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Stillbirth aftercare in a tertiary obstetric center – parents' experiences

https://doi.org/10.1515/jpm-2022-0246
Received May 19, 2022; accepted May 30, 2022;
published online June 14, 2022

Abstract

Objectives: This study aimed to assess parents' satisfaction with received care and support when experiencing stillbirth.

Methods: This was a questionnaire survey conducted at Helsinki University Hospital, Helsinki, Finland during 2016–2020. Separate questionnaires were sent to mothers and partners who had experienced an antepartum singleton stillbirth at or after 22 gestational weeks during 2016–2019. The questionnaire covered five major topics: stillbirth diagnosis, delivery, information on postmortem examinations, aftercare at the ward, and follow-up appointment.

Results: One hundred nineteen letters were sent and 57 (47.9%) of the mothers and 46 (38.7%) of their partners responded. Both mothers and their partners felt well supported during delivery. They were also satisfied with the time holding their newborn. Partners reported even higher satisfaction in this aspect with a significant within-dyad difference (p=0.049). Parents were generally pleased with the support at the ward. However, both groups were less satisfied with social worker counseling (mothers 53.7%, partners 61.0%). The majority felt that the follow-up visit was helpful. Nonetheless, a remarkable proportion felt that the follow-up visit increased their anxiousness (25.9%, 14.0%, p=0.018). Partners rated their mood higher than mothers (p=0.001). Open feedback revealed that the support received after discharge from hospital was often insufficient.

Conclusions: Our study showed that the parents who experience stillbirth in our institution receive mostly adequate care and support during their hospital stay. However, there is room for further training of healthcare professionals and other professionals contributing in stillbirth aftercare.

Keywords: aftercare; parental experience; perinatal mortality; stillbirth.

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Introduction

Stillbirth is a tragedy affecting millions of parents worldwide every year [1]. It is often stigmatized and the parental grief overlooked. Particularly fathers may feel left alone by healthcare professionals as well as friends and family and treated rather as supporters of the mothers than grieving parents [2–4].

While stillbirth literature is mostly focused on stillbirth's global medical burden, its emotional aspects have been studied to a lesser extent [5]. A Cochrane Database Systematic Review in 2013 found no randomised controlled trials of interventions specifically designed to support parents who have experienced stillbirth in making decisions about their options for postmortem investigations [6]. Still, the need for guidance through making difficult decisions is indisputable [7]. In a questionnaire survey on over four hundred parents almost twice as many parents who declined postmortem examination later regretted their decision compared to those who accepted the offer [8]. Parents participating in the Investigation into Stillbirth to Inform and Guide Healthcare Training (INSIGHT) study stated that they would have consented to autopsy if the staff would have convinced them that it was useful [9].

While there is lack of high-level evidence to support bereavement practices after stillbirth, assumptions and misconceptions due to insufficient staff training may lead to insensitive interactions [9]. Differences in personal views and cultural expectations related to death of an unborn child modify the experience of the grieving parents. Offering a range of options valued by parents and

joint-decision making have become indicators of care quality. A recent online survey on over 3,000 parents from 40 countries discovered remarkable differences even between high-income countries in stillbirth aftercare practices. A widespread occurrence of all nine studied practices was reported only in one country reflecting that there is room for improvement in most countries [7].

Our aim was to study both mothers' and their partners' experiences of care throughout the process beginning from the diagnosis of stillbirth to a follow-up appointment after discharge from hospital. The possible differences within the couple were investigated as well.

Materials and methods

This study was conducted at the Department of Obstetrics and Gynecology, Helsinki University Hospital, Finland during 2016–2020. A questionnaire was sent by mail to mothers and their partners who had experienced antepartum singleton stillbirth at or after 22 gestational weeks during 2016–2019. We included only parents whose language of communication was either Finnish or Swedish.

The parents were given written information about the study including contact information of the researchers at the follow-up appointment approximately three months after hospital discharge. One to three months after the visit they received the questionnaires with a cover letter and a stamped, return-addressed envelope. Separate questionnaires were included for mothers and their partners. No attempts were made to contact non-responders.

The questionnaire was designed with input from clinicians using recent research data and pilot-tested by grieving parents. It was originally written out in Finnish and translated to Swedish by a native Finnish and Swedish speaking colleague. The participant satisfaction and experiences of stillbirth care were assessed by multiple-choice questions and closed-ended propositions. Closed-ended propositions used a five-point Likert scale ranging from fully disagree to fully agree. At the end of the form there was space for open comments.

After collecting obstetric history details, the questionnaire covered five major topics: stillbirth diagnosis, delivery, information on postmortem examinations, aftercare at the ward, and follow-up appointment.

At first we assessed the way the diagnosis of stillbirth was mediated to the parents. The possibility to pain relief as well as the support of the midwife to both parents during delivery was assessed. We also evaluated if and how the parents were guided through difficult decisions including consent to autopsy, holding the newborn, and receiving mementoes (photos, hand- and footprints, curl of hair).

In addition, the care at the ward was evaluated. The benefit of meeting the priest/psychologist/psychiatrist and the social worker as well as the possibility to receive written information about peer organisations and practical arrangements were assessed. Concerning the follow-up appointment the parents were asked if the reason for stillbirth was revealed and if they were prepared for the fact that the reason might not be revealed. We sought to find out if parents were satisfied with the presentation of the results, if they found the visit distressing, and if they regretted giving consent to postmortem examinations. We also asked them to rate their emotional condition at the time of the survey from one to ten, one representing a very bad condition and ten a very good condition. The frequency of psychiatric contacts of the parents was recorded.

Ethical approval

The Ethics Committee of the Helsinki and Uusimaa Hospital District approved the study with permission number 92/13/03/03/2014.

Statistical analysis

Data were analyzed using Microsoft Excel for Windows, version 2201 (Microsoft Corp., Redmond, WA, USA) and IBM SPSS Statistics for Windows, version 28.0 (IBM Corp., Armonk, NY, USA). Responses using the five-point Likert scale were analyzed under the five above mentioned topics. Differences within the couple (dyads) concerning multiple choice questions and the rating of mood at the time of the survey were assessed using paired samples sign test. A two-sided p-value <0.05 denoted statistical significance. Open comments were categorized as positive or negative. Respondents' suggestions how to improve stillbirth aftercare practices were listed.

Results

In our institution 166 singleton antepartum stillbirths were recorded during 2016–2019. One hundred twenty (72.3%) of these spoke Finnish or Swedish when dealing with health care professionals. One woman had delivered outside the hospital and was excluded from this study. Altogether, 119 letters were sent. Fifty-seven (47.9%) mothers and forty-six (38.7%) partners responded. Forty-five partners were male and one was female. Two mother respondents were excluded because the death of their baby had occurred during or after delivery. One partner had to be excluded due to incompletely filled questionnaire.

Table 1 presents the baseline obstetric history characteristics of the mothers and their partners. Thirty-seven (67.3%) of the mothers and twenty-nine (64.4%) of their partners had no previous children. None of the mothers and one (2.2%) of the partners had previously experienced stillbirth.

The vast majority of the parents agreed that the information of stillbirth was given to them appropriately and tactfully and that the stillbirth treatment protocol was explained to them in an understandable way. No significant within-dyad differences emerged (Table 2).

Most mothers agreed that they were given good pain relief and that their labor proceeded well. Both the mothers and their partners were satisfied with the support given during labor (Table 3). Each mother and 42/43 (97.7%) of their partners had been offered to hold their child after

Table 1: Baseline and obstetric history characteristics of the mothers and their partners.

	Mothers n=55	Partners n=45
Age, Years	33.6 ± 5.6 (mean ± SD)	35.2 ± 6.5 (mean ± SD)
Previous child	18 (32.7%)	16 (35.6%)
Number of previous children		
0	37 (67.3%)	29 (64.4%)
1–2	12 (21.8%)	10 (22.2%)
3 or more	6 (10.9%)	6 (13.3%)
Previous miscarriage	14 (25.5%)	N/A
Number of previous miscarriages		N/A
0	40 (72.7%)	
1–2	14 (25.4%)	
3 or more	1 (1.8%)	
Previous stillbirth	0 (0.0%)	1 (2.2%)

SD, standard deviation; N/A, not applicable.

delivery. The vast majority of mothers and their partners did not feel any pressure from heathcare professionals regarding holding the newborn. Partners were more satisfied with the time holding their child compared to mothers (p=0.049). Nobody regretted seeing or holding the newborn (Table 3).

A memento of the stillborn was offered to 54/55 (98.2%) of the mothers and 43/44 (97.7%) of their partners. All the mothers and 40/44 (90.9%) of their partners had been asked for informed consent to autopsy and 48/55 (87.3%) of the mothers and 38/42 (90.5%) of the partners gave permission to autopsy.

The majority of the mothers and their partners agreed that they were given information about postmortem examinations in an understandable way. Also, they became aware of the fact that the cause of death might not be revealed despite thorough examinations. Three out of four agreed that they were asked for informed consent for autopsy at an appropriate moment. Also, most respondents agreed that the permission for autopsy was asked appropriately and tactfully. Very few felt that they had been pushed to give permission to autopsy (Table 4).

During treatment at the maternity ward 52/55 (94.5%) of the mothers and 41/44 (93.2%) of their partners were offered an opportunity to talk to a priest/psychologist/psychiatrist. An appointment with priest/psychologist/psychiatrist was accepted by 46/54 (85.2%) of the mothers and by 37/44 (84.1%) of their partners, while 50/54 (92.6%) of the mothers and 37/44 (84.1%) met the social worker.

Both groups mostly felt that they got psychological support at the maternity ward when they needed it. The mothers were less satisfied with the conversation with the priest/psychologist/psychiatrist compared to their partners (63.0% vs. 81.0%). The within-dyad difference was not significant, however. Furthermore, only 53.7% of the mothers and 61.0% of their partners felt that the conversation with the social worker was useful. The vast majority answered that they received enough written information about peer organisations. Moreover, 69.1% of the mothers and 79.5% of the partners agreed that they

Table 2: Mothers' and their partners' satisfaction of received care at the time of diagnosis of stillbirth.

	Mothers n=55	Partners n=45	p-Value
The information about stillbirth was given appropriately	Fully agree 40 (72.7%)	Fully agree 29 (67.4%)	0.424
Mothers: 55 answers	Partly agree 9 (16.4%)	Partly agree 8 (18.6%)	
Partners: 43 answers	No opinion 2 (3.6%)	No opinion 5 (11.6%)	
Dyads: 43	Partly disagree 4 (7.3%)	Partly disagree 1 (2.3%)	
	Fully disagree 0 (0.0%)	Fully disagree 0 (0.0%)	
The information about stillbirth was given tactfully	Fully agree 36 (65.5%)	Fully agree 22 (51.2%)	0.824
Mothers: 55 answers	Partly agree 7 (12.7%)	Partly agree 15 (34.9%)	
Partners: 43 answers	No opinion 6 (10.9%)	No opinion 4 (9.3%)	
Dyads: 43	Partly disagree 5 (9.1%)	Partly disagree 2 (4.7%)	
	Fully disagree 1 (1.8%)	Fully disagree 0 (0.0%)	
The stillbirth treatment protocol was explained to me in an understandable way	Fully agree 33 (60.0%)	Fully agree 24 (54.5%)	0.815
Mothers: 55 answers	Partly agree 13 (23.6%)	Partly agree 15 (34.1%)	
Partners: 44 answers	No opinion 4 (7.3%)	No opinion 1 (2.3%)	
Dyads: 42	Partly disagree 5 (9.1%)	Partly disagree 3 (6.8%)	
	Fully disagree 0 (0.0%)	Fully disagree 1 (2.3%)	

Table 3: Mothers' and their partners' satisfaction of received care and support at the labor ward.

	Mothers n=55	Partners n=45	p-Value
I was given good pain relief during labor	Fully agree 30 (54.5%)	N/A	
Mothers: 55 answers	Partly agree 13 (23.6%)		
	No opinion 0 (0.0%)		
	Partly disagree 9 (16.4%)		
	Fully disagree 3 (5.5%)		
The labor proceeded smoothly	Fully agree 36 (65.4%)	N/A	
Mothers: 55 answers	Partly agree 14 (25.5%)		
	No opinion 0 (0.0%)		
	Partly disagree 2 (3.6%)		
	Fully disagree 3 (5.5%)		
The midwife supported me well during labor/the midwife also paid attention to me during my partner's delivery and supported me when needed	Fully agree 39 (70.9%)	Fully agree 29 (65.9%)	1.000
Mothers: 55 answers	Partly agree 11 (20.0%)	Partly agree 11 (25.0%)	
Partners: 44 answers	No opinion 2 (3.6%)	No opinion 3 (6.8%)	
Dyads: 44	Partly disagree 3 (5.5%)	Partly disagree 1 (2.3%)	
	Fully disagree 0 (0.0%)	Fully disagree 0 (0.0%)	
I was pushed to hold the child although I did not want to mothers: 54 answers	Fully agree 2 (3.7%)	Fully agree 0 (0.0%)	1.000
Partners: 44 answers	Partly agree 2 (3.7%)	Partly agree 2 (4.5%)	
Dyads: 44	No opinion 3 (5.6%)	No opinion 4 (9.1%)	
	Partly disagree 1 (1.9%)	Partly disagree 3 (6.8%)	
	Fully disagree 46 (85.1%)	Fully disagree 35 (79,5%)	
I was able to hold my child for an appropriate time	Fully agree 35 (64.8%)	Fully agree 39 (90.7%)	0.049
Mothers: 54 answers	Partly agree 9 (16.7%)	Partly agree 2 (4.7%)	
Partners: 43 answers	No opinion 4 (7.4%)	No opinion 1 (2.3%)	
Dyads: 43	Partly disagree 5 (9.3%)	Partly disagree 1 (2.3%)	
	Fully disagree 1 (1.8%)	Fully disagree 0 (0.0%)	
I have afterwards regretted seeing or holding the newborn	Fully agree 0 (0.0%)	Fully agree 0 (0.0%)	0.500
Mothers: 54 answers	Partly agree 0 (0.0%)	Partly agree 0 (0.0%)	
Partners: 43 answers	No opinion 0 (0.0%)	No opinion 1 (2.3%)	
Dyads: 43	Partly disagree 0 (0.0%)	Partly disagree 1 (2.3%)	
	Fully disagree 54 (100.0%)	Fully disagree 41 (95.3%)	

N/A, not applicable.

had been given enough information about practical arrangements (Table 5).

A considerable proportion of the mothers (55.8%) and 40.9% of their partners answered that a clear reason for the death of their child was found. Furthermore, 45/54 (83.3%) of the mothers and 42/44 (95.5%) of their partners were prepared for the fact that a clear reason for the death might not be found. At the time of the survey 4/54 (7.4%) of the mothers and 4/44 (9.1%) had a contact with a psychiatrist.

The vast majority agreed that the obstetrician at the follow-up appointment explained the results to them in an understandable way. The respondents mostly felt that they got sufficient answers for their questions; the within-dyad satisfaction was slightly higher among partners (p=0.015). 25.9% of the mothers 14.0% of their partners felt that the follow-up consultation made them more anxious with a significant within-dyad difference (p=0.018). Only a couple of the respondents regretted giving permission to autopsy (mothers 3.7%; partners 2.3%) (Table 6).

Only dyads were taken into account when rating the moods of mothers and their partners at the time of the survey. The partners rated their mood significantly higher than did the mothers (mean 7.86, SD 1.32 vs. mean 6.53, SD 1.62, p=0.001).

Open comments were given by 46/55 (83.6%) of the mothers and 25/44 (56.8%) of their partners. 19/46 (41.3%) of those mothers and 20/25 (80.0%) of their partners were satisfied with the treatment and support they had received

Table 4: Mothers' and their partners' experiences of presentation of the postmortem examination protocol.

	Mothers n=55	Partners n=45	p-Value
I was given information about the post-mortem examinations in an understandable way	Fully agree 24 (43.6%)	Fully agree 21 (47.7%)	0.690
Mothers: 54 answers	Partly agree 14 (25.5%)	Partly agree 18 (40.9%)	
Partners: 44 answers	No opinion 5 (9.1%)	No opinion 1 (2.3%)	
Dyads: 44	Partly disagree 9 (16.4%)	Partly disagree 2 (4.5%)	
	Fully disagree 2 (3.6%)	Fully disagree 2 (4.5%)	
I was also informed that the cause of death might not be revealed despite thorough examinations	Fully agree 46 (83.6%)	Fully agree 38 (86.4%)	1.000
Mothers: 55 answers	Partly agree 7 (12.7%)	Partly agree 4 (9.1%)	
Partners: 44 answers	No opinion 2 (3.6%)	No opinion 1 (2.3%)	
Dyads: 44	Partly disagree 0 (0.0%)	Partly disagree 1 (2.3%)	
	Fully disagree 0 (0.0%)	Fully disagree 0 (0.0%)	
I was asked for the informed consent at an appropriate moment	Fully agree 32 (58.2%)	Fully agree 26 (60.5%)	1.000
Mothers: 55 answers	Partly agree 9 (16.4%)	Partly agree 7 (16.3%)	
Partners: 43 answers	No opinion 11 (20.0%)	No opinion 10 (23.3%)	
Dyads: 43	Partly disagree 3 (5.5%)	Partly disagree 0 (0.0%)	
	Fully disagree 0 (0.0%)	Fully disagree 0 (0.0%)	
The permission was asked appropriately and tactfully	Fully agree 37 (67.3%)	Fully agree 29 (70.7%)	1.000
Mothers: 55 answers	Partly agree 8 (14.5%)	Partly agree 6 (14.6%)	
Partners: 41 answers	No opinion 6 (10.9%)	No opinion 6 (14.6%)	
Dyads: 41	Partly disagree 4 (7.3%)	Partly disagree 0 (0.0%)	
	Fully disagree 0 (0.0%)	Fully disagree 0 (0.0%)	

during their hospital stay and follow-up visit. Positive and negative feedback as well as suggested improvements in stillbirth aftercare practices are shown in Table 7.

Discussion

Our main finding was that the majority of the mothers and partners were generally satisfied with the care and support they received during their hospital stay after stillbirth. However, the satisfaction of care was poor when focusing on support given by priests/psychologists/psychiatrists and social workers. The respondents agreed that the follow-up appointment after hospital discharge was useful, although many felt that they were more anxious after the control visit. Some statistically significant within-dyad differences emerged showing a slightly better satisfaction of care and better recovery among the partners. Open comments highlighted the importance of a structured and integrated support system for parents during hospital stay as well as after discharge.

The main strength of this study was the inclusion of both mothers and their partners. Many earlier studies have focused on mothers only [2–4]. Also in studies where partners have had an equal possibility to participate, a vast majority of the participants have been mothers [7]. Studies support the fact that both parents, especially partners need guidance in appropriate rituals such as holding and seeing the child to create tangible memories [10, 11].

In our study partners were fairly well represented. The vast majority of the partners felt that they were well supported during their spouse's delivery. Also, a greater proportion of the partners felt that they could hold their child for an appropriate time after delivery. Furthermore, although the difference was not significant, partners were more often satisfied with the conversation with the psychologist/psychiatrist/priest. This might reflect the fact that they could better focus on these conversations than the mothers who had newly delivered.

Also, at the follow-up visit partners felt more satisfied with the response to their questions compared to mothers and rated their mood higher. A remarkable proportion of both mothers and their partners, however, felt that the follow-up appointment increased their anxiousness. This might be attributed to the support after discharge from hospital, which seems to be insufficient and could be even

Table 5: Mothers' and their partners' satisfaction of received treatment and support at the maternity ward.

	Mothers n=55	Partners n=45	p-Value
I got psychological support when I needed it	Fully agree 30 (55.6%)	Fully agree 28 (63.6%)	0.170
Mothers: 54 answers	Partly agree 14 (25.9%)	Partly agree 9 (20.5%)	
Partners: 44 answers	No opinion 5 (9.3%)	No opinion 4 (9.1%)	
Dyads: 43	Partly disagree 5 (9.3%)	Partly disagree 2 (4.5%)	
	Fully disagree 0 (0.0%)	Fully disagree 1 (2.3%)	
I felt the conversation with the psychologist/psychiatrist/priest was useful	Fully agree 14 (25.9%)	Fully agree 18 (42.9%)	0.210
Mothers: 54 answers	Partly agree 20 (37.0%)	Partly agree 16 (38.1%)	
Partners: 42 answers	No opinion 9 (16.7%)	No opinion 5 (11.9%)	
Dyads: 42	Partly disagree 7 (13.0%)	Partly disagree 3 (7.1%)	
	Fully disagree 4 (7.4%)	Fully disagree 0 (0.0%)	
I felt the conversation with the social worker was useful	Fully agree 14 (25.9%)	Fully agree 13 (31.7%)	0.201
Mothers: 54 answers	Partly agree 15 (27.8%)	Partly agree 12 (29.3%)	
Partners: 41 answers	No opinion 12 (22.2%)	No opinion 8 (19.5%)	
Dyads: 41	Partly disagree 6 (11.1%)	Partly disagree 4 (9.8%)	
	Fully disagree 7 (13.0%)	Fully disagree 4 (9.8%)	
I got sufficient written material about peer support organisations	Fully agree 41 (74.5%)	Fully agree 36 (81.8%)	0.791
Mothers: 55 answers	Partly agree 9 (16.4%)	Partly agree 5 (11.4%)	
Partners: 44 answers	No opinion 2 (3.6%)	No opinion 2 (4.5%)	
Dyads: 44	Partly disagree 3 (54.5%)	Partly disagree 1 (2.3%)	
	Fully disagree 0 (0.0%)	Fully disagree 0 (0.0%)	
I got sufficient advice and written material about practical arrangements	Fully agree 18 (32.7%)	Fully agree 14 (31.8%)	0.541
Mothers: 55 answers	Partly agree 20 (36.4%)	Partly agree 21 (47.7%)	
Partners: 44 answers	No opinion 5 (9.1%)	No opinion 3 (6.8%)	
Dyads: 44	Partly disagree 10 (1.8%)	Partly disagree 4 (9.1%)	
	Fully disagree 2 (3.6%)	Fully disagree 2 (4.5%)	

Table 6: Mothers' and their partners' experiences of the follow-up appointment.

	Mothers n=55	Partners n=45	p-Value
The obstetrician explained the postmortem results in an understandable way	Fully agree 23 (42.6%)	Fully agree 19 (44.2%)	0.441
Mothers: 54 answers	Partly agree 22 (40.7%)	Partly agree 17 (39.5%)	
Partners: 43 answers	No opinion 0 (0.0%)	No opinion 1 (2.3%)	
Dyads: 43	Partly disagree 7 (13.0%)	Partly disagree 5 (11.6%)	
	Fully disagree 2 (3.7%)	Fully disagree 1 (2.3%)	
I got sufficient answers for my questions	Fully agree 20 (37.0%)	Fully agree 25 (58.1%)	0.015
Mothers: 54 answers	Partly agree 23 (42.6%)	Partly agree 10 (23.3%)	
Partners: 43 answers	No opinion 1 (1.9%)	No opinion 3 (7.0%)	
Dyads: 43	Partly disagree 8 (14.8%)	Partly disagree 5 (11.6%)	
	Fully disagree 2 (3.7%)	Fully disagree 0 (0.0%)	
The control visit made me more anxious	Fully agree 5 (9.3%)	Fully agree 2 (4.7%)	0.018
Mothers: 54 answers	Partly agree 9 (16.7%)	Partly agree 4 (9.3%)	
Partners: 43 answers	No opinion 10 (18.5%)	No opinion 7 (16.3%)	
Dyads: 43	Partly disagree 15 (27.8%)	Partly disagree 7 (16.3%)	
	Fully disagree 15 (27.8%)	Fully disagree 23 (53.5%)	
I regret giving permission for postmortem examinations	Fully agree 1 (1.9%)	Fully agree 1 (2.3%)	0.687
Mothers: 54 answers	Partly agree 1 (1.9%)	Partly agree 0 (0.0%)	
Partners: 44 answers	No opinion 1 (1.9%)	No opinion 2 (4.5%)	
Dyads: 43	Partly disagree 1 (1.9%)	Partly disagree 3 (6.8%)	
	Fully disagree 50 (92.6%)	Fully disagree 38 (86.4%)	

Table 7: Open comments and suggested improvements in stillbirth aftercare practices.

Positive feedback	Negative feedback	Suggested improvements
"Thank you for the good care" (19 mothers, 20 partners)	"The death of our child would have been preventable, if the personnel would have taken our concern seriously" (×3)	"Written information about suggested postmortem information and their goals would be beneficial"
"Thank you for helping me through this experience to get over my fear of childbirth"	"The midwives were emphatic but the obstetricians seemed too busy and sometimes unkind" (×4)	"I would like to know more precisely, how and wherefrom the samples from the baby are taken"
"Thank you for calling us as mother and father" (×2)	"I was called as mother although I did not feel like one."	"A support group comprising parents who have experienced stillbirth during the same year might be necessary"
"Thank you for the dignified way our baby was treated" (×2)	"The information about postmortem examinations and the course of delivery was imperfect and defective. The entirety seemed not to be in anybody's possession."	"A separate leaflet about physical rehabilitation for women who have experienced stillbirth should be designed"
"The memories of the childbirth are beautiful"	"I got pain relief too late" (×2)	"There is need for improvement in psychological support after hospital discharge; a uniform nationwide support model would be necessary"
"Although the stillbirth was a sad episode, I could still experience a happy event, the birth of my own child"	"I was left too alone during delivery"	
	"The midwife insisted me to decide on the mode of burial at an inappropriate moment, straight after delivery"	
	"I was pushed to hold the baby although I did not want to" (×2)	
	"The baby was not treated with respect and dignity" (×2)	
	"The social worker was not professional and the conversation with her/him was no use at all" (×4)	
	"There was no psychologist/psychiatrist available. A priest came to visit although we did not wish that. The interaction was negative"	
	"The laughter from a nearby personnel room hurt me"	
	"Seeing pregnant mothers and live babies hurt me"	
	"The obstetrician at the follow-up visit was inadequately prepared"	
	"They told us the placenta had disappeared and that these things sometimes happen" (×2)	
	"All the results were not available at the follow-up visit" (×2)	
	"The obstetrician went through incomplete postmortem results at a visit that was only supposed to confirm the mother's physical wellbeing. We were not prepared"	
	"The support after hospital discharge was nonexistent" (×4)	
	"The information about practical arrangements was difficultly attainable." (×4)	
	"We had to contact the hospital 3–4 times to ascertain funeral arrangements."	
	"Nobody called home after hospital discharge although promised." (× 2)	
	"The questionnaire that arrived without beforehand notice ripped my wounds again."	

less attainable for partners. When only seen as unflinching supporters of the mothers partners may internalize their grief. This can lead to long-term consequences in mental health or result in avoidance behaviour [2].

One of the limitations of this study was the rather small sample size. We had to exclude all non-Finnish and non-Swedish speaking parents because it is not possible to respond adequately to a questionnaire concerning such a specific topic with insufficient language skills. Going through a tragic event like stillbirth is indisputably more challenging for parents with immigrant background, different cultural perception of stillbirth, and language barrier [12]. Also, mothers and their partners of other than heterosexual orientation may have specific needs after pregnancy loss [13]. There was only one such couple in our cohort.

The response rate of our study was relatively low. However, sample sizes in many earlier studies have been even smaller and response rates at a lower level [4, 14, 15]. It is understandable that many parents do not wish to participate; returning to negative memories requires exceptional strength.

We did not explore bereavement care practices after discharge from hospital, which was a limitation as well. The Royal College of Obstetricians and Gynecologists recommends that counseling and support meetings should be offered to all parents who have experienced stillbirth. Also other family members such as children and grandparents need to be considered as participants [16].

A primary-support meeting was introduced in our institution to parents of children with special needs already in 1996. During the study period, this meeting guided by nurses with special training was included in stillbirth aftercare. Parents and other family members as well as friends can participate. The purpose of this meeting is to help parents handle the difficult emotions arising from their child's death, enable difficult conversations, and build a support network. An obstetrician is available to respond to medical questions. Peer-support parents can also attend. It is notable that the parents in our study did not mention this meeting separately. The lack of ratings of this intervention might reflect a space for improvement also in this aspect of care.

A recent study assessed the quality of stillbirth aftercare and follow-up in Sydney. The results concerning hospital care and management were very similar to ours. Almost all were satisfied with the information about delivery, the opportunity to ask questions, the time to make decisions, the time spent with their newborn, the hospital environment, and the support in making tangible memories. Slightly fewer were satisfied with the postmortem information received. When asked about help and support received from different directions fewer were satisfied with the support from doctors and social workers and less than a half were content with pastoral care, results in line with ours [15].

In our study, a remarkable proportion felt they were more anxious after the follow-up appointment. A clear majority, however, agreed that the obstetrician explained the results of the postmortem examinations in an understandable way. In the Sydney study, on the other hand, only 2/3 of the respondents found the information given at the follow-up appointment adequate [15].

A recent Finnish online study found out that only 47.8% of the mothers who had experienced stillbirth had received enough help and support to recover mentally from their loss. Furthermore, 17.4% experienced that that they did not receive any help. Most respondents in this study were satisfied with the care during the hospital stay (NPS, Net Promoter Score +3.3%) but the care after discharge from hospital was often unsatisfactory (NPS –18.5%), results similar to ours [17].

In the Sydney study, respondents brought up very similar themes in their open comments compared to themes stated by the respondents in our study. They appreciated staff with integrity, honesty, and empathy. They felt they had too little time for verbal discussion, too few opportunities to ask questions, and insufficient written information. Both the physical environment and the time spent with the child were important themes raised by the respondents [15]. Open comments in the Finnish online study also revealed that the care experience very much depends on the individual professional who the parents meet. Better communication between different professionals and units was called for, in line with our study [17]. A systematic review suggests employing specialist bereavement staff to ensure adequate support and continuity of care and even special bereavement suites, rooms away from main maternity wards [18]. According to a global consensus, staff training and clear local guidelines are asked for across all settings [19].

Currently, mixed evidence exists whether seeing or holding the stillborn child affects the parents positively or negatively. A Cochrane review from 2013 could not conclude the effect to be detrimental [20]. According to a subsequent systematic review the evidence of the impact of seeing and holding the child was sparse [21]. A more recent study found higher anxiety levels and more relationship problems in women who had seen or held their newborn. However, the symptoms were self-reported and the study had a low response rate [22]. In our study, only one respondent felt that she was pushed to hold her newborn while others were confident to do so. Clinicians should bear

in mind that the stillbirth protocols were developed without empirical evidence of their benefit, on the basis of clinical impression [23].

One of the most difficult conversations the parents must face is the decision on autopsy. A Swedish study revealed an autopsy rate of 84% and a good satisfaction with the information on postmortem results, an outcome in line with our study [24]. In an earlier questionnaire study, 81% had agreed to autopsy and 86% of the respondents believed the findings were explained appropriately. 7% regretted giving consent to autopsy but 14% had regrets because of refusing one [25]. In our study, on the other hand, very few regretted giving permission to postmortem examinations.

These results highlight the fact that healthcare professionals need to be trained in how to ask for the consent. In an internet-based survey on obstetricians, midwives, perinatal pathologists and parents, midwives were the professional group most frequently involved in counseling for postmortem examination. At the same time, they were the least well informed about the process of postmortem and the most likely to underestimate its value [8]. In addition to seeking after the cause of death, an important role of the postmortem examination is to help to alleviate false apprehensions and guilt feelings of the parents [26].

To maximize the wellbeing for bereaved parents, communities have to acknowledge grief and loss without stigmatizing those experiencing stillbirth and governments have to provide tangible support including funeral costs and paid leave from work commitments [27]. In Finland mothers are entitled to a 105-days maternity leave during which they are paid maternity grant corresponding their salary. Fathers are accordingly entitled to a 18-days paternity grant. If necessary, fathers are on sick leave after this period. Although our respondents rated their mental condition at the time of the survey quite high and there were very few contacts with the psychiatrist, their entire burden may not be visible.

In our questionnaire, open comments brought forth the need for a more attainable and integrated support system for bereaved parents after discharge from hospital. It is evident that the manner in which healthcare professionals provide care and support for parents experiencing stillbirth may have an impact on their life and memories well into the distant future [28, 29].

Conclusions

Our study showed that parents received adequate care and support during the hospital stay after stillbirth and were satisfied with the follow-up appointment. However, it is inevitable to constantly train professionals how to meet and guide parents who have experienced stillbirth in order to avoid inconsiderate comments or actions. In addition, a more structured, evidence-based support system after hospital discharge needs to be created and implemented.

Acknowledgments: We thank Christer Carlson, M.D., for translating the questionnaires to Swedish language.
Research funding: This study was funded by Helsinki University Research grants (TYH2019119).
Author contributions: All authors have accepted responsibility for the entire content of this manuscript and approved its submission.
Competing interests: Authors state no conflict of interest. The funding organization(s) played no role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the report for publication.
Informed consent: Informed consent was obtained from all individuals included in this study.
Ethical approval: The Ethics Committee of the Helsinki and Uusimaa Hospital District approved the study with permission number 92/13/03/03/2014.

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