby (94%), arranged a memorial (83%) and/or a funeral (93%), had their baby buried in a marked grave (90%) and visit the grave at least once a year (83%).

Most of the women (91.1%) received short-term interventions by invitation from the hospital or on own initiative. The majority (75.2%) had a postpartum consultation at the hospital of which 87% were satisfied. In addition 17 (16.8%) had a consultation with a psychologist/psychiatrist, 54 (53.5%) participated in a bereavement group, 58 (57.4%) had a consultation with the midwife, 25 (24.8%) received follow-up from their general practitioner/gynaecologist, 34 (33.7%) had a consultation with a priest/religious counsellor, and 15 (14.9%) had a consultation with other health care professionals/hospital staff. Only nine women (8.9%) did not receive any follow-up of which three (33.3%) wished they had.

The women expressed mixed emotions about experiencing the delivery, but the majority felt that the staff was supportive and showed respect towards their baby (Table 3).

Posttraumatic stress symptoms

Current IES total scores and scores on the subscales are presented in Table 4. The distribution of the IES total score was skewed with a median of 10.0 and a mean of 15.8. One third (31.6%) had IES total score above the predefined clinical case level (≥20) and 13.3% above the PTSD level (≥35).

Table 4: Scores on Impact of Event Scale (IES) 5-18 years after stillbirth (N=98)

IES	Median (IQR)	Mean (SD)	95 % CI of the mean
Intrusion (0-35)	7.5 (16.3)	10.2 (10.3)	8.2–12.3
Avoidance (0-40)	2.5 (7.0)	5.6 (8.3)	3.9–7.3
Total score (0–75)	10.0 (23.0)	15.8 (17.1)	12.4–19.3
	n (%)		
IES score ≥20	31 (31.6)		
IES score ≥35	13 (13.3)		

IQR; interquartile range, SD; standard deviation, CI; confidence interval

Results from the bivariate and multivariate logistic regression analyses of risk factors for PTSS are presented in Table 5. Younger age (≤27 years) was the only independent socio-demographic risk factor for PTSS (OR 6.60, 95% CI 1.99-21.83). Higher parity at index (OR 3.46, 1.19-10.07) and induced abortion prior to stillbirth (OR 5.78, 95% CI 1.56-21.38) were independent pregnancy history risk factors. Having held the baby was strongly protective of PTSS (OR 0.17, 0.05-0.56), but other experiences related to the stillbirth were not significantly associated with PTSS. The variance inflation factor was <5 for all variables in the final model, showing that collinearity does not invalidate the results.

There was a significant interaction between age at index and parity at index (p=0.029). Higher parity (>1) among those aged >27 years at index was associated with a significant higher odds of IES ≥20 (OR 12.61, 95% CI 2.13-74.64, p = 0.005). The association between parity and IES ≥20 was not seen among those aged ≤27 years (OR 1.20, 95% CI 0.19-7.77, p = 0.848).

There was no statistically significant association between time since birth and PTSS (p=0.234). Accordingly, if included in the final model, time since stillbirth was not significantly associated with IES ≥20 (p= 0.055) whereas young age at time of stillbirth remained highly significant (p= 0.001).

Table 5: Risk factors for IES ≥20 at follow up (5-18 years after stillbirth)

	IES ≥20 (n)	IES <20 (n)	Bivariate			Multivariate		
Socio-demographic variables			OR	95% CI	*P* value	aOR	95% CI	*P* value
*Age at the time of stillbirth**								
>27 years	19	54	1 (ref)			1 (ref)		
≤27 years	12	13	2.62	1.02, 6.74	0.045	6.60	1.99, 21.83	0.002
Civil status								
Married/cohabiting	25	59	1 (ref)					
Living alone	6	8	1.77	0.56, 5.63	0.334			
Divorce/break up after stillbirth								
No	23	56	1 (ref)					
Yes	8	11	1.77	0.63, 4.97	0.278			
Country of birth								
Born in Norway	25	63	1 (ref)					
Not born in Norway	5	4	3.15	0.78, 12.70	0.107			
Household income								
<750 000 NOK	19	31	1 (ref)					
≥750 000 NOK	10	35	0.47	0.19, 1.15	0.099			
Education								
Primary/secondary/high school	11	13	1 (ref)					
High school + 1-5 years	17	40	0.50	0.19, 1.34	0.170			
High school + >5 years	3	14	0.25	0.06, 1.12	0.070			
Occupational status								
Working full time (90-100%)	16	41	1 (ref)					
Not working full time	15	26	1.48	0.63, 3.49	0.372			
Pregnancy history								
*Parity at the time of stillbirth**								
1	11	38	1 (ref)			1 (ref)		
>1	20	29	2.38	0.99, 5.75	0.053	3.46	1.19, 10.07	0.023
Gestational age at stillbirth			0.976	0.91, 1.05	0.516			
Time since stillbirth			0.935	0.84, 1.04	0.234			
Spontaneous abortion								
No	19	40	1 (ref)					
Yes	12	27	0.94	0.39, 2.24	0.881			
Induced abortion prior to stillbirth								
No	21	60	1 (ref)			1 (ref)		

Yes	10	7	4.08	1.38, 12.09	0.011	5.78	1.56, 21.38	0.009
Live birth after stillbirth								
No	7	6	1 (ref)					
Yes	24	61	0.34	0.10, 1.11	0.073			
Experiences in relation to stillbirth								
Awareness of the baby's death before the delivery								
No	5	11	1 (ref)					
<24 hours	20	39	1.13	0.34, 3.70	0.842			
≥24 hours	6	17	0.78	0.19, 3.18	0.725			
Baby's father/close relative present during the delivery								
No/at times	7	10	1 (ref)					
The whole time	24	57	0.60	0.2, 1.77	0.355			
Held the baby								
No	11	7	1 (ref)			1 (ref)		
Yes	20	60	0.21	0.07, 0.62	0.005	0.17	0.05, 0.56	0.004
Time spent with the baby								
<1 hour (or just after birth)	13	10	1 (ref)					
1-11 hours (or 1 time per day)	8	19	0.32	0.10, 1.04	0.058			
≥12 hours (or ≥2-4 times per day)	9	38	0.18	0.06, 0.55	0.002			
Autopsy								
No	8	9	1 (ref)					
Yes	23	58	0.45	0.15, 1.30	0.138			
Postpartum consultation with the obstetrician								
No	9	10	1 (ref)					
Yes	22	53	0.46	0.17, 1.29	0.140			
Additional follow-up								
No	6	3	1 (ref)					
Yes	25	64	0.20	0.05, 0.84	0.028			
Arranged memorial								
No	8	9	1 (ref)					
Yes	23	54	0.48	0.16, 1.40	0.178			

* Significant interaction between age at index and parity at index in the multivariable model

IES; Impact of Event Scale, OR; odds' ratio, aOR; adjusted odds' ratio, CI; confidence interval

DISCUSSION

The women in this study were to a large degree satisfied with the care they received around the time of stillbirth and how health care professionals approached their baby. The level of PTSS after 5-18 years was noticeably high with approximately one third with a clinically relevant symptom level and 13% above a predefined (possible) PTSD level. Independent risk factors for a high symptom level were young age and high parity at the time of stillbirth and prior induced abortion. Having held the baby appeared to be protective.

Most of the women wished and were to a large degree encouraged by health care professionals to see and hold their stillborn baby. The women found honesty, clarity, empathy, availability, information and guidance to be positive elements among health care professionals when informing the women of the baby's death and in the following days at the hospital. Collecting tokens of remembrance was also regarded as positive. These findings are consistent with previous studies.[4, 13, 23, 31] Our study also confirmed the finding by Christoffersen that being at the postnatal ward after the delivery and having to confront live-born babies is considered to be emotionally stressful for women with stillbirth.[23]

We have previously reported long-term quality of life and depression among the women with stillbirth and found that they did not differ significantly from controls when adjusted for other factors.[21] This indicates that even though a substantial proportion of the women have IES scores above a possible case level, the daily functioning seems to be reasonably good. A diagnosis of PTSD or other clinical psychiatric problems cannot be based on a questionnaire alone. Furthermore, the IES scale does not measure symptoms of hyper-arousal that are required to fulfil a PTSD diagnosis according to the ICD-10 or DSM–IV systems. Therefore we find it likely that the number of women with an IES score above a clinical or PTSD level is somewhat overestimated in our study. This point could be studied more thoroughly with a clinical interview in addition to a questionnaire.

Young age and higher parity were risk factors for more PTSS in our study and have previously been shown to increase the risk of long-term anxiety- and depression symptoms.[14, 18] A previous study with a shorter mean follow up (2.3 years) found

longer time since stillbirth to be significantly associated with less PTSD symptoms.[19] In contrast, our study found no significant association with time after a mean follow-up of 10.8 years. This may indicate that in the longer term, time since stillbirth may be a less important risk factor for PTSS. The interaction between parity and age indicates that having a stillbirth as the second or later birth is associated with a high PTSS level among women aged >27 years, but this was not a predefined end point in our study and must be considered with caution. Prior induced abortion remained the strongest predictor for a high PTSS level. This is a new finding that should be confirmed and explored in future studies. Our finding that holding the stillborn baby is protective for a high PTSS level in the long-term supports the general opinion that contact with the baby is beneficial, even though it has been speculated that this effect may be temporarily reversed during a subsequent pregnancy.[14, 16] Rådestad and Christoffersen have previously suggested that one reason for the findings by Hughes et al, that holding the stillborn baby increases psychological morbidity,[16] could be that the women were not sufficiently prepared for this contact.[32] Even though contact with the baby seems to have a positive effect in our study, it is possible that forced encounter could be potentially traumatic for a subgroup of women who do not want this contact.

Limitations and strengths

As an observational study, there are a number of limitations. We consider the low response rate (31%) to be the most critical limitation as this poses a risk of selection bias. We cannot exclude the possibility that a larger proportion of women with a high-level of avoidance symptoms declined participation in the study. If so, this would have resulted in an underestimation of the mean score for the avoidance subscale. With a higher mean score on avoidance symptoms our main conclusion would still be that the long-term level of overall PTSS is fairly high in this group. We found no significant differences on available socio-demographic and clinical variables between responders and non-responders, and the women in our study report similar experiences as reported by other studies. We would therefore argue that our main findings, with some consideration, could be generalised to other women who have suffered stillbirth. There is inevitably a risk of recall bias concerning descriptive variables due to the retrospective design and the long follow-up time. However,

studies indicate that recollection of potentially traumatic events is more accurate than for other life events.[33] The multivariable analysis of risk factors for IES ≥20 is limited by small numbers and wide confidence intervals and should therefore be interpreted with some caution.

Strengths of our study are that we have used an acknowledged validated instrument to measure PTSS and, to our knowledge, this is the first time risk factors for PTSS have been assessed using a multivariate model in a large group of non-pregnant women many years after stillbirth.

Conclusions

The great majority of the women saw and held their baby after the stillbirth and felt that the health care professionals were supportive. One in three women presented with a clinically significant level of PTSS 5-18 years after stillbirth. Having held the stillborn baby was associated with less long-term PTSS, implicating that health care professional should continue to provide the opportunity and encourage women to have contact with their stillborn baby.

Acknowledgements

The authors are grateful to Professor Leiv Sandvik for generous help with the statistical analyses and to all the women who participated in the study.

Contributions to authorship

IKG performed the analyses, interpreted the results and wrote the main draft of the manuscript. LBH designed the original study, collected the data, helped to interpret the results and revised the manuscript. EMJ designed the original study, helped to interpret the results and revised the manuscript. IR helped design the study, helped to interpret the results and revised the manuscript. PMS designed the original study, helped to interpret the results, revised the manuscript and supervised the study. ØE helped design the study, helped with the statistical analyses, helped to interpret the results and revised the manuscript. All authors read and approved the final version of the manuscript.

Competing interests

The authors have no competing interests.

Funding

This work was supported by grants from the South-Eastern Norway Health Authority, the Oslo University Hospital Scientific Trust and the Norwegian Research Council (grant no 160805-V50). The sponsors of the study had no role in the study design; the collection, analysis and interpretation of data; or writing, reviewing or approval of the manuscript. The authors are fully independent of the sponsors.

REFERENCE LIST

[1] LaRoche C, Lalinec-Michaud M, Engelsmann F, et al. Grief reactions to perinatal death--a follow-up study. *Can J Psychiatry* 1984 Feb;**29**:14-9.

[2] Nicol MT, Tompkins JR, Campbell NA, et al. Maternal grieving response after perinatal death. *Med J Aust* 1986;**144**:287-9.

[3] Kelley MC, Trinidad SB. Silent loss and the clinical encounter: Parents' and physicians' experiences of stillbirth-a qualitative analysis. *BMC Pregnancy Childbirth* 2012;**12**:137. doi: 10.1186/1471-2393-12-137

[4] Radestad I, Steineck G, Nordin C, et al. Psychological complications after stillbirth--influence of memories and immediate management: population based study. *BMJ* 1996;**312**:1505-8.

[5] Adeyemi A, Mosaku K, Ajenifuja O, et al. Depressive symptoms in a sample of women following perinatal loss. *J Natl Med Assoc* 2008;**100**:1463-8.

[6] Boyle FM, Vance JC, Najman JM, et al. The mental health impact of stillbirth, neonatal death or SIDS: prevalence and patterns of distress among mothers. *Soc Sci Med* 1996;**43**:1273-82.

[7] Turton P, Hughes P, Evans CD, et al. Incidence, correlates and predictors of post-traumatic stress disorder in the pregnancy after stillbirth. *Br J Psychiatry* 2001;**178**:556-60.

[8] Stainton MC. The fetus: a growing member of the family. *Family Relations* 1985;**34**:321-6.

[9] Lumley JM. Attitudes to the fetus among primigravidae. *Aust Paediatr J* 1982;**18**:106-9.

[10] Nissen E, Lilja G, Widstrom AM, et al. Elevation of oxytocin levels early post partum in women. *Acta Obstet Gynecol Scand* 1995;**74**:530-3.

[11] Froen JF, Cacciatore J, McClure EM, et al. Stillbirths: why they matter. *Lancet* 2011;**377**:1353-66.

[12] Lewis E. The management of stillbirth: coping with an unreality. *Lancet* 1976;**2**:619-20.

[13] Radestad I, Nordin C, Steineck G, et al. Stillbirth is no longer managed as a nonevent: a nationwide study in Sweden. *Birth* 1996;**23**:209-15.

[14] Cacciatore J, Radestad I, Frederik FJ. Effects of contact with stillborn babies on maternal anxiety and depression. *Birth* 2008;**35**:313-20.

[15] Radestad I, Surkan PJ, Steineck G, et al. Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery* 2009;**25**:422-9.

[16] Hughes P, Turton P, Hopper E, et al. Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet* 2002;**360**:114-8.

[17] Turton P, Evans C, Hughes P. Long-term psychosocial sequelae of stillbirth: phase II of a nested case-control cohort study. *Arch Womens Ment Health* 2009;**12**:35-41.

[18] Surkan PJ, Radestad I, Cnattingius S, et al. Events after stillbirth in relation to maternal depressive symptoms: a brief report. *Birth* 2008;**35**:153-7.

[19] Crawley R, Lomax S, Ayers S. Recovering from stillbirth: the effects of making and sharing memories on maternal mental health. *J Reprod Infant Psychol* 2013;**31**:195-207. doi: 10.1080/02646838.2013.795216

[20] Cacciatore J, Schnebly S, Froen JF. The effects of social support on maternal anxiety and depression after stillbirth. *Health Soc Care Community* 2009;**17**:167-76.

[21] Gravensteen IK, Helgadottir LB, Jacobsen EM, et al. Long-term impact of intrauterine fetal death on quality of life and depression: a case-control study. *BMC Pregnancy Childbirth* 2012;**12**:43. doi: 10.1186/1471-2393-12-43

[22] Salvesen KA, Oyen L, Schmidt N, et al. Comparison of long-term psychological responses of women after pregnancy termination due to fetal anomalies and after perinatal loss. *Ultrasound Obstet Gynecol* 1997;**9**:80-5.

[23] Christoffersen L. Helsevesenet ved dødfødsel: Foreldres opplevelse og bruk av det norske helsevesenet før, under og etter en dødfødsel - et pilotprosjekt. (Report in Norwegian) *Oslo School of Management/Landsforeningen Uventet Barnedød*;2008.

[24] Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. *Psychosom Med* 1979;**41**:209-18.

[25] Wohlfarth TD, van den Brink W, Winkel FW, et al. Screening for Posttraumatic Stress Disorder: an evaluation of two self-report scales among crime victims. *Psychol Assess* 2003;**15**:101-9.

[26] Sundin EC, Horowitz MJ. Impact of Event Scale: psychometric properties. *Br J Psychiatry* 2002;**180**:205-9.

[27] Sundin EC, Horowitz MJ. Horowitz's Impact of Event Scale evaluation of 20 years of use. *Psychosom Med* 2003;**65**:870-6.

[28] Neal LA, Busuttil W, Rollins J, et al. Convergent validity of measures of post-traumatic stress disorder in a mixed military and civilian population. *J Trauma Stress* 1994;**7**:447-55.

[29] Johansen VA, Wahl AK, Eilertsen DE, et al. Prevalence and predictors of post-traumatic stress disorder (PTSD) in physically injured victims of non-domestic violence. A longitudinal study. *Soc Psychiatry Psychiatr Epidemiol* 2007;**42**:583-93.

[30] Bland JM, Altman DG. Cronbach's alpha. *BMJ* 1997;**314**:572.

[31] Trulsson O, Radestad I. The silent child--mothers' experiences before, during, and after stillbirth. *Birth* 2004;**31**:189-95.

[32] Rådestad I, Christoffersen L. Helping a woman meet her stillborn baby while it is soft and warm. *British Journal of Midwifery* 2008;**16**:588-91.

[33] Lalande KM, Bonanno GA. Retrospective memory bias for the frequency of potentially traumatic events: A prospective study. *Psychological Trauma:*

Theory, Research, Practice, and Policy 2011;**3**:165-170.

doi: 10.1037/a0020847

STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*

Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any pre-specified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	6
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	6
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	Not applicable
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6-7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6-7
Bias	9	Describe any efforts to address potential sources of bias	7
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7-8
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	8
		(*b*) Describe any methods used to examine subgroups and interactions	8
		(*c*) Explain how missing data were addressed	7
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	Not applicable

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy	
		(*e*) Describe any sensitivity analyses	
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	6, Table 1-5
		(b) Give reasons for non-participation at each stage	6
		(c) Consider use of a flow diagram	
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1-3, Table 5
		(b) Indicate number of participants with missing data for each variable of interest	Table 1-5
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	9
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	9-17
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—Report numbers of outcome events or summary measures	
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	8, 16-17, Table 5
		(*b*) Report category boundaries when continuous variables were categorized	8, Table 5
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	16
Discussion			
Key results	18	Summarise key results with reference to study objectives	20
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	21-22
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20-22
Generalisability	21	Discuss the generalisability (external validity) of the study results	21
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	24

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.
Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

Women's experiences in relation to stillbirth and ~~predictors~~ risk factors for long-term post-traumatic stress symptoms: a retrospective study

Ida Kathrine Gravensteen, MedStud [1,2,3], Linda Björk Helgadóttir MD, PhD[1,4], Eva-Marie Jacobsen MD, PhD[1,3], Ingela Rådestad, RN, RM, PhD[5], Per Morten Sandset MD, PhD[1,3] and Øivind Ekeberg MD, PhD[2,6]

[1]Departments of Haematology, [4]Obstetrics and Gynaecology, and [6]Acute Medicine, Oslo University Hospital, Oslo, Norway, and

[2]Department of ~~Behavioral~~Behavioural Sciences in Medicine and [3]Institute of Clinical Medicine, University of Oslo, Oslo, Norway, and

[5]Sophiahemmet University, Stockholm, Sweden.

Corresponding author:

Eva-Marie Jacobsen

Oslo University Hospital, Department of ~~Hematology~~Haematology

Box 4950 Nydalen, N-0424 Oslo, Norway

Tel. +47 22119240 – fax. +47 22119040

E-mail: e.m.jacobsen@medisin.uio.no

Keywords: stillbirth, fetal death, long-term memories, quality of health care, post-traumatic stress

Word count: ~~3711~~3926

ABSTRACT

Objectives: 1) To investigate the experiences of women with a previous stillbirth and their appraisal of the care they received at the hospital. 2) To ~~, and to~~ assess the long-term level of post-traumatic stress symptoms (PTSS)~~risk~~ in this group and identify risk factors~~possible predictors~~ for this outcome~~of posttraumatic stress symptoms (PTSS).~~.

Design: A retrospective study.

Setting: Two university hospitals.

Participants: The study population comprised 379 women with a verified diagnosis of stillbirth (≥23 gestational weeks or birth weight ≥500 g) in a singleton or twin~~duplex~~ pregnancy 5-18 years previously. 101 women completed a comprehensive questionnaire in two parts.

Primary and secondary outcome measures: The women's experiences and appraisal of the care provided by health care professionals before, during and after stillbirth. PTSS at follow-up was assessed using the Impact of Event Scale (IES).

Results: The great majority saw (98%) and held (82%) their baby ~~and felt that they were supported in doing so~~. Most women felt that health care professionals were supportive during the delivery (85.6%) and showed respect towards their baby (94.9%). The majority (91.1%) had received some form of short-term follow up. One third showed clinically significant long-term PTSS (IES≥20). Independent risk factors ~~predictors for PTSS~~ were younger age (OR 6.60, 95% CI 1.99-21.83), induced abortion prior to stillbirth (OR 5.78, 95% CI 1.56-21.38) and higher parity (OR 3.46, 95% CI 1.19-10.07) at the time of stillbirth. ~~.~~ Having ~~Protective of PTSS was having~~ held the baby (OR 0.17, 95% CI 0.05-0.56) was associated with less PTSS.

Conclusion: The great majority saw and held their baby and was satisfied with the support from health care professionals. One in three women presented with a clinically significant level of PTSS 5-18 years after stillbirth. Having held the baby was protective, whereas prior induced abortion was a risk factor for a high level of PTSS.

Trial registration: The study was registered at www.clinicaltrials.gov, with registration number NCT 00856076.

ARTICLE SUMMARY

Article focus:

- How do women with a previous stillbirth experience the diagnosis, the delivery and their time at the hospital?
- How do these women appraise, in the long-term, the care they received from health care professionals?
- What is the long-term risk of post-traumatic stress symptoms (PTSS) among these women and what factors ~~predic~~are associated with~~t~~ this outcome?

Key messages:

- Most of the women in our study wanted to see and hold their stillborn baby and were encouraged by health care professionals to do so.
- A clinically significant level of long-term PTSS was present among approximately one in three women. Having held the baby was protective, whereas prior induced abortion was a risk factor.
- The great majority had received some form of short-term follow-up after the stillbirth.

Strengths and limitations of this study:

- We have used an acknowledged validated instrument to measure the level of PTSS. To our knowledge, this is the first study to assess risk factors~~predictors~~ for~~of~~ PTSS, using a multivariate model, in a large group of non-pregnant women many years after stillbirth.
- The risk of selection bias and memory bias cannot be excluded.

INTRODUCTION

Stillbirth is a traumatic event for the mother and represents a significant loss. This causes normal grief reactions, but can also cause traumatic experiences that require processing of psychological sequelaes.[1-3] Women experiencing a stillbirth have been shown to have more anxiety and depression symptoms in the following months and years compared to women with live births,[4-6] and are also at risk of posttraumatic stress symptoms in the subsequent pregnancy.[7]

Grief involves a separation process and the bond to the person that is lost is central in this process. Throughout the pregnancy an attachment between the mother and the unborn baby develops,[8, 9] which is further enhanced shortly after the birth, possibly mediated by high oxytocin levels in maternal blood.[10] Thus, 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.

Previously it was common that the mother was not given the opportunity to recognise her dead baby and this still applies in many cultures.[11, 12] In the recent decades it has become procedure in many industrialised countries to encourage the mother and other close relatives to see, hold and dress the stillborn baby. In a Swedish study from 1996 on 314 women with stillbirths, nearly every mother had seen and 80% caressed her baby.[13] The general opinion is that seeing and holding the stillborn baby facilitates healthy mourning and reduces the risk of long-term psychological distress.[14, 15] However, some researchers have called this benefit into question and claim that holding the stillborn infant accounts for more psychological morbidity in the subsequent pregnancy and postpartum perioddyear, and an increased risk of posttraumatic stress symptoms (PTSS) in the longer term.[16, 17]

Other factors shown to be predictive of psychological morbidity after stillbirth are: a long time from diagnosis to delivery (≥25 hours),[4] not being with the baby for as long as desired,[4, 18] not possessing any token of remembrance,[4], being unmarried, low education and young age,[14] a short time since stillbirth,[7, 14, 19] high parity at the time of loss and no subsequent pregnancy.[18] Sharing memories of the baby, sSocial support and counseling from health care professionals and

~~bereavement groups~~and professional support is shown to be associated with better mental health following stillbirth~~seem to have positive effects on the mourning process~~.[7,19, 20]

We have previously shown that there are no substantial differences in long-term quality of life (QOL) and depression between women with a previous stillbirth and women with only live births.[2~~1~~0] This is probably due to the effect of time, and possibly adequate guidelines and short-term interventions. However, there are limited data on how experiences and care given at the time of stillbirth are remembered and affect women in the long-term. Stillbirth has previously been defined as a potent stressor for development of posttraumatic stress reactions. However, studies conducted so far are limited by small numbers and short observation periods (one year), or are restricted to follow-up of women with a subsequent live birth and lack multivariate models.[7, 17, 2~~2~~1]

Health care professionals play an important role in providing care and guidance to parents in the first few days following a stillbirth.[15, 2~~3~~2] Parents want guidance, but there should also be room for their own wishes.[2~~3~~2] Rather than enforcing mourning rituals, health care professionals should be flexible towards the mother's needs.[4] This is a delicate and sometimes difficult balance.

The main objective of this study was to investigate how the women experienced the procedures of the diagnosis of stillbirth, the delivery and the postpartum period, and how they appraise, in the long-term, the care they received at the hospital. Secondly, we wanted to assess the women's level of posttraumatic stress symptoms (PTSS), and identify possible risk factors for~~factors that predict~~ this outcome.

METHODS

Women with a diagnosis of stillbirth at Oslo University Hospital, Ullevål, Oslo, Norway, and Akershus University Hospital, Lørenskog, Norway, from January 1 1990 through December 31 2003, were identified through the hospitals' administrative systems. We searched for relevant World Health Organization (WHO) International Classification of Diseases codes, versions 9 or 10, and identified 439 possible cases of stillbirth, defined as fetal death at ≥23 gestational weeks or birth weight ≥500 g. After reviewing the medical records, we excluded 49 cases wrongly diagnosed, eight with non-retrievable records, and three with triplet pregnancies, leaving 379 women with a verified diagnosis of stillbirth in a singleton or twin~~duplex~~ pregnancy. Women who had emigrated, died or had an invalid or foreign address ~~Invalid or unknown address was recognized in 19 cases~~were excluded, ~~and~~ thus a total of 346 women received a postal invitation to participate in the study. After two reminders, 106 (31%) agreed to participate. The data were collected in 2008–2009, accordingly 5-18 years after the stillbirth. We have previously published a more detailed description of the selection process.[2~~1~~0]

Of the women who agreed to participate, 101 completed a comprehensive questionnaire in two parts. The first part included information on demographic, pregnancy, and health-related variables.[2~~1~~0] The other part was designed to investigate and quantify the women´s experiences at the hospital before, during and after the delivery, and especially what they thought of the procedures and care conducted by health care professionals. ~~There were also~~Also included were some open questions with fields to describe positive and negative experiences in own words. ~~fields to elaborate the answers or describe positive and negative experiences in own words.~~ The questionnaire comprised four scales measuring PTSS, QOL, symptoms of depression, and well-being. The questionnaire was optically scanned and the data were transferred electronically to the project database. All the extracted data were manually verified for scanning errors.

Current PTSS at follow up (5-18 years after stillbirth) were quantified using the Impact of Event Scale (IES).[2~~4~~3] This is a frequently used instrument with good psychometric properties to measure the degree of subjective psychological distress after a traumatic event and to screen for a possible post-traumatic stress disorder (PTSD).[2~~5~~4-2~~7~~6] The participants were instructed to answer the questions using

their prior stillbirth as the reference traumatic event. The scale has a total range of 0-75 and two subscales, one with seven items to measure intrusion, the other with eight items to measure avoidance. Each item has six response alternatives from 0 = 'never' to 5 = 'a high degree'. In accordance with previous studies we regarded an IES score ≥20 as a possible clinical case level and a score ≥35 as a possible PTSD level.[254, 287, 298] One missing item was accepted in each of the subscales and the missing item was replaced with the mean score of the other items for that respondent. Three of 101 women had more than one missing item in a subscale and were excluded, resulting in 98 respondents for the IES analyses. Cronbach´s alpha of internal validity in our study was 0.94 for the intrusion subscale, 0.90 for the avoidance subscales and 0.94 for the total IES score. An acceptable value of Cronbach's alpha is considered to be >0.7.[3029]

We had access to information from medical records on demographic and clinical factors for all eligible participants at the time of the index pregnancy. The data The data included information on the date of the stillbirth, delivery hospital, gestational age,information on the date of the stillbirth date of index , maternal age, parity, and civilmarital status, birth weight, number of fetuses (single or twins), hypertensive disorders, diabetes, placental abruption and smoking. These variables were compared between responders and non-responders in order to assess the risk of selection bias.

Statistical analyses

Categorical data are presented as counts and percentages. Continuous variables are presented as mean or median and standard deviation (SD), range, 95% confidence interval (CI) or interquartile range (IQR).

To identify variables independently associated with an IES score above the predefined cut-off value of 20, we used bivariate and multivariate logistic regression. Possible predictors (established and plausible risk factors) were selected among socio-demographic factors, history of pregnancies, events in relation to the stillbirth and contact with the baby, and presented as odds' ratios (OR) and adjusted OR (aOR) with 95% confidence intervals. Variables associated with IES >20 with p <0.2 in the unadjusted analyses were included in a multivariate logistic regression model, using forward Wald variable selection. Variables with <10 subjects in at least one of

the categories were not included in the models. Interactions between variables in the final model were tested individually.

Findings with two-sided P values <.05 were considered significant. All data were analysed using the Statistical Package for the Social Sciences version 18.0 (IBM SPSS Inc, Chicago, Illinois, USA).

Ethics

Authorisation for the use of information from medical records for research purposes was obtained from the Norwegian Ministry of Health and Social Affairs. The study was approved by the Data Protection Official at Oslo University Hospital, which serves as an institutional review board, and the Regional Ethics Committee, Region East, Norway. All participants provided written informed consent. The study was registered at www.clinicaltrials.gov, with registration number NCT 00856076.

RESULTS

The mean time from stillbirth to assessment was 10.8 years (range 5-18, SD 4.0). Time since fetal death, socio-demographic and clinical factors did not differ significantly between participants and non-responders (data not shown). Socio-demographic- and pregnancy related characteristics are presented in Table 1. None of the women were pregnant at follow-up.

Table 1: Socio-demographic and pregnancy-related factors at follow up (2008)

	N (missing)	Mean (range, SD) n (%)
Age *Age at the time of stillbirth*	101 (0)	41.6 (28-54, 5.2) 30.8 (18-43, 4.6)
Country of birth Norway Other	100 (1)	 88 (88.0) 12 (12.0)
Civil status Married/cohabitating Living alone *At the time of stillbirth* Married/cohabiting Living alone	101 (0)	 86 (85.1) 15 (14.9) 94 (93.1) 7 (6.9)
Education Primary/secondary/high school High school + 1–5 years High school + >5 years	101 (0)	 25 (24.8) 58 (57.4) 18 (17.8)
Occupational status Working full time (90–100%) Not working full time	101 (0)	 58 (57.4) 43 (42.6)
Household income <750 000 NOK ≥750 000 NOK	97 (4)	 52 (53.6) 45 (46.4)
Number of pregnancies, mean (SD)	101 (0)	4.2 (1.6)
Number of live-born children, mean (SD)	101 (0)	2.2 (1.0)
Experienced spontaneous abortion	101 (0)	39 (38.6)
Experienced induced abortion	101 (0)	24 (23.8)
Achieved the number of children wished for	96 (7)	58 (60.4)

SD, standard deviation; NOK, Norwegian kroner (100 NOK= ~13 euros)

Women´s experiences before, during and after the delivery

Many women (68%) suspected that something was wrong with their unborn baby before they were informed by a health care professional that the fetus had died in utero (Table 2). Most frequently (66%) they had felt less or absence of fetal movements, but some believed this was normal at the end of the pregnancy. The majority (88%) contacted health care services, 63% of these were admitted to the hospital. Most of the women (83%) were aware that the baby was dead before the delivery. They were often (62%) informed of the baby's death by the obstetrician at the hospital and 79% were satisfied with the way the message was conveyed. When describing in their own words what was positive with the way they were informed, synonyms with honesty/clarity (n=19) and empathy/intimacy (n=17) were most frequently reported. On the opposite, lack of eye contact or empathy and hesitations from health care professionals in confirming the baby's death was described as negative experiences.

After giving birth 39 (39%) women were admitted to a standard postnatal ward, but nine women expressed in their own words that they wished they did not have had to stay at the postnatal ward after the delivery. The majority (82%) was asked for permission to perform an autopsy and 25% found the question slightly or very uncomfortable. However, in the case where an autopsy was performed (81%), none of the women stated that they wished it had not been done. In 44% of the cases where an autopsy was not performed, this was because the woman objected to it. Approximately half of the women did not receive any or only a very uncertain explanation for the stillbirth. The majority (71%) felt ~~meant~~ that such an explanation was very important and only one woman stated this not to be important.

Table 2: The time before, during and after the delivery of a stillborn baby

BEFORE THE DELIVERY	**N (missing)**	**n (%)**
Did you suspect that something was wrong with the baby?		
Yes	98 (3)	67 (68.4)
No		31 (31.6)

Did you contact health care services about your suspicion?		
Yes	66 (1)	58 (87.9)
No/waited for the next check-up		8 (12.1)
WWas further investigations conducted?		
Examined and admitted to the hospital	57 (1)	36 (63.2)
Examined and sent home		12 (21.1)
No		9 (15.8)
Did you know about the baby´s death before the delivery started?		
<24 hours	101 (0)	61 (60.4)
24-48 hours		19 (18.8)
>48 hours		4 (4.0)
No		17 (16.8)
Who informed you of the baby´s death?		
Obstetrician	84 (0)	52 (61.9)
Midwife		26 (31.0)
General practitioner		6 (7.1)
Are you satisfied with the way the information was passed?		
Very or quite satisfied	82 (2)	65 (79.3)
Not satisfied		17 (20.7)
THE DELIVERY		
Where did you deliver your baby?		
Labor ward	101 (0)	91 (90.1)
Other department		610
/Not suredo not remember		(59.9)
		4 (3.9)
How did the delivery start?		
Spontaneously	100 (1)	24 (24.0)
Induced by medication		70 (70.0)
Caesarian section		6 (6.0)
Did you receive any medication?		
Pain relief, sedativesAnalgesics or acupuncture*	101 (0)	77 (76.2)
General anesthesiaNarcosis		6 (5.9)
No		11 (10.9)
Do not remember		7 (6.9)
Did you have the baby´s father, a close relative or a friend with you?		
Yes, the whole time	101 (0)	84 (83.2)
Yes, at times		8 (7.9)
No		9 (8.9)
AFTER THE DELIVERY		
Where did you stay after the delivery?		

Postnatal department	99 (2)	39 (39.4)
Labor ward		25 (25.3)
Observation unit		21 (21.2)
Other department		1014
/Not suredo not remember		(9.914.1)
		4 (4.0)
Were you asked for permission to perform an autopsy?		
Yes	101 (1)	83 (82.2)
No		718
/Ddo not remember		(6.917.8)
Was an autopsy performed?		11 (10.9)
Yes	101 (0)	
No		82 (81.2)
/Ddo not remember		189
		(178.8)
		1 (1.0)
Did you receive an explanation for your baby´s death?		
Yes, a certain or likely explanation	101 (0)	49 (48.5)
No or a very uncertain explanation		52 (51.5)

* Pain relief: Epidural analgesia, spinal analgesia, pudendal block, paracervical block, pethidine/morphine, nitrous oxide, paracetamol

Contact with the baby and appraisal of the delivery and the role of the health care professionals

The majority of the women (94%) wished to see their baby (Table 3). All but two did see the baby and 82% also held their baby. The women were most frequently either shown/given the baby without being asked, encouraged by the health care professionals or asked if they wanted to see/hold the baby. The women felt to a large degree that the health care professionals supported them in having contact with the baby, and to a slightly lesser degree supported them in making their own decisions regarding this. One in four stated that the staff should have been more active in suggesting things to do with the baby, but seven percentper cent stated that the staff should have been more withdrawn and let the women decide more. All but one of the 163 women who did not wish to hold their baby felt that the staff supported them in

this decision, whereas the women who did not want to see their child reported a varying degree of support and pressure from health care professionals. None of the women felt that the staff tried to persuade or pressure them into holding the baby against their wishes.

The women expressed mixed emotions about seeing and holding the baby, but a larger proportion expressed more positive than negative emotions (Table 3). The majority stated "it felt good" to see (82%) and to hold (86%) the baby. The majority of the women who saw their baby felt they got to spend as much time with the baby as they wanted. At follow-up, one of the two women who did not see her baby was completely sure she wished she had done so, whereas the other was completely sure of her earlier decision. Eight (62%) of the women who did not hold the baby regretted this in retrospect.

Table 3: The women's contact with the baby and experiences of the delivery and health care professionals

CONTACT WITH THE BABY	**N (missing)**	**n (%)**	
Seeing		**Yes**	**No**
Wished to see the baby	101 (0)	95 (94.1)	6 (5.9)
Saw the baby		99 (98.0)	2 (2.0)
Circumstances of seeing			
Was showed without being asked	95 (0)	29 (30.5)	
Was asked		33 (34.7)	
Asked herself		9 (9.5)	
Was encouraged by the staff		24 (25.3)	
Holding		**Yes**	**No**
Wished to hold the baby	101 (0)	85 (84.2)	16 (15.8)
Held the baby		83 (82.2)	18 (17.8)
Circumstances of holding			
Was given the child without being asked	80 (3)	18 (22.5)	
Picked up the baby herself		10 (12.5)	
Was asked		35 (43.8)	
Asked herself		4 (5.0)	
Was encouraged by the staff		13 (16.3)	
Time spent with the baby			

<1 hour (or just after the birth)	100 (1)	25 (25.0)
1-11 hours (or 1 time per day)		27 (27.0)
≥12 hours (or 2-4 times per day)		48 (48.0)
Sufficient time with the baby	95 (0)	74 (77.9)
Too little time		19 (20.0)
Too much time		2 (2.1)
~~ALLEGATIONS~~ STATEMENTS ABOUT THE BIRTH		**Agree**
I have good memories of the delivery	99 (2)	46 (46.5)
I have unpleasant memories of the delivery	97 (4)	60 (61.9)
I was too sedated~~was too jaded~~/had been given too much medication	95 (6)	11 (11.6)
I wish I was asleep/in general anesthesia~~narcosis~~	91 (10)	25 (27.5)
I received too little pain relief~~analgesics~~	94 (7)	26 (27.7)
ROLE OF HEALTH CARE PROFESSIONALS		
They were a good support when I gave birth	97 (4)	83 (85.6)
They showed respect towards the baby	99 (2)	94 (94.9)
They showed tenderness towards the baby	96 (5)	91 (94.8)
They showed fear towards the baby	97 (4)	6 (6.2)
They distanced themselves from the baby	98 (3)	2 (2.0)
EXPERIENCE OF SEEING / HOLDING THE BABY		
It was unpleasant	86 / 74	36 (41.9) / 24 (32.4)
It was upsetting	88 / 75	57 (64.8) / 49 (65.3)
It was sad	94 / 80	90 (95.7) / 79 (98.8)
It felt good	92 / 79	75 (81.5) / 68 (86.1)
It felt calming	88 / 75	63 (71.6) / 57 (76.0)
It felt completely natural	88 / 77	71 (80.7) / 62 (80.5)
~~ALLEGATIONS~~ STATEMENTS ABOUT THE HEALTH CARE PROFESSIONALS		
They supported me in seeing the baby	94	91 (96.8)
They supported me in holding the baby	91	80 (87.9)
They supported me in choosing whether or not to see the baby	89	70 (78.7)
They supported me in choosing whether or not to hold the baby	90	68 (75.6)
They should have been more active in suggesting things to do with the baby	89	22 (24.7)
They should have been more withdrawn and let me decide more	89	6 (6.7)

Most of the women have one or more photographs of the baby (97%) and at least one other token of remembrance (99%), most often a foot- or handprint (85%). The majority also named their baby (94%), arranged a memorial (83%) and/or a funeral (93%), had their baby buried in a marked grave (90%) and visit the grave at least once a year (83%).

Most of the women (91.1%) received short-term interventions by invitation from the hospital or on own initiative. The majority (75.2%) had a postpartum consultation at the hospital of which 87% were satisfied. In addition 17 (16.8%) had a consultation with a psychologist/psychiatrist, 54 (53.5%) participated in a bereavement group, 58 (57.4%) had a consultation with the midwife, 25 (24.8%) received follow-up from their general practitioner/~~gynecologist~~gynaecologist, 34 (33.7%) had a consultation with a priest/religious ~~counselor~~counsellor, and 15 (14.9%) had a consultation with other health care professionals/hospital staff. Only nine women (8.9%) did not receive any follow-up of which three (33.3%) wished they had.

The women expressed mixed emotions about experiencing the delivery, but the majority felt that the staff was supportive and showed respect towards their baby (Table 3).

Posttraumatic stress symptoms ~~and predictors~~

Current IES total scores and scores on the subscales are presented in Table 4. The distribution of the IES total score was skewed with a median of 10.0 and a mean of 15.8. One third (31.6%) had IES total score above the predefined clinical case level (≥20) and 13.3% above the PTSD level (≥35).

Table 4: Scores on Impact of Event Scale (IES) 5-18 years after stillbirth (N=98)

IES	Median (IQR)	Mean (SD)	95 % CI of the mean
Intrusion (0-35)	7.5 (16.3)	10.2 (10.3)	8.2–12.3
Avoidance (0-40)	2.5 (7.0)	5.6 (8.3)	3.9–7.3
Total score (0–75)	10.0 (23.0)	15.8 (17.1)	12.4–19.3
	n (%)		
IES score ≥20	31 (31.6)		
IES score ≥35	13 (13.3)		

IQR; interquartile range, SD; standard deviation, CI; confidence interval

Results from the bivariate and multivariate logistic regression analyses of risk ~~predictors~~ for PTSS are presented in Table 5. Younger age (≤27 years) was the only independent socio-demographic risk ~~predictor~~ for ~~of~~ PTSS (OR 6.60, 95% CI 1.99-21.83). Higher parity at index (OR 3.46, 1.19-10.07) and induced abortion prior to stillbirth (OR 5.78, 95% CI 1.56-21.38) were independent pregnancy history risk ~~pregnancy history predictors~~. Having held the baby was strongly protective of PTSS (OR 0.17, 0.05-0.56), but other experiences related to the stillbirth were not significantly associated with PTSS. The variance inflation factor was <5 for all variables in the final model, showing that collinearity does not invalidate the results.

There was a significant interaction between age at index and parity at index (p=0.029). Higher parity (>1) among those aged >27 years at index was associated with a significant higher odds of IES ≥20 (OR 12.61, 95% CI 2.13-74.64, p = 0.005).

The association between parity and IES ≥20 was not seen among those aged ≤27 years (OR 1.20, 95% CI 0.19-7.77, p = 0.848).

There was no statistically significant association between time since birth and PTSS (p=0.234). Accordingly, if included in the final model, time since stillbirth was not significantly associated with IES >20 (p= 0.055) whereas young age at time of stillbirth remained highly significant (p= 0.001).

Table 5: Risk factors~~Predictors~~ for IES ≥20 at follow up (5-18 years after stillbirth)

	IES ≥20 (n)	IES <20 (n)	Bivariate			Multivariate		
Socio-demographic variables			OR	95% CI	*P* value	aOR	95% CI	*P* value
*Age at the time of stillbirth**								
>27 years	19	54	1 (ref)			1 (ref)		
≤27 years	12	13	2.62	1.02, 6.74	0.045	6.60	1.99, 21.83	0.002
Civil status								
Married/cohabiting	25	59	1 (ref)					
Living alone	6	8	1.77	0.56, 5.63	0.334			
Divorce/break up after stillbirth								
No	23	56	1 (ref)					
Yes	8	11	1.77	0.63, 4.97	0.278			
Country of birth								
Born in Norway	25	63	1 (ref)					
Not born in Norway	5	4	3.15	0.78, 12.70	0.107			
Household income								
<750 000 NOK	19	31	1 (ref)					
≥750 000 NOK	10	35	0.47	0.19, 1.15	0.099			
Education								
Primary/secondary/high school	11	13	1 (ref)					
High school + 1-5 years	17	40	0.50	0.19, 1.34	0.170			
High school + >5 years	3	14	0.25	0.06, 1.12	0.070			
Occupational status								
Working full time (90-100%)	16	41	1 (ref)					
Not working full time	15	26	1.48	0.63, 3.49	0.372			
Pregnancy history								
*Parity at the time of stillbirth**								
1	11	38	1 (ref)			1 (ref)		
>1	20	29	2.38	0.99, 5.75	0.053	3.46	1.19, 10.07	0.023
Gestational age at stillbirth			0.976	0.91, 1.05	0.516			
	~~12~~	~~26~~	~~1 (ref)~~					
	~~19~~	~~39~~	~~1.06~~	~~0.44, 2.54~~	~~0.904~~			
Time since stillbirth			0.935	0.84, 1.04	0.234			
~~≤10 years~~	~~18~~	~~32~~	~~1 (ref)~~					
~~11-18 years~~	~~13~~	~~35~~	~~0.66~~	~~0.28, 1.56~~	~~0.344~~			
Spontaneous abortion								

No	19	40	1 (ref)					
Yes	12	27	0.94	0.39, 2.24	0.881			
Induced abortion prior to stillbirth								
No	21	60	1 (ref)			1 (ref)		
Yes	10	7	4.08	1.38, 12.09	0.011	5.78	1.56, 21.38	0.009
Live birth after stillbirth								
No	7	6	1 (ref)					
Yes	24	61	0.34	0.10, 1.11	0.073			
Experiences in relation to stillbirth								
Awareness of the baby's death before the delivery								
No	5	11	1 (ref)					
<24 hours	20	39	1.13	0.34, 3.70	0.842			
≥24 hours	6	17	0.78	0.19, 3.18	0.725			
Baby's father/close relative present during the delivery								
No/at times	7	10	1 (ref)					
The whole time	24	57	0.60	0.2, 1.77	0.355			
Held the baby								
No	11	7	1 (ref)			1 (ref)		
Yes	20	60	0.21	0.07, 0.62	0.005	0.17	0.05, 0.56	0.004
Time spent with the baby								
<1 hour (or just after birth)	13	10	1 (ref)					
1-11 hours (or 1 time per day)	8	19	0.32	0.10, 1.04	0.058			
≥12 hours (or ≥2-4 times per day)	9	38	0.18	0.06, 0.55	0.002			
Autopsy								
No	8	9	1 (ref)					
Yes	23	58	0.45	0.15, 1.30	0.138			
Postpartum consultation with the obstetrician								
No	9	10	1 (ref)					
Yes	22	53	0.46	0.17, 1.29	0.140			
Additional follow-up								
No	6	3	1 (ref)					
Yes	25	64	0.20	0.05, 0.84	0.028			
Arranged memorial								
No	8	9	1 (ref)					
Yes	23	54	0.48	0.16, 1.40	0.178			

* Significant interaction between age at index and parity at index in the multivariable model

IES; Impact of Event Scale, OR; odds' ratio, aOR; adjusted odds' ratio, CI; confidence interval

DISCUSSION

The women in this study were to a large degree satisfied with the care they received around the time of stillbirth and how health care professionals approached their baby. The level of PTSS after 5-18 years was noticeably high with approximately one third with a clinically relevant symptom level and 13% above a predefined (possible) PTSD level. Independent risk factors~~predictors~~ for~~of~~ a high symptom level were young age and high parity at the time of stillbirth and prior induced abortion. Having held the baby appeared to be protective.

Most of the women wished and were to a large degree encouraged by health care professionals to see and hold their stillborn baby. The women found honesty, clarity, empathy, availability, information and guidance to be positive elements among health care professionals when informing the women of the baby's death and in the following days at the hospital. Collecting tokens of remembrance was also regarded as positive ~~experience~~. These findings are consistent with previous studies.[4, 13, 2~~3~~2, 3~~1~~0] Our study also confirmed the finding by Christoffersen that being at the postnatal ward after the delivery and having to confront live-born babies is considered to be emotionally stressful for women with stillbirth.[2~~3~~2]

We have previously reported long-term quality of life and depression among the women with stillbirth and found that they did not differ significantly from controls when adjusted for other factors.[2~~1~~0] This indicates that even though a substantial proportion of the women have IES scores above a possible case level, the daily functioning seems to be reasonably~~ather~~ good. A diagnosis of PTSD or other clinical psychiatric problems cannot be based on a questionnaire alone. Furthermore, the IES scale does not measure symptoms of hyper-arousal that are required to fulfil~~l~~ a PTSD diagnosis according to the ICD-10 or DSM–IV systems. Therefore we find it likely that the number of women with an IES score above a clinical or PTSD level is somewhat overestimated in our study. This point could be studied more thoroughly with a clinical interview in addition to a questionnaire.

Young age and higher parity were risk factors~~s~~ for~~predicted~~ more~~a higher~~ PTSS ~~level~~ in our study and have previously been shown to increase the risk of long-term anxiety- and depression symptoms.[14, 18] A previous study with a shorter mean

follow up (2.3 years) found longer time since stillbirth to be significantly associated with less PTSD symptoms.[19] In contrast, our study found no significant association with time after a mean follow-up of 10.8 years. This may indicate that in the longer term, time since stillbirth may be a less important risk factor for PTSS. The interaction between parity and age indicates that having a stillbirth as the second or later birth is associated with a high PTSS level among women aged >27 years, but this was not a predefined end point in our study and must be considered with caution. Prior induced abortion remained the strongest predictor for a high PTSS level. This is a new finding that should be confirmed and explored in future studies. Our finding that holding the stillborn baby is protective for a high PTSS level in the long-term supports the general opinion that contact with the baby is beneficial, even though it has been speculated that this effect may be temporarily reversed during a subsequent pregnancy.[14, 16] Rådestad and Christoffersen have previously suggested that one reason for the findings by Hughes et al, that holding the stillborn baby increases psychological morbidity,[16] could be that the women were not sufficiently prepared for this contact.[324] Even though contact with the baby seems to have a positive effect in our study, it is possible that forced encounter could be potentially traumatic for a subgroup of women who do not want this contact.

Limitations and strengths

As an observational study, there are a number of limitations. ~~to consider, which have been discussed to some degree in our previous publication.[20]~~ We consider the low response rate (31%) to be the most critical limitation as this poses a risk of selection bias. We cannot exclude the possibility that a larger proportion of women with a high-level of avoidance symptoms declined participation in the study. If so, this would have resulted in an underestimation of the mean score for the avoidance subscale. With a higher mean score on avoidance symptoms our main conclusion would still be that the long-term level of overall PTSS is fairly high in this group. We found no significant differences on available socio-demographic and clinical variables between responders and non-responders, and the women in our study report similar experiences as reported by other studies. ~~The women in our study report similar experiences as have been found in other studies and~~ We would therefore argue that our main findings, with some consideration, could be generalised to other women

who have suffered stillbirth. There is inevitably a risk of recall bias concerning descriptive variables due to the retrospective design and the long follow-up time. However, studies indicate that recollection of potentially traumatic events is more accurate than for other life events.[33]~~we therefore argue that our main findings can be generalized to other women who have suffered stillbirth. A higher response rate would presumably not have changed our main conclusions. Since the women were asked about events occurring many years earlier there is a risk of recall bias. However, as a stillbirth usually is considered a substantial event in a woman's life it is reasonable to assume that they have relatively good memory of these critical events.~~ The multivariable analysis of risk factors ~~predictors~~ for IES ≥20 is limited by small numbers and wide confidence intervals and should therefore be interpreted with some caution.

Strengths of our study are that we have used an acknowledged validated instrument to measure PTSS and, to our knowledge, this is the first time risk factors~~predictors~~ for PTSS have been assessed using a multivariate model in a large group of non-pregnant women many years after stillbirth.

Conclusions

The great majority of the women saw and held their baby after the stillbirth and felt that the health care professionals were supportive. One in three women presented with a clinically significant level of PTSS 5-18 years after stillbirth. Having held the stillborn baby ~~protected~~ was associated with less~~against a high level of~~ long-term PTSS, implicating ~~that health care professionals~~that health care professional should continue to provide the opportunity and encourage women to have contact with their stillborn baby.

Acknowledgements

The authors are grateful to Professor Leiv Sandvik for generous help with the statistical analyses and to all the women who participated in the study.

Contributions to authorship

IKG performed the analyses, interpreted the results and wrote the main draft of the manuscript. LBH designed the original study, collected the data, helped to interpret the results and revised the manuscript. EMJ designed the original study, helped to interpret the results and revised the manuscript. IR helped design the study, helped to interpret the results and revised the manuscript. PMS designed the original study, helped to interpret the results, revised the manuscript and supervised the study. ØE helped design the study, helped with the statistical analyses, helped to interpret the results and revised the manuscript. All authors read and approved the final version of the manuscript.

Competing interests

The authors have no competing interests.

Funding

This work was supported by grants from the South-Eastern Norway Health Authority, the Oslo University Hospital Scientific Trust and the Norwegian Research Council (grant no 160805-V50). The sponsors of the study had no role in the study design; the collection, analysis and interpretation of data; or writing, reviewing or approval of the manuscript. The authors are fully independent of the sponsors.

REFERENCE LIST

[1] LaRoche C, Lalinec-Michaud M, Engelsmann F, et al. Grief reactions to perinatal death--a follow-up study. *Can J Psychiatry* 1984 Feb;**29**:14-9.

[2] Nicol MT, Tompkins JR, Campbell NA, et al. Maternal grieving response after perinatal death. *Med J Aust* 1986;**144**:287-9.

[3] Kelley MC, Trinidad SB. Silent loss and the clinical encounter: Parents' and physicians' experiences of stillbirth-a qualitative analysis. *BMC Pregnancy Childbirth* 2012;**12**:137. doi: 10.1186/1471-2393-12-137

[4] Radestad I, Steineck G, Nordin C, et al. Psychological complications after stillbirth--influence of memories and immediate management: population based study. *BMJ* 1996;**312**:1505-8.

[5] Adeyemi A, Mosaku K, Ajenifuja O, et al. Depressive symptoms in a sample of women following perinatal loss. *J Natl Med Assoc* 2008;**100**:1463-8.

[6] Boyle FM, Vance JC, Najman JM, et al. The mental health impact of stillbirth, neonatal death or SIDS: prevalence and patterns of distress among mothers. *Soc Sci Med* 1996;**43**:1273-82.

[7] Turton P, Hughes P, Evans CD, et al. Incidence, correlates and predictors of post-traumatic stress disorder in the pregnancy after stillbirth. *Br J Psychiatry* 2001;**178**:556-60.

[8] Stainton MC. The fetus: a growing member of the family. *Family Relations* 1985;**34**:321-6.

[9] Lumley JM. Attitudes to the fetus among primigravidae. *Aust Paediatr J* 1982;**18**:106-9.

[10] Nissen E, Lilja G, Widstrom AM, et al. Elevation of oxytocin levels early post partum in women. *Acta Obstet Gynecol Scand* 1995;**74**:530-3.

[11] Froen JF, Cacciatore J, McClure EM, et al. Stillbirths: why they matter. *Lancet* 2011;**377**:1353-66.

[12] Lewis E. The management of stillbirth: coping with an unreality. *Lancet* 1976;**2**:619-20.

[13] Radestad I, Nordin C, Steineck G, et al. Stillbirth is no longer managed as a nonevent: a nationwide study in Sweden. *Birth* 1996;**23**:209-15.

[14] Cacciatore J, Radestad I, Frederik FJ. Effects of contact with stillborn babies on maternal anxiety and depression. *Birth* 2008;**35**:313-20.

[15] Radestad I, Surkan PJ, Steineck G, et al. Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery* 2009;**25**:422-9.

[16] Hughes P, Turton P, Hopper E, et al. Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. *Lancet* 2002;**360**:114-8.

[17] Turton P, Evans C, Hughes P. Long-term psychosocial sequelae of stillbirth: phase II of a nested case-control cohort study. *Arch Womens Ment Health* 2009;**12**:35-41.

[18] Surkan PJ, Radestad I, Cnattingius S, et al. Events after stillbirth in relation to maternal depressive symptoms: a brief report. *Birth* 2008;**35**:153-7.

[19] Crawley R, Lomax S, Ayers S. Recovering from stillbirth: the effects of making and sharing memories on maternal mental health. *J Reprod Infant Psychol* 2013;**31**:195-207. doi: 10.1080/02646838.2013.795216

[2019] Cacciatore J, Schnebly S, Froen JF. The effects of social support on maternal anxiety and depression after stillbirth. *Health Soc Care Community* 2009;**17**:167-76.

[210] Gravensteen IK, Helgadottir LB, Jacobsen EM, et al. Long-term impact of intrauterine fetal death on quality of life and depression: a case-control study. *BMC Pregnancy Childbirth* 2012;**12**:43. doi: 10.1186/1471-2393-12-43

[221] Salvesen KA, Oyen L, Schmidt N, et al. Comparison of long-term psychological responses of women after pregnancy termination due to fetal anomalies and after perinatal loss. *Ultrasound Obstet Gynecol* 1997;**9**:80-5.

[232] Christoffersen L. Helsevesenet ved dødfødsel: Foreldres opplevelse og bruk av det norske helsevesenet før, under og etter en dødfødsel - et pilotprosjekt. (Report in Norwegian) *Oslo School of Management/Landsforeningen Uventet Barnedød*;2008.

[243] Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. *Psychosom Med* 1979;**41**:209-18.

[254] Wohlfarth TD, van den Brink W, Winkel FW, et al. Screening for Posttraumatic Stress Disorder: an evaluation of two self-report scales among crime victims. *Psychol Assess* 2003;**15**:101-9.

[265] Sundin EC, Horowitz MJ. Impact of Event Scale: psychometric properties. *Br J Psychiatry* 2002;**180**:205-9.

[276] Sundin EC, Horowitz MJ. Horowitz's Impact of Event Scale evaluation of 20 years of use. *Psychosom Med* 2003;**65**:870-6.

[287] Neal LA, Busuttil W, Rollins J, et al. Convergent validity of measures of post-traumatic stress disorder in a mixed military and civilian population. *J Trauma Stress* 1994;**7**:447-55.

[298] Johansen VA, Wahl AK, Eilertsen DE, et al. Prevalence and predictors of post-traumatic stress disorder (PTSD) in physically injured victims of non-domestic violence. A longitudinal study. *Soc Psychiatry Psychiatr Epidemiol* 2007;**42**:583-93.

[3029] Bland JM, Altman DG. Cronbach's alpha. *BMJ* 1997;**314**:572.

[310] Trulsson O, Radestad I. The silent child--mothers' experiences before, during, and after stillbirth. *Birth* 2004;**31**:189-95.

[321] Rådestad I, Christoffersen L. Helping a woman meet her stillborn baby while it is soft and warm. *British Journal of Midwifery* 2008;**16**:588-91.

[33] Lalande KM, Bonanno GA. Retrospective memory bias for the frequency of potentially traumatic events: A prospective study. *Psychological Trauma:*

Theory, Research, Practice, and Policy 2011;**3**:165-170.

doi: 10.1037/a0020847