BEING ALONE IN SILENCE – MOTHERS’ EXPERIENCES UPON CONFIRMATION OF THEIR BABY’S DEATH IN UTERO

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BEING ALONE IN SILENCE – MOTHERS’ EXPERIENCES UPON CONFIRMATION OF THEIR BABY’S DEATH IN UTERO

Running head; Confirmation of intrauterine death

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Abstract

Objective To explore mothers’ experiences of the confirmation of ultrasound examination results and how they were told that their baby had died in-utero. **Design** In-depth interviews **Setting** Sweden **Participants** 26 mothers of stillborn babies. **Measurement** Narratives were analysed using a qualitative content analysis with an inductive approach. **Findings** The mothers’ experienced that silence prevailed during the entire process of confirming the ultrasound results. Typically all present in the ultrasound room were concentrated and focused on what they observed on the screen, no one spoke to the mother. The mothers had an instinctive feeling that their baby might be dead based on what they observed on the ultrasound screen and on their interpretation of the body language of physicians and midwives. Some mothers reported a time delay in receiving information about their baby’s death. Experiencing uncertainty about the information received was also noticed. **Conclusion** Mothers emphasized an awareness of silence and feelings of being completely alone while being told of the baby’s death. **Implication for practice** The prevalence of silence during an ultrasound examination may in certain cases cause further psychological trauma for the mother of a stillborn baby. One way to move forward given these results may be to provide obstetric personnel sufficient training on how difficult information might be more effectively and sensitively provided in the face of an adverse pregnancy outcome.

**Key words:** stillbirth, intrauterine death, ultrasound, information.

**Key conclusion:** A mother’s understanding of her baby’s death is an ongoing process influenced by the image on the ultrasound screen, the body language of the staff, and the information received.
INTRODUCTION

Being the one who has to provide difficult information is a trying task for healthcare professionals (Asplin et al., 2012, Heazell et al., 2012). The diagnosis of fetal death is usually made on the basis of ultrasound examination, an examination that the mother can follow on the screen. Thus, the physician who makes the diagnosis tells the mother that her baby has died. Stillbirth can be classified as one of the most devastating experiences a woman can experience and it also creates a high risk for post-traumatic stress (Heazell et al., 2012, Horey et al., 2012, Kelley and Trinidad, 2012). Stillbirths also have psychological impacts on obstetricians (Farrow et al., 2013).

In a Swedish study (Erlandsson et al., 2012) of 614 mothers who had given birth to stillborn babies, 70% had had a premonition that their unborn baby might be unwell. Noticing weakening fetal movements and a decrease in the frequency of movements led the mother to have this premonition. The ‘Staircase to insight’ is a model built on what mothers of stillborn babies remember about what they felt before they contacted the healthcare provider for an investigation of their unborn baby (Malm et al., 2011). The insight steps in the model describe how the mothers lost contact with their babies; they were worried and felt that something was wrong. At the same time they could not understand the unbelievable, that a baby can die in the womb. Some mothers waited almost two days before they contacted healthcare for an examination.

In the Lancet series on stillbirth, Lawn and Kinney (2011) state that globally, more than three million babies die each year before they are born. Of these, about one-fourth die during birth, but the rest of the deaths occur before the start of the delivery. The aim of this study was to explore mothers’ experiences of the confirmation of their baby’s death in utero and to learn how they remember how they were informed of their baby’s death. If we can understand the mother’s perspective during this process, we may be better armed to avoid secondary and avoidable traumatizing actions.

METHOD

Participants

Participants were self-recruited using information and an inquiry about participation through the Swedish National Infant Foundation website. The foundation is a member organization of the International Stillbirth Alliance, and it supports parents who have lost a baby before or
after birth. Inclusion criteria were that the mothers should have given birth to a dead child after 28 gestational weeks. After the information about the study was published at the website, the research team was contacted by 52 women expressing interest of participating in the study, of those 26 did not meet the inclusion criteria. All mothers in this study (n=26) had given birth to a dead baby after 28 gestational weeks. For 19 mothers this was their first child. The mothers lived in 21 different municipalities and had been cared for at 15 different hospitals in different parts of Sweden. One mother was single, and the other 25 were married or lived together with the baby’s father at the time of the birth. For 18 mothers, the interview took place one to six years after the stillbirth. For the other eight mothers, less than one year had passed.

**Interviews**

The rationale for using a qualitative approach was to give the mothers time to speak freely about what they had experienced during the ultrasound examination. The in-depth interviews took place in 2006 and 2007. Twenty-two of the interviews were performed in the mother’s home and four in another place comfortable for the mother. The interviewer was a skilled midwife (ACM) and the interview provided an opportunity for the participants to tell their story and also time to reflect on the question “What did you experience during the ultrasound examination and how were you told that your baby had died?” The question was one component of a broader interview including questions about the birth of the baby. The recorded interviews lasted between 55 and 90 minutes and were transcribed verbatim (names and places were changed) by a professional transcriber.

**Data analysis**

First, the interviews were read through several times in order to gain an overall impression of the content. Then significant patterns in the text were identified. In the next step, differences and similarities were identified and linked together into smaller units of text. Patterns of content emerged from this process. The patterns were then compared with each other and turned into themes and sub-themes. Finally, themes and sub-themes were discussed within the research team until a common understanding was reached. Quotations were used to support the findings (Patton, 2002; Thorne, 2008) (Table 1).

**Ethical Considerations**
The women interested in participating in this study contacted the interviewer by phone or e-mail. After this first contact the interviewer mailed a letter with written information about the study to the women i.e. they were informed of the aim of the study and about the voluntary nature of their participation. By sending a reply letter to the research team, the woman gave her consent to participate; thereafter the time and the place for the interview were booked. The participants were guaranteed confidentiality and the anonymous presentation of the results. The study was approved by the ethical committee at Dalarna University College (2004-08-18).

**FINDINGS**

The interview data were divided into five sub themes; *Watching the ultrasound screen; Body language of staff; Inconsiderate and unclear communication; Elucidate information; Panic, devastation and total loneliness* and three main themes; Mother’s anticipation; Confirmation of the death; A world of chaos and loneliness.

The experience of the ultrasound examination can be described in terms of parallel processes taking place simultaneously. One process is the mother’s development of insights that her baby might be seriously ill as she follows the examination by looking at the ultrasound screen. Another part is the mother’s interpretation of what the physician sees as he or she moves the ultrasound transducer to scan the fetus.

The screen shows an image of the fetus where there is no heartbeat and no movement. The mother watches the screen as does the physician, the midwife and other healthcare professionals in the room. There is complete silence; all present in the ultrasound room are concentrated on the screen and focus totally on what they observed on the screen. This is a moment of anticipation that something may be seriously wrong. When final confirmation of the baby’s death is given, the mother may feel as if she is falling into a world of chaos and loneliness.

**Mother’s anticipation**

*Watching the ultrasound screen*

The ultrasound examination was described as a period during which there was total concentration on the screen with both the mother and physician focused on the image of the fetus. Each mother had her own understanding of the images seen. She could see that the baby was still and that there was no heartbeat, but she was still not fully able to interpret what she
sees. The mother may have reason to believe that the baby might be dead or very ill. Still, she may be hoping for a miracle. The mother is waiting for a verbal response from the physician to confirm or dispel her fears. The mother’s description of the situation in front of the ultrasound screen reveals that all persons in the room are concentrating on the images, and do so in silence.

...but I saw at once that little ‘coin’ (the baby’s heart) was totally still but still I waited for her to tell me, but she took so long. (15)

…I was thinking keep looking at the screen, if we keep looking for a while it will soon move, soon it (the heart) will beat. To keep looking at the screen was all I could think of. (13)

I looked at the screen and...PLEASE GOD; a stronger prayer can’t exist than to make that heart beat again. But it didn’t, it didn’t. It was a totally unreal situation. (7)

Body language of staff

At the same time that the mothers follow the examination on the screen, they can also monitor the body language of the physician or other staff present and can see that sometimes these people “talk” to each other using body language. The mothers report that the staff seemed to have an unspoken understanding between them, not shared with the mothers. The mothers understand that something serious has happened by simply reading the body language of the staff and the combination of silence and body language confirms their fears. Memories of loneliness and a feelings of not being seen by the others who are present in the ultrasound room, is described by the mothers. Also, they report that any delay in presenting verbal information triggers feelings of anxiety and makes them feel that they are being excluded, at least during the period of silence.

I saw how they just looked at each other. (2)

I was just waiting for information about what was happening, but she did not say anything either, she just looked very upset. (23)

I just got this feeling that now something is wrong. There is something they want. I asked several times if they wanted to say something but we just had to watch while they were looking. I probably asked a hundred times during those minutes, what they were doing and if something was wrong. (5)
Confirmation of the death

Inconsiderate and unclear communication

The verbal report of the baby’s death was experienced by the mothers as being unclear and in some cases presented in such a way as to indicate a lack respect for the situation on the part of the messenger. The information was sometimes presented bluntly and no further discussion of what was seen on the screen was encouraged. Some physicians delegated the task of presenting the devastating news of the death to a colleague. The mother was sometimes left in the room alone while the examining doctor went away to find a colleague. Supposedly the examiner wanted a second opinion, but this could be interpreted by the mothers as not taking the responsibility for telling them that the baby was dead i.e. leaving that to a colleague. Several of the mothers said that they were left alone by the physician after being given the shocking news that their baby was dead. Some mothers said that although some explanation was provided, it was difficult to understand this explanation.

Then I didn’t really understand what they were saying... when they left I just stared at the walls, and asked myself where I am and what is this about? (8)

They didn’t say much. The doctor looked at me and she didn’t say anything either, she left it to another doctor and she just mumbled. (1)

…I saw the heart but it didn’t beat and you could see that the baby was very still she just said; the baby is not alive and then she left. (25)

Then she said the heart doesn’t beat, the baby is not alive. She held us then she said; I am going to leave you for a while so you get some time alone. I grabbed her and said; what the hell you cannot leave us now. Now is when we need you! So, she stayed for a while. (23)

Elucidate information

Three mothers described how the physician had explained step by step what was seen on the screen. He or she wanted the mothers to understand what had happened by explaining what had led to the death. These mothers said that the death was put in a context that helped them to comprehend what had happened. The mothers said they felt better able to comprehend what had happened through sharing the death of their baby with another person who was present, a
person who could explain and break the silence; a 'stepwise' collaborative procedure created by the physician.

_They really explained in detail what they were doing the whole time, and what the next step was. Here you can see this, and here you can see that, and then here’s the heart and it doesn’t beat._ (7)

_I remember that he took my hand and held me. The midwife was sitting next to us. I asked him to look again and he did. He turned on the ultrasound machine and looked and showed us again._ (18)

**A world of chaos and loneliness**

This theme describe the mother’s moment of understanding that her baby was dead. The death was unexpected in a sense because up until this moment the women were prepared for motherhood and then, in an instant, the close tie between the mother and the baby could be described as having been abruptly cut off. The mothers said that they had entered a world of chaos and loneliness - in total silence. The mothers did not remember any dialogue taking place between them and the physician or other staff at this moment. They described the time immediately after they understood their baby was dead as being _unreal and crying out for help and_ had difficulty comprehending what had happened and what it all meant.

_Panic, devastation and total loneliness_

The mothers reacted to the death with feelings of unreality, panic and shock. Some screamed and some had physical reactions such as vomiting; others asked for a cesarean section. Some said that they pleaded for help feeling that “I cannot do this”, “Please do something shake her bring her back to life”, or “Cut me open”. The mothers described panic attacks occurring at the moment they understood that the baby was dead. The devastating understanding that their baby was dead was overwhelming and the mothers experienced an intense psychological pain. In the moment of the confirmation that their baby was dead, the mothers experienced loneliness, although they were in the company of the baby’s father or another companion. At this particular moment the mothers reported experiencing a sense of” free falling” into something unknown. They were mothers who had lost their babies and in an instant their life was disrupted.
...the panic attack started. It can’t be true, I just screamed, it’s not true! I really screamed, I did, I screamed like, do something, help me, do something, I was in shock. I laid there on that birthing bed and I started to vomit. (23)

Everything just collapsed; bang! It was like everything just fell apart. My first thought was, just get the knife out and cut me open. (10)

DISCUSSION

For most mothers in this study the information about the baby’s death was seen as being unclear and in some cases presented in such a way as to suggest that the person delivering this information was lacking in respect for the mother and her situation. Only three mothers stated that the physician had talked to them and had satisfactorily explained the process during the examination of their baby by informing them step by step what was seen on the screen. Mothers emphasized an awareness of silence and feelings of being completely alone while being told of the baby’s death.

Silence

During the ultrasound examination, most mothers in our study observed that the examination was carried out in silence. In spite of this, they began to sense that something was seriously wrong or even that the baby, in part on the basis of what they saw on the ultrasound screen and in part by interpreting the body language of the obstetric provider, with facial expressions being the most readily observable. During these minutes they experienced “being left out and being all alone”. Physicians often perceive their task as clinicians to be primarily the finding of answers for the parents, and they find it challenging to focus simultaneously on the clinical situation and on the emotional needs of the patients in a charged and often clinically complex situation (Kelley and Trinidad, 2012). We do not know if the silence the mother in our study perceived during the ultrasound examination was due to difficulties connected with confirming the intrauterine death or due to the physician’s insecurity about providing the difficult information to the mother. Further, Back and Bauer-Wu (2009) describe a typology of silence i.e. silence can be awkward and felt like it drags on too long. They suggest that the feeling of awkwardness that is transmitted to the patient is likely to be interpreted as something else, often judgment, ambivalence, disapproval, or withholding.
Communicating bad news

The mothers in our study did want information about what was happening during the ultrasound examination. Parent’s preferences for clear communication and information have been reported previously in studies of seriously ill children (Mack, 2006). Further, apart from clear and timely information the mothers in our study also wanted and appreciated human kindness and empathy from the physician who performed the ultrasound examination and then confirmed their baby’s death. One communication model from the oncology field has demonstrated that patients at the end of life value the physician’s ability to move fluidly between providing recognition of suffering, and giving emotional support and guidance (Back and Bauer-Wu, 2009; Back et al., 2011). Some key elements in giving bad news are that the person should be well prepared for saying what must be said, should be able to create a calm environment, and should not show any sense of being rushed (Säflund, 2003; Kavanaugh and Moro, 2006). However, at the time when a baby is confirmed as being dead in utero, everything is happening in real time with the mother watching the screen. Thus, the real-time preparation for delivering bad news is minimal; training in how difficult information might be more sensitively provided during the ongoing examination of the fetus can be one way to improve the care given.

The mothers in our study were not only emotionally, psychologically, and socially “left out and alone”, but they were also physically left alone in the ultrasound room; in some cases this was due to the physician fetching a senior doctor for a second opinion. Studies from neonatal and pediatric palliative care practices indicate that parents of a baby who dies need support in order to get a deeper understanding of what has happened and thus become able to integrate this knowledge into a comprehensive sense of coherence. Meaning was also associated with feelings of safety and security (Durall et al., 2012; Kendall and Guo, 2008; Reilley-Smarowski and Armstrong, 2002; Christ et al., 2003). In contrast, feelings of being alone and separate had a negative impact on being able to develop a personal deeper understanding and meaning of events (Christ et al., 2003). Based on the experiences of the mothers in this study as well as in the study by Kelley et al (2012) there seems to be a gap between what the women feel they need and the actual care they receive. One important aspect of the lack of care identified in this study concerns communicating with the mother during the ultrasound examination. Human contact and communication with healthcare professionals are described by Cutler et al (2013) as one of the most important ways for patients who had faced a critical incident to find deeper meaning and a sense and understanding of what had happened.
Communicating with patients about their feelings is an important but challenging element of care. Recognizing and understanding practices and their consequences can help physicians tailor their communication to individual circumstances and thereby support patients in very difficult situation (Parry et al., 2012). A starting point in such conversation may be a “stepwise” conversation (Maynard, 1996; Maynard, 2006). This means that the communication is designed to guide the person through the process of the diagnosis, step by step.

**Methodological considerations**

The data shed light on a sensitive topic, and with 26 participants sharing their experiences in in-depth interviews the results can be seen as trustworthy and transferrable to women in the same situations in similar contexts. All participants were self-selected and recruited from a support website. They had varying lengths of time since their loss. A main goal in the analysis process was to comply with standards for ensuring credibility, dependability, transferability and conformability of the results. Therefore, careful attention was given to thoroughly describing the process of analysis, especially by providing a context through the use of exact quotations. During the analysis, the results were regularly discussed together with all authors to ensure consistency.

**Conclusion**

Mothers emphasize that what they remember most strongly is the silence and the feeling of being completely alone while being told of the baby’s death.

**Implications for practice**

The prevalence of silence during an ultrasound examination may in certain cases cause further psychological trauma for the mother of a stillborn baby. One way to move forward given these results may be to provide obstetric personnel sufficient training on how difficult information might be more effectively and sensitively provided in the face of an adverse pregnancy outcome.
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Table 1. Examples of the analysis process

<table>
<thead>
<tr>
<th>Examples of recurring units/phrases</th>
<th>Sub-theme</th>
<th>Main-theme</th>
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<tbody>
<tr>
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<td>Body language of staff</td>
<td>Anticipation</td>
</tr>
<tr>
<td>I saw the heart but it didn’t beat and you could see that the baby was very still she just said; the baby is not alive and then she left. (25)</td>
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