Mothers’ experiences of the time after the diagnosis of an intrauterine death until the induction of the delivery: A qualitative Internet-based study

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Abstract

Aim: This study aims to describe how mothers spend the period of time between being diagnosed with a dead baby in utero and the induction of the delivery.

Material and Methods: Data were collected using a web questionnaire. Five hundred and fifteen women who had experienced a stillbirth after the 22nd week of gestation answered the open question: ‘What did you do between the diagnosis of the child’s death and the beginning of the delivery?’ A qualitative content analysis method was used.

Results: The results show that some mothers received help to adapt to the situation, while for others, waiting for the induction meant further stress and additional psychological trauma in an already strained situation.

Conclusion: There is no reason to wait with the induction unless the parents themselves express a wish to the contrary. Health care professionals, together with the parents, should try to determine the best time for the induction of the birth after the baby’s death in utero. That time may vary, depending on the parents’ preferences.

Key words: labor management, obstetric complication, obstetrics, pregnancy loss, stillbirth.

Introduction

More than three million babies die each year before they are born. Of these, about one-fourth die during birth, but most intrauterine deaths occur before the start of the delivery.1 In Sweden, the stillbirth rate is around 4 per 1000 babies born.2 The definition of a stillbirth, according to the World Health Organization (WHO), is a child being born dead and weighing more than 500 grams, or being stillborn after 22 weeks of pregnancy.3Earlier there were no drugs to induce delivery after a child had died in utero. A mother could wait for weeks, sometimes even months, with the dead child in her uterus before labor would start spontaneously.4 Women have described the waiting for delivery as very hard.5 However, today the administration of prostaglandins followed by oxytocin is common practice to induce delivery in the case of a stillbirth.6–8 There are different opinions as to when it is most appropriate to induce the delivery after the death of a child has been confirmed; some think that it is good to wait a day or
two in order to give the parents time to understand that the child is dead.\textsuperscript{9}

Nearly a quarter, 15 out of 65 (23\%), of the women with a delay of more than 25 h between being diagnosed with a dead baby \textit{in utero} and the induction of the delivery showed long-term anxiety-related symptoms, compared with only 5 out of 83 (6\%) women who waited less than 6 h until induction.\textsuperscript{10} However, sometimes parents wish to delay induction, and sometimes, for practical reasons, it takes time to induce labor. A delay of induction carries the risk of disseminated intravascular coagulation and infection, but it is small, according to Neilson, Hickey and Vazquez.\textsuperscript{7,8}

There is a lack of qualitative description of mothers’ activities and feelings between being diagnosed with a dead baby \textit{in utero} and the induction of the birth. In this study, we aim to describe how mothers’ spend the period of time between being diagnosed with a dead baby \textit{in utero} and the induction of the delivery.

\section*{Material and Methods}

On the homepage of the Swedish National Infant Foundation, written information about our study and access to the web questionnaire could be found between 27 March 2008 and 1 April 2010. The Fund is a member organization of the International Stillbirth Alliance (ISA). The study was open to all mothers who had experienced a stillbirth, even if it occurred many years ago. Also, no limit was given for the number of gestational weeks that had passed before the loss. Prospective participants were informed that they would remain anonymous and gave their informed consent before proceeding to the questionnaire. The Regional Ethics Committee in Lund, Sweden, had approved the study (reg. no. 467/2006).

The web questionnaire, developed on the basis of theoretical knowledge and clinical experience of meeting parents after the loss of a baby, consisted of 94 items covering personal information and topics related to the support received and the memories of the stillborn baby. The questionnaire took about 30 min to complete, depending on the time spent on answering open questions. The mothers could choose among multiple-choice alternatives and were encouraged to write as much as they wished about their experiences in response to open questions. In the invitation to the study, it was pointed out that participation was guaranteed confidential and that complaints after filling in the questionnaire could be addressed to professionals at the Swedish National Infant Foundation.

A total of 1034 mothers answered the questionnaire on the web. Included in the present study are 515 mothers who had experienced a medically induced stillbirth after the 22nd week of gestation and who had answered the open question: ‘What did you do between the diagnosis of the child’s death and the beginning of the delivery?’ The mothers were born between 1938 and 1988 (median 1973), and the stillbirths took place between 1959 and 2010 (median 2005). At the time of the stillbirth, the mothers were between 16 and 44 years old (median 31). For 303 mothers (59\%), the stillborn baby was their first child. The babies were 258 girls and 256 boys, while one mother answered ‘I don’t know’ to the question about the sex of the baby. The time between the diagnosis of the baby’s death and the induction of the delivery was for 80 (15.5\%) of the mothers less than 6 h, for 270 (52.4\%) between 6 and 24 h, for 99 (19.2\%) between 25 and 48 h, and for 62 (12.0\%) of the mothers the time was longer than 48 h.

In the evaluation of the answers to the open question under discussion here, content analysis inspired by Elo and Kyngäs was used.\textsuperscript{11} The counting of meaning units/statements was inspired by Hildingsson and Thomas.\textsuperscript{12} At first, the text was read and re-read several times. Thereafter, the manifest content of a sentence or paragraph was labeled with one of the 14 codes that emerged inductively during the analytical process. The separate meaning units/statements labeled with a code were 959 in total. The textual units given the same code were analyzed further and divided into subcategories. As a result of further interpretation, two superordinate categories and an overall theme emerged. To complete the analysis, the descriptions were discussed and validated in two seminars with the help of two independent experts within the field. The final step in the analysis was to go back to the original answers and for each participating mother create a binary index (0 = absent/1 = present) for each code belonging to the 515 participating mothers. In quantitative descriptions, absolute numbers and percentages (%) are given.

\section*{Results}

The overall theme ‘Striving to cope with loss when carrying death in the body’ is what combines the superordinate categories ‘Including others, one’s own feelings and the lost baby’ and ‘Shutting oneself off from others, oneself and the lost baby’. The statements falling into the first category were made by 358 mothers (70\%), while the statements belonging to the
second category were derived from 157 (30%) mothers’ answers. The theme, categories, subcategories and codes with the number of meaning units/statements are presented in Table 1.

Including others, one’s own feelings and the lost baby

With time, the mothers managed to gain a certain amount of control over the situation, to structure it and make it comprehensible as they shared their feelings of despair, sorrow and anger with others. Being physically close to, and communicating with, close friends, family and hospital staff helped the mothers to stay focused in this situation. Close relatives and friends embraced the mother’s body and mind with care, and the mothers were given the time and space to vent their grief.

I got to stay with my sister-in-law in the morning, the day after, and rest there and eat lunch until the hospital could receive us at 2 o’clock. It was really nice to be taken care of a little before and not have to take responsibility for our 2-year-old. (Questionnaire 510)

By telephone and SMS, the mothers informed everybody they thought needed to be informed about the death of their baby: relatives, friends and workmates. Before the delivery was induced, we called our families and told them what had happened. (Questionnaire 755)

The mothers’ changed life situation meant that they were losing the thread in their lives. At the hospital during the time between being diagnosed with a dead baby in utero and the induction of delivery, the mothers did not want midwives and other hospital staff to leave them alone.

Got a shock, a nurse was sitting by my side all the time and it was an incredible comfort for me not to be left alone. (Questionnaire 811)

When the mothers searched for explanations or causes behind the death of the baby or had questions in general, they asked the hospital staff that informed them of what was going to happen during birth. The physicians, while informing the mothers about the alternatives, tried to make them responsible for their own birth process. Counselors and priests helped the mothers to gain insight into their situation, and they informed and supported them in decisions about taking farewell of the stillborn child.

The mothers also offered the baby’s siblings care and attention, hugging them, answering their questions, crying together with them, when they told them about their dead sister or brother.
Went home, held my other two children, and told them what had happened. They got to feel the belly, and we explained that the little baby was no longer alive. (Questionnaire 908)

In order to calm themselves and to try to take control of their future, some of the mothers, through the Internet, contacted others that had experienced the same kind of loss. Some used the time between the diagnosis and the induction of the delivery to collect facts from personal contacts, the Internet, books and brochures.

We also had the time to read brochures by ‘The Infant Foundation’ and some other things to allow us to make good, conscious choices about how we wanted to do different things. If we hadn’t had the information from the brochure, we wouldn’t have made such good choices. We managed to prepare ourselves mentally. (Questionnaire 919)

Including one’s own feelings
The mothers used the time between being diagnosed with a dead baby in utero and the induction of the birth to adjust to the situation and make it comprehensible. The mothers described themselves as being preoccupied with thoughts about changing their lives. However, when they became aware of the necessity of giving birth, they pulled themselves together, focusing on the birth of their baby.

We sat up at night, singing for life and lighting candles. Tried to gain strength in each other and in ourselves since we knew that what was to come would require enormous resources. (Questionnaire 908)

Those who focused on the labor that awaited them prepared their bodies. They rested, slept and ate good food. They tried to derive power from nature and from beautiful scenery. They started to plan for the birth, making arrangements for their home, children, animals and work situation, and they prepared a bag ready to take with them to the hospital.

The evening was spent packing, crying, and trying to fix a babysitter in time for the induction the next day. (Questionnaire 732)

Including the lost baby
Some mothers described themselves as waiting eagerly for the birth moment that would enable them to see and feel the baby themselves. They started to gather baby paraphernalia to bring with them to the hospital, such as nice clothes and blankets. They bought, for example, casting kits for making foot or hand prints and soft toys in order not to leave the dead baby alone in the hospital when the parents/family would have to go home later on.

. . . when the panic had gone and sense returned, I absolutely wanted to see and feel my child, so I was then waiting just as impatiently to be induced, as for the other two I had already delivered. (Questionnaire 978)

According to some mothers, while the dead baby was still in its mother’s uterus, nobody could take it away from her, as would be the case after birth. According to the mothers, the baby in the womb was not homeless, as would be the case after it had been born. In the mother’s womb, the baby had a home. The mothers who shared this attitude tried to create as many memories as possible. They expressed their pride in the pregnancy, and they took their time saying goodbye to the present family situation, the pregnancy and the dead baby in utero.

As long as we were at home together me, my husband and our two other children), the entire family was in one place including the little baby that no longer lived. (Questionnaire 980)

The entire family lit candles or went to church, or sat together on the sofa or lay in bed, talking to the unborn child or looking at pictures from the ultrasound examination. They mothers described how they gently stroked the belly and then took pictures of it. Or they took a last shower together with the unborn baby. Some mothers described being engaged in trying to find a name or giving a name to the baby before the induction of its birth. Together with priests and undertakers, some of them also moved on by starting to plan for the funeral ceremony and by arranging for advertisements in the newspaper.

Shutting oneself off from others, oneself and the lost baby

Shutting oneself off from others
Some mothers felt responsible for letting friends and relatives down by being pregnant with a baby that is no longer alive. These feelings led to them taking care of
people around them, in order not to show their weakness or let their own grief out. When the death of the baby involved guilt about negatively affecting older siblings’ lives, the mothers either sent someone else to tell them what had happened or did not tell them at all. They chose to live as normally as possible. During the mothers’ stay in the hospital environment, they had a desire to be acknowledged by hospital staff and other patients. When they did not get confirmation, they experienced being abandoned and felt disconnected from those around them.

My partner and I had our own room on the ward. It was all just waiting and examinations. Don’t remember much from that time. Had strong feelings that staff and other patients avoided us, which was unfortunate. We needed a lot of support, which we didn’t get. (Questionnaire 579)

Care provided for mothers’ individual needs at the hospital between being diagnosed with a dead baby in utero and the induction of the delivery should include being acknowledged and allowed to take part in decision making. When mothers experienced that they did not get the care they needed from the hospital staff, they felt neglected by them. At the delivery ward, they could feel dissatisfied with being left alone in a delivery room without support, while at the same time hearing other mothers giving birth to healthy babies. Exposure of their pregnant bodies to others in the hospital environment while they were carrying a dead baby sometimes also caused feelings of discomfort.

We had a room on the delivery ward where we could hear children crying. We therefore went to the hospital entrance to get away from that. (Questionnaire 682)

Shutting oneself off from oneself
Some mothers described themselves as being in a state of chaos during the time between the diagnosis of the intrauterine death and the induction. To them, that time was the worst part of the whole process.

That was the absolutely worst time and part of the process itself. I was at my parents’ home with my boyfriend and just waited. Every minute felt like an entire year. Torture. And we didn’t know what would happen. Everything felt dark. (Questionnaire 1013)

When looking back at that time, memories are hazy. Some mothers described emotional turns of emptiness, darkness, chaos, despair, denial, or a sense of unreality and blunted feelings.

Is this happening, or are we part of a bad movie? Weird, I have to pee, am thirsty and cold, and already I’m talking about us having to try to have another child! (Questionnaire 149)

When mothers were occupied with their emotions, they could not focus and sometimes their bodies reacted. They could not eat or sleep, which meant that they did not prepare themselves for the pending birth:

Was allowed to go home to sleep at night. My partner and I were so shocked that we could neither eat nor sleep. Those were horrible hours at home, we mostly sat on the couch, crying. I wasn’t in the best of shape when it was time to drive to the maternity ward the next day. (Questionnaire 437)

Some respondents described anxiety of such severity that they could not be left alone in a room even for a short period. They considered their frailty as a threat to themselves and feared that they might harm themselves. Others, in despair, threw baby things around at home, screaming and crying, getting mad. At the same time, they blamed themselves and everybody getting in their way for the death of their baby, or they started to search for reasons and explanations by themselves, hiding from others that could have supported them.

I was desperate and considered taking my life. (Questionnaire 980)

Cried a lot, had difficulties sleeping, wanted to go out into the woods and never return again. (Questionnaire 127)

Other mothers waited passively for the time of induction to come. They describe themselves as thinking, crying or praying alone during that time.

I had grave thoughts about the delivery and a heap of questions about why she was dead. Locked myself up in a dark room and cried and slept. (Questionnaire 154)

Some mothers went on with their daily routines and acted as if nothing had happened fulfilling their usual
role in the family, maintaining various social contacts, and doing their job without letting anybody know about their secret. Some said they chose denial in order to let life remain normal for themselves and others around them as long as possible. One mother escaped by getting drunk.

Later, my sister and Mum came, and I made coffee for them – afterwards I understood that I was in shock – I just functioned without being really present. (Questionnaire 417)

To some, the time before the induction of the delivery meant feeling disconnected from the outside world. Everything else ceased to exist. It also meant an altered experience of time:

Woke up at 3 o’clock in the morning and the sun was shining and we sat down on the sofa and cried. Couldn’t understand that the bus was still running as normal. That the world simply continued. (Questionnaire 594)

Shutting oneself off from the lost baby

Some mothers suffered from the absence of signs of a living baby in utero, with ambiguous feelings vis-à-vis their bellies. Being disconnected from the baby sometimes also meant imagining a living baby soon to be born, despite the knowledge that it could not be. As time passed, the mothers lost faith and trust in the unborn baby, realizing it was no longer alive when they could not have contact with it.

...I had some little hope that it was alive, but I understood that it wasn’t because I hadn’t felt fetal movements for several days. (Questionnaire 686)

Some mothers experienced mortal dread and fear of death when they were pregnant with a dead baby. To them, the induction of labor meant making life worth living again, as it relieved them from carrying death in their body. The birth of the dead child gave them hope of access to their own body again. Others covered their mirrors at home in order not to be reminded of, and exposed to, their pregnant body.

I talked to some friends and tried to find something that could help me through the delivery – the solution was to think that I could have my body back through the delivery and be rid of that dead child inside me. (Questionnaire 186)

Discussion

We found that, for some mothers, the time between being diagnosed with a dead baby in utero and the induction of the delivery meant receiving support to help adapt to the situation, while for others, it meant further stress and an additional psychological trauma in a strained situation.

The category ‘Including others, one’s own feelings and the lost baby’, describes how mothers were ready to take care of themselves, their body and mind, as well as their families. They describe having had the inner strength to make decisions and choose the way that was right for them, their families and their stillborn baby. This is in line with Väisenän’s findings of mothers coping openly with their loss. She concluded that the more the mothers had bonded with the expected baby and the more they had organized their lives around the pregnancy, the more openly they were able to cope with the loss. In literature about attachment and loss theories, strong attachment is more likely to yield a more positive loss experience. On the other hand, in the category ‘Shutting oneself off from others, oneself and the lost baby’, a strained situation is described. Hence, the connection between waiting more than 25 h for the induction of the delivery and long-term anxiety symptoms, which was shown in a population-based study, can be a consequence of the fact that the time between diagnosis and induction is very stressful. Maybe this turns into memories that are difficult to cope with and thus causes persistent symptoms of anxiety. Mothers feeling their lives to be in chaos may not always be able to prepare themselves psychologically after all, despite the attention of those who suggest waiting for the induction until the day after the diagnosis. In addition, the mothers thus afflicted may not be able or willing to articulate their needs, as shown in the present study. Some mothers, while they were waiting, were left in confusion and uncertainty and were thus not able to focus on the upcoming birth. Our findings are in line with a study by McCreight describing 23 women who had suffered a stillbirth and thus an emotionally demanding loss: of being a parent, of their identity, of their self-control, and of their expected future. Furthermore, Dyregrov pointed out that anxiety is contagious; therefore, the impact that mothers have on the sibling of the dead child and their family when shutting themselves off from others needs to be further investigated, in order to enhance the entire family’s wellbeing after a stillbirth.
Some mothers in the present study described how they hid from others that could possibly have helped them, even though they felt lonely while they were waiting for the induction, or they denied what had happened, just keeping it a secret and maintaining daily routines. This can be related to the avoidance of loss in the dynamic regulatory coping process described by Stroebe and Schut, allowing oneself limited doses of grief over time as a way to handle loss.13,20 Taken together, the mothers' accounts in the present study can be seen as reflecting the spectrum between confrontation and avoidance,20 as they faced the situation of carrying death in their body. These accounts should not be understood as either good or bad ways to handle loss.13 These findings must be made known to the obstetrician community before decisions are taken between immediate or differed interpretation of pregnancy, as well as the psychological support that some women need to face up to this moment. Hence, health professionals, together with the parents could find out the most appropriate time for the induction of the birth, which for some mothers can be as soon as possible after the diagnosis, while for others it can be the following day.

The main limitation of this study is that the stillbirths took place over a long period of time, 1959–2010, and that the participants were self-recruited. This gives rise to volunteer bias as it is only the women who are conversant with Internet communication who will be able to participate.22 Routines in connection with, and attitudes towards, stillbirth might also have changed in Sweden over the years,23 and the mothers might have forgotten, or altered their memory of, what happened as time passed.22 However, experiences in a situation, such as being diagnosed with a dead baby in utero and waiting for the induction of labor are largely independent of time and space.2 We could have chosen to identify time trends showing whether mothers who had the stillbirth loss a long time ago gave different responses to mothers who suffered stillbirth loss more recently. However, our chosen qualitative method does generate findings, with its limitations, and raises awareness regarding women’s feelings and coping mechanisms at a time of extreme distress.

The anonymity of Internet questioning increases participation rates and gives free rein to participants to express their views. However, it addresses the disadvantages of not being able to clarify or expand on a point made. If qualitative interviews had been carried out, an even deeper analysis could have been achieved. Furthermore, if a mixed methods study had been performed, analyzing the qualitative findings vis-à-vis the quantitative data, we might have got beneficial findings. We described the data collection carefully and honestly and the qualitative analytical process followed, allowing the reader to evaluate it, thus we believe strengthening credibility. In addition, analytical choices were discussed and validated in two seminars with experts within the field, which further strengthened reliability. We therefore assume our findings are trustworthy and in line with the literature within the field.

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References