A summary of results from scientific work

Dissertation

Dissertation *To give birth to a dead baby – care given during birth and the woman's situation three years after the stillbirth*, based on six articles. Here is a short summary of the results presented in these articles and also from a seventh article that summarizes the dissertation itself.

A questionnaire was sent to 314 women who had experienced a stillbirth in 1991 and to 322 women (control group) who had experienced a live birth. All completed a questionnaire anonymously. We compared information in the medical birth register with information from the questionnaires; at the group level, the results were almost identical. We found that the women who had spent as much time as they wanted with the stillborn baby and the women who had tokens of remembrance related to the baby, were at a lower risk for anxiety symptoms three years after the stillbirth than those who had no tokens of remembrance and who had not spent as much time as they wanted with their baby. A delay in inducing the delivery of more than 24 h after the diagnosis of intrauterine fetal death was a strong risk factor for experiencing anxiety symptoms three years later. It is probably not desirable to induce delivery directly after the diagnosis has been made; the mother needs time (hours but not days) to digest the medical information about delivery and, of equal importance, to be prepared for the first moments with the longed for but silent infant. The results indicate that having the dead baby in the uterus is very stressful and that this trauma can partially explain the increased risk of experiencing anxiety symptoms in the long run. It is to the credit of the staff at Sweden's delivery wards that the women said that the staff showed the same consideration and respect for a dead baby as they did for a living. It was also noted that mothers who had experienced stillbirth, as compared with mothers who had given birth to a live baby, had a better relationship with their partners and felt more satisfied with family life three years after the delivery. Almost all of the mothers who had lost their child said that it was important to know the reason for the death; determining the cause of death can therefore be motivated not only for medical reasons but for psychological reasons as well.

1. Rådestad I, Steineck G, Nordin C, Sjögren B. Psychological complications after stillbirth-influence of memories and immediate management: population based study. *British Medical Journal* 1996;312:1505-1508.

2. Rådestad I, Steineck G, Nordin C, Sjögren B. Psychic and social consequences of women in relation to memories of a stillborn child - a pilot study. *Gynecologic and Obstetric Investigation* 1996; 41:194-198.

3. Rådestad I, Nordin C, Steineck G, Sjögren B. Stillbirth is no longer managed as a non-event: a nationwide study in Sweden. *Birth* 1996;23:209-215.

4. Rådestad I, Sjögren B, Nordin C, Steineck G. Stillbirth and maternal well-being.
Acta Obstetricia et Gynecologica Scandinavica 1997;76:849-855.

5. Rådestad I, Nordin C, Steineck G, Sjögren B. A comparison of women´s memories of care during pregnancy labour and delivery after stillbirth or live birth. *Midwifery* 1998;14:111-117.

6. Rådestad I, Otterblad-Olausson P, Steineck G. Measuring errors and non-participation in a nation-wide study of stillbirth. *Acta Obstetricia et Gynecologica Scandinavica* 1999;78:592-598.

7. Rådestad I. Stillbirth: obstetric care and long-term psychological effects. *British journal of midwifery* 2001;9:474-480.

New studies provide an improved understanding the results in the dissertation

My work for the dissertation was based on a large data collection, a quantitative study using epidemiological methodology. Such studies can investigate the effect of, for example,

different approaches to care giving. Midwife Margaret Samuelsson helped me to become familiar with qualitative research methods. In such studies, data are collected that can help us identify and more carefully define phenomena and thus help us to understand better how an event is experienced. Margaret Samuelsson interviewed 11 fathers who had lost their baby before birth. We wrote an article in which we reported our finding that fathers who had lost their child before birth could feel frustrated and helpless during the delivery, but nevertheless did find meaning in supporting their partner. The fathers wanted to be treated with understanding for their own grieving, both from staff and from family. It was also important for them to have mementos of the baby even if they were at first doubtful about that. From the beginning the men saw a c-section as the clear alternative but they changed their opinion and said that it was good that the infant was delivered vaginally and that a c-section had not been chosen.

8. Samuelsson M, Rådestad I, Segesten K. A waste of life: fathers experience of losing a child before birth. *Birth* 2001;28:124-130.

In another qualitative study, midwife Otti Trulsson interviewed 12 women who had lost their infant before birth. They reported having a feeling of premonition and the feeling that something was not right before they were told that the fetus had died. Their feelings of worry and of premonition were difficult to convey, the women said. After being told that the baby was no longer alive the women expressed having feelings of unreality and said they wanted to get rid of the fetus as quickly as possible while, at the same time, the task of giving birth seemed to be impossible. The women expressed their wish that the staff would use the time after diagnosis of the death of the fetus up to the time of induction of labor to prepare them for the delivery and for meeting the warm but silent new born baby.

9. Trulsson O, Rådestad I. The silent child - mother´s experiences before, during and after stillbirth. *Birth* 2004;31:189-195.

Symptoms of depression three years after stillbirth

There was much left to be analyzed in the large body of data on which my dissertation was based, and Pamela Surkan, a doctoral student from the USA was able to make use of these data in her own dissertation research. She wanted to find out if there was a relationship between not having had as much time with the dead infant as the mother herself wanted and how each mother reported symptoms related to being depressed. An almost seven times greater risk for reporting symptoms of depression was found among women who had *not* been able to be with the baby as long as they had wished than among women who had spent as long as they wanted after delivery. In addition we found that the women who had not become pregnant three years after the stillbirth had an almost three times greater risk for experiencing symptoms of depression than those who became pregnant within six months of the stillbirth. Pamela Surkan also wanted to determine if social support affected the risk of experiencing symptoms of depression after a stillbirth. If the mother felt that the father did not want to talk about the baby and what had happened, the mother, had an almost five times greater risk of displaying symptoms of depression than women who could talk about this with their partners. It is important to point out that studies of this kind cannot diagnose clinical depression. The data simply show how many symptoms the woman marks in the questionnaire and the degree to which she is affected by each symptom checked off.

10. Surkan PJ, Rådestad I, Cnattingius S, Steineck G, Dickman PW. Events after stillbirth in relation to maternal depressive symptoms: a brief report. *Birth* 2008;35:153-157.

11. Surkan PJ, Rådestad I, Cnattingius S, Steineck G, Dickman PW Social support after stillbirth for prevention of maternal depression. *Acta Obstetricia et Gynecologica Scandinavica* 2009;88:1358-1364.

Diagnosis and waiting for the delivery to begin

The death of a child in the womb is ordinarily determined with the help of ultrasound that shows that the child's heart is no longer beating. In an interview study initiated by midwife Mari-Cristin Malm, we studied what 26 women remembered about receiving the information that the baby had died. The overall result was that the women experienced a *marked* silence during the examination. The person making the examination and even everyone else in the room were totally concentrated on the ultrasound screen, nobody said anything but the women understood that something was not right. They interpreted the silence and the staff person's body language, and felt that reporting that the baby's heart was no longer beating was delayed and was then not clearly presented. The women reported feelings of chaos and being alone during the ultrasound examination.

12. Rådestad I, Malm M-C, Lindgren H, Pettersson K, Franklin Larsson LL. Being alone in silence – mothers' experiences upon confirmation of their baby's death in utero. *Midwifery* 2014;30:91-95.

In my dissertation, I reported that the women who had to wait longer than 24 hours before the start of induction of delivery reported more symptoms of anxiety three years later than did the women for whom induction of labor was started in less than 24 hours. In a web-based data collection using the Swedish National Infant Fund website, we were able to collect information from 515 women who had experienced a stillbirth. We posed the question: What did you do between the time you received the diagnosis of your unborn baby´s death in utero and the induction of delivery? The results showed that many were helped in dealing with the situation but for some of them the waiting time before the start of delivery was stressful and that they were faced with yet another psychological trauma in an already difficult situation. We concluded from this analysis that there is no reason to delay the start of induction unless the parents themselves ask for such a delay. The parents' understanding of when delivery should start should be given much weight.

13. Erlandsson K, Lindgren H, Malm M-C, Davidsson-Bremborg A, Rådestad I. Mothers´ experiences of the time after the diagnosis of an intrauterine death until the induction of the delivery: a qualitative internet- based study.*Journal of Obstetrics and Gynaecology Research* 2011;37:1677-1684.

In order to develop a more complete understanding of what women experience by having a dead baby in utero while waiting for the induction of labor, we analyzed the answers from 21 mothers in Mari-Cristin Malm's interview study. The dominant theme that appeared from the analysis was that waiting was to find oneself in a *No-man's land*. The women reported feeling as if they found themselves on foreign ground far from any kind of normality. For some of them, the waiting was completely involuntary and they lacked any information about what was next to come. Another aspect was that the women said that they had to deal with the incomprehensible; their expectations of having a living baby and a future family live with the child had been crushed.

14. Malm M-C, Rådestad I, Erlandsson K, Lindgren H. Waiting in no-man´s land-mothers´ experiences before the induction of labour after their baby has died in utero. *Sexual & Reproductive HealthCare* 2011;2:51-55.

To see and hold the child

In 2002 a debate took form in England in which health-care professionals discussed whether it is desirable for parents to see and hold a stillborn baby. The debate was preceded by a study (that later was seen by Hughes et. al. to have been misinterpreted) that found that the mothers who had held their babies were likely to experience more anxiety and depression symptoms after delivery than those who had not. The study was small, only 55 women were included and there was a large dropout during the follow-up period. The majority of the women in the

study had lost their baby early in pregnancy, during week 18-20. The debate led me to once again analyze the data from the dissertation. We found then that it was overall better for the women to have held the baby. The results showed also that support from the staff was important if the mother was to hold her baby. These findings have since been confirmed by several qualitative studies.

15. Rådestad I, Surkan P, Steineck G, Cnattingius S, Onelöv E, Dickman PW. Long-term outcomes for mothers who have or have not held their stillborn baby. *Midwifery* 2009;25:422-429.

The debate about whether one should or should not hold the baby continued in England. The national guidelines were changed from the earlier position, that it was important for staff to support the parents in seeing and holding their baby, to stating that staff must *always ask* if the parents wanted to see and hold their baby. My own conviction is that it is good for almost all, in both the short and long run, to see and hold their dead baby. If one asks *if* the parents want to see the baby, posing the question implies that it is not certain that all parents will want to see their baby, and this can make the parents uncertain. To give birth to a dead baby, creates in itself a feeling of doubt and the parents need support to be able to *normalize* what they face. *Even a dead baby has parents and the parents need to be supported in their parenthood.* When I am discussing this at international conferences my position has always been: if one is to ask these parents *if they want to see* their baby then one must ask this of *all* who give birth, not just those whose baby was still born. This position usually gets most of the listeners to understand that it is absurd to believe that it is not perfectly clear that parents want to see their baby, even if they may fear being confronted by death. I have together with researchers from the USA, Norway, and colleagues in Sweden continued to study the question in order to understand what can affect how parents will feel long after their baby has been still born.

Together with Frederik Frøen from Norway and Joanne Cacciatore from the USA, both central figures in this research area, I studied the effects of being with the dead baby after birth. Data were collected via a web-based questionnaire. A total of 2000 women who had lost their baby before birth were questioned, and of this total nearly 300 were pregnant again when they completed the questionnaire. The women who were *not* pregnant when they completed the questionnaire had statistically significant fewer anxiety and depression symptoms if they had seen and held their dead baby in comparison with those who had not seen and held their baby. The participants who were pregnant also had a significantly lower occurrence of depression symptoms if they had seen and held their baby in comparison with those who had not done that. However, the women who had held their baby and who were pregnant when they answered the questions had more anxiety symptoms. We concluded that it was helpful to see and hold the baby even if this positive effect can temporarily (as concerns anxiety symptoms) decrease during a current pregnancy.

16. Cacciatore J, Rådestad I, Froen JF. Effects of contact with stillborn babies on maternal anxiety and depression. *Birth* 2008;35:313-320.

In an article written with Line Christoffersen from Norway, we report on research that shows the importance of parents having the chance to hold their baby for the first 30 minutes after birth. At that time the body is still warm and soft.

17. Rådestad I, Christoffersen L. Helping a woman meet her stillborn baby while it is soft and warm. *British Journal of Midwifery* 2008;16:588-591.

In an additional two studies of the mothers' experience of seeing and holding the stillborn baby we found that the mothers feel both tenderness and sorrow when they hold their baby but this is not frightening for them. We also found that the feelings experienced when the mother holds her child is influenced by the manner in which the mother receives the child from a caregiver. If the midwife or other person shows the mother the baby without first asking her if she wants to see the infant it feels natural and the mother feels more comfortable than if she has not been asked if she wants to see the baby. Feelings of fear before seeing the baby are also less if the midwife or other person has not asked the mother if she wants to see her baby.

18. Rådestad I, Säflund K, Onelöv E, Wredling R, Steineck G. Holding a stillborn baby: mothers' feelings of tenderness and grief. *British Journal of Midwifery* 2009;17:178-180.

19. Erlandsson K, Warland J, Cacciatore J, Rådestad I. Seeing and holding a stillborn baby: mother´s feelings in relation to how their babies were presented to them after birth – findings from an online questionnaire. *Midwifery* 2013;29:246-250.

Premonitions

Different studies have shown that many women who have lost their baby before birth have felt a premonition that something might be wrong before they learned that it was so. Becoming aware of this led to the thought that pregnant women perhaps had been given incorrect information concerning how the fetus normally moves toward the end of pregnancy. Several studies indicated that the women had felt a decrease in fetal movement but that they had been given information by those close to them and even from their midwife that this is normal. In an interview study we were able to describe this with a theoretical model that we named *The staircase to insight*. The women experienced losing contact with their unborn baby when the fetus began to move less or even to not move all; they got no reaction when they pushed on their stomach. However, the women were reassured and calmed by others or were even made more comfortable by telling themselves that this was normal at the end of pregnancy, that the fetus moves less. There was often a delay before they sought care. When they then did seek care it was done in order to get assurance that all was well; for many it was impossible to take in and understand that a baby can die in the womb.

20. Malm M-C, Lindgren H, Rådestad I. Losing contact with one's unborn baby – mothers' experiences prior to receiving news that their baby has died in utero. *Omega* 2010-2011;62:353-367.

In a study using a web-based questionnaire we gathered information from 614 women who had lost their baby before birth. Of this total, 392 (64%) had a feeling of premonition that something could be wrong, often because the baby was moving less. Seventy percent of them contacted maternal care but it was too late, the baby had already died. Twenty-two percent did not contact maternal care even though they felt worried; they held off until the next scheduled mother-health care-control in the belief that the decrease in fetal movement was normal, this even though they were worried. Eight percent of the women telephoned the hospital but were advised to wait since the contact person apparently felt that the reduced fetal movement was normal even though the mother had not been examined. We summarized the study results by observing that fetal movement is an important indicator of the baby's well being.

21. Erlandsson K, Lindgren H, Davidsson-Bremborg A, Rådestad I. Women's premonitions prior to the death of their baby in utero and how they deal with the feeling that their baby may be unwell. *Acta Obstetricia et Gynecologica Scandinavica* 2012;91:28-33.

In many studies I have subsequently tried to obtain more information on how a fetus normally moves toward the end of pregnancy and how women who have lost their baby experienced fetal movement before they were told that the baby had died in the womb. My hope is that improved knowledge can save the lives of more babies. This insight is a strong motivation for

me to continue carrying out research. Anders Linde, MD, a doctoral student in my research group, is presently focusing on decreased fetal movement; the first article that will be part of Linde's dissertation shows that some of the women whose baby has died in the womb have misinterpreted uterus contractions as being movements of the fetus. Because of this it is important to talk with the pregnant women during their pregnancy about fetal movement, what it feels like and how contractions differ from fetal movement.

22. Linde A, Pettersson K, Rådestad I. Women´s experiences of fetal movements before the confirmation of fetal death – contractions misintepreteted as fetal movements. *Birth* 2014;41:100-107.

A new pregnancy

Using data collected by Karin Säflund, who has a background as social worker, we were able to determine what advice women who had lost a baby had been given about when to begin pregnant again. Thirty-one women were followed for one year after they had given birth to a dead baby; 11 were advised to rely on their own feelings about when they were ready for a new pregnancy and six women were advised that they should wait until they had completed grieving before they should consider becoming pregnant again. The women themselves thought that the best advice they could be given would be for themselves to decide when they were ready for a new pregnancy.

23. Rådestad I, Hutti M, Säflund K, Onelöv E, Wredling R. Advice given by health-care professionals to mothers concerning subsequent pregnancy after stillbirth. *Acta Obstetricia et Gynecologica Scandinavica* 2010;89:1084-1086.

Siblings of a stillborn baby

In a series of studies of the siblings of stillborn babies we have sought to find out what takes place when there are other children in a family that has lost a baby. Four of the studies are part of RN, Pernilla Avelin's dissertation: *Stillbirth - A loss for the whole family*. These studies give insights into how one can improve the support given to the siblings of a stillborn baby.

Sixteen parents, 12 mothers and four fathers who had lost a baby before birth and at the time had older children, siblings to the stillborn baby, completed a questionnaire one year after the baby's death. The parents described how they, right in the middle of their own grieving, also had to keep a close watch on the reactions of the siblings. The siblings were made a part of memorial observances and could in their own way say goodbye and grieve over a little sister or little brother. The study was based on data collected by Karin Säflund.

24. Erlandsson K, Ahlström P, Säflund K, Wredling R, Rådestad I. Siblings farewell to a stillborn sister or brother and parents´ support to their older children: a questionnaire study from the parents´ perspective. *Journal of Child Health Care* 2010;14:151-160.

By bringing together parents who had lost a baby into focus groups where five or six parents could tell how it had been for them, we were able to learn more about what it was like to be a parent of a dead baby when one is at the same time a parent of a living sibling to that stillborn baby. A total of 27 parents took part in the six focus groups that were set up. The overall theme was that parenthood during the entire time requires the parent to find a balance between grieving and everyday life. The parents struggled to maintain an ordinary life for the siblings while at the same time they were deep in sorrow. They were highly aware of the situation of each sibling, and sometimes they felt as if they had been left alone in their parenthood and expressed a need for support and guidance from others in this period of acute sorrow.

25. Avelin P, Erlandsson K, Hildingsson I, Rådestad I. Swedish parent´s experiences of parenthood and the need for support to siblings when a baby is stillborn. *Birth* 2011;38:150-158.

In a study based on a questionnaire made available at a website, parents who had lost a baby answered this question: *What advice would you like to give to parents who have lost a baby where there are older siblings to the stillborn baby?* Two main categories appeared in the answers; 903 answers concerned making the loss real for the siblings, and 223 answers said it was important during the entire period to adapt to the siblings' resources and situations. The parents emphasized the importance of grieving together as a family, and that it was alright to show sadness in front of the baby's siblings and that the siblings should be given honest and straightforward information. The parents also advised other parents to make clear that the older siblings had become big brothers and sisters even though their little brother or sister was dead. It was also important to create mementos and to have enough time for the parting from the dead baby. The parents said that it was important to adapt the parting and the information given on the basis of the siblings' degree of maturity. The parents expressed the importance of showing respect for the siblings' feelings, not obliging them to do anything specific, showing understanding of their needs, and preparing them for the meeting with the dead sibling.

26. Avelin P, Erlandsson K, Hildingsson I, Davidsson Bremborg A, Rådestad I. Make the stillborn baby and the loss real for the siblings: parents´ advice on how the siblings of a stillborn baby can be supported. *Journal of Perinatal Education* 2012;21:90-98.

In another study of the sibling's situation after a stillbirth, Pernilla Avelin interviewed 15 siblings who had lost a little brother or sister to stillbirth, siblings who were between 13 and 17 years old at the time of the interviews. They described their situations as having to *be in the middle* but to also being just *at the side*, looking on. They grieved for their small siblings but also grieved for the relation they had with their parents before their sibling's death. A very special situation arose if the parents were separated and the sibling only lived part of the time with the parent who had lost the child. As half sibling, they could feel left out.

27. Avelin P, Gyllenswärd G, Erlandsson K, Rådestad I. Adolescents´ experiences of having a stillborn half-sibling. *Death Studies* 2014;38;557-562.

In one study we wanted to determine if and in what way experiencing sorrow on having a stillborn baby affected the relationship between the parents. Fifty.five parents, 33 mothers and 22 fathers took part and answered questions about their relationship two years after the loss. Both mothers and fathers said that they had come closer to one another after the loss, and that their relationship had been strengthened. The couples said that they had grieved together and also grieved alone. Even if mothers and fathers reported similarities in the way they grieved, the intensity and the mode of expression varied and were unique from one person to the other. The data were originally collected by Karin Säflund.

28. Avelin P, Rådestad I, Säflund K, Wredling R, Erlandsson K. Parental grief and relationship after the loss of a stillborn baby. *Midwifery* 2013;29:668-73.

Sorrow and memories

Feeling sorrow after a little baby has died is lifelong; the ways of experiencing this sorrow are personal and unique for each individual, but there are also similarities. Minister Anna Davidsson-Bremborg and I studied how the dead child is viewed in the years after the death. In a web-based study, we asked parents how they usually observed the anniversary of the death. A variety of rituals were reported. Many went to the child's grave and did something good at the grave; others lighted a candle at home. Some released a balloon or soap bubbles up into the air. Others said they always prepared heart-shaped waffles on the anniversary. The complete article is available at this website.

29. Davidsson-Bremborg A, Rådestad I. Memory Triggers and Anniversaries of Stillborn Children. *Nordic Journal of Religion and Society* 2013;26:157-174.

Care giving during and after the birth

The routines followed outlining how support is to be given to the parents have changed greatly during the past 30 to 40 years. Earlier, care givers tried to ”protect” the parents by keeping them from seeing their baby; at present the policy is to give the parents time to meet their longed-for baby, now dead. Using a web-based questionnaire, we collected data from 799 women whose baby was stillborn. The women had lost a child over a very long time span. The women who had given birth since 1990 were to a high degree much more grateful and better satisfied with the support they had received compared with women who had given birth before 1990. The women who had given birth after 1990 were grateful for the support they had been given during their motherhood and for the encouragement offered by care givers to see and hold their baby.

30. Rådestad I, Ekholm A, Westerberg A, Davidsson-Bremborg A, Erlandsson K.
Mothers Gratefulness for care after stillbirth before and after 1990. *British Journal of Midwifery* 2011;19:646-652.

As the basis for a Master’s thesis, two experienced midwives, Eva Nordlund and Astrid Börjesson, examined how women who had lost a baby answered the question: Are you saddened or angry about something that happened in connection with giving birth to your baby? The women reported they had felt sad if caregivers had not confirmed or supported the woman’s motherhood. The women were also sad, hurt, and angry if they had not been given support and been given confirmation in their sorrow or if the care giver was experienced as cold and insensitive and did not show respect for the baby.

31. Nordlund E, Börjesson A, Cacciatore J, Pappas C, Randers I, Rådestad I. When a baby dies: Motherhood, psychosocial care, and negative affect. *British Journal of Midwifery* 2012;20:780-784.

In a web-based questionnaire fathers were asked about their experience of losing their baby before birth. One-hundred thirteen (86%) of the 131 fathers who answered the questionnaire reported feelings of gratitude for something the midwife or other had done in connection with the birth of their child, 14% could not recall something they felt thankful for. Twenty two (16%) of the fathers reported feelings of having been hurt, sad, or angry about something a staff member had done, and 84 percent could not remember anything that had been done to make them sad, hurt, or angry. What the fathers appreciated care givers having done was that they showed respect for the baby without showing any fear and that they confirmed the fathers’ parenthood, giving them mementos of the child. Feelings of being sad, hurt, or angry were experienced when the care giver did not show respect for the child.

32. Cacciatore J, Erlandsson K, Rådestad I. Fatherhood and suffering: a qualitative exploration of Swedish men´s experiences of care after the death of a baby. *International Journal of Nurs Studies* 2013;50;664-670.

In one study we wanted to learn more about the experience women have on leaving the hospital and returning home without the baby they have given birth to. Twenty-three mothers who had a stillborn baby answered a questionnaire in which they reported that it was an unnatural experience to leave the hospital without the child, to leave empty handed. They stated that it was important to be able to come back and see the baby again. It was also important to feel trust for the staff and to know that someone took care of the baby when they left the hospital; it was difficult to leave the baby alone in a room and go away from the baby. It helped if they could hand the baby over into the arms of a care giver. The results are based on an interview study carried out by Mari-Cristin Malm.

33. Lindgren H, Malm M-C, Rådestad I. You don´t leave your baby – mother´s experiences after a stillbirth. *Omega* 2013-2014;68:337-346.

In a study two years after the infant's death 33 mothers and 22 fathers reported that they got most of their support from a midwife, physician, social worker, or minister. They also said that getting support from family and friends two years after the stillbirth was very important. Their need for support from staff varied depending on well family and friends were able to give support. Some of them said some family members had difficulty in understanding the breadth of the adverse effects of losing a baby.

34. Erlandsson K, Säflund K, Wredling R, Rådestad I. Support after stillbirth and its effect on parental grief over time. *Journal of social work in end-of-life and palliative care* 2011;7:139-152.

Attitudes toward autopsy

Using a questionnaire posted at a website, we investigated mothers' attitudes toward autopsy of their dead baby and how they viewed the information they were given about the autopsy. Fifty four of 72 mothers answered the questions, 51 (94%) of them getting information from a physician about the possibility of autopsy; three women were given no information about an autopsy. Autopsies were carried out in 83% of the cases, and 36 mothers said they had received adequate information about autopsy and 25 of them were satisfied with the result given to them. Eleven women were positive about having direct contact with the pathologist who had carried out the autopsy. Fifty-one women said that they had made the right decision concerning granting permission for an autopsy. Our conclusions were that mothers do not regret making the decision to allow autopsy but not all get the right information at the right time.

35. Holste C, Pilo C, Pettersson K, Rådestad I, Papadogiannakis N. Mothers' attitudes towards perinatal autopsy after stillbirth. *Acta Obstetricia et Gynecologica Scandinavica* 2011;90;1287-1290.

Post-traumatic stress, health care during subsequent pregnancy, and well being

Together with a research group in Norway I have taken part in the analysis of three studies, the first an investigation of post-traumatic stress among women who had experienced stillbirth. One hundred of the 379 questioned completed a questionnaire five to 18 years after they had lost their child. One third of the women who took part reported symptoms that indicated post traumatic stress (PTSS). Risk factors for PTSS were that the woman was young when she gave birth to the dead baby and that she had had an abortion prior to giving birth to the dead infant. Holding the stillborn baby was a protective factor against PTSS, which is to say that women who had held their baby had a lower incidence of PTSS.

36. Gravensteen IK, Helgadóttir LB, Jacobsen EM, Rådestad I, Sandset PM, Ekeberg O. Women's experiences in relation to stillbirth and predictors for long-term post-traumatic stress symptoms: a retrospective study.*BMJ Open* 2013;3:e003323.

In another study the number of visits and the mode of delivery were studied in 174 women who had become pregnant again after previously experiencing stillbirth and they were compared with 362 women who had become pregnant again after previously giving birth to a living infant. An additional control group consisted of 365 women who were pregnant for the first time. The women who had a previous stillbirth had more visits to maternal care for checkups than did those in both control groups. Induction of delivery and even c-sections were more common among women who had previously experienced a stillbirth than among women in both control groups.

37. Gravensteen IK, Jacobsen E-M, Sandset PM, Bjørk Helgadottir L, RådestadI, SandvikL, Ekeberg Ø. Health care utilization, induced labor and caesarean section in the pregnancy after stillbirth – a prospective study. (Accepted for publication)

In the Norwegian co-operative project we wanted to study how being pregnant after a stillbirth affects a woman's well being. Data were obtained from a large-scale Norwegian population-based data collection that focused on giving birth in general. Results were based on replies from 899 women, 173 of whom were pregnant after a previous stillbirth and 360 of whom were pregnant after a previous live birth. The women who were pregnant after a previous stillbirth displayed symptoms of depression and anxiety more often than women in the comparison group. The symptoms decreased six months after a live birth. There was no difference depending on whether the women became pregnant within 12 months of a stillbirth or after 12 or more months.

38. Gravensteen IK, Jacobsen E-M, Sandset PM, Bjørk Helgadottir L, RådestadI, SandvikL, Ekeberg Ø. Anxiety, depression and relationship dissatisfaction in the pregnancy following stillbirth and after the birth of a live born baby: A prospective study. (Accepted for publication).

Afterword

The results in this review were published between 1996 and 2017, a time span of 21 years. As researcher and midwife, my driving force has been to understand the effects of various forms of maternal care and to develop new knowledge that may help those who lose a child. During the entire time it has been important for me to work with care-giver professionals and equally important to cooperate with parents who have lost a child. When motherhood and fatherhood are properly confirmed the dead baby is placed in contact with its parents. The infant who will live in the memory of its parents for the rest of their lives is also given a more worthwhile kind of care. When parents are allowed to be parents to their dead baby we help to prevent future complications in the long run. My message to my midwife colleagues as expressed in an article I wrote in a journal for midwives in 1986 was *It is a child who has been born, even if the child is dead*. When my daughter was born dead after 35 weeks of pregnancy in 1981 I did not get the chance to meet her in an appropriate manner, and I still experience sorrow over that, not only for my sake, but for hers. My hope is that the good care now given in Sweden when babies are not born live will continue and be continuously refined.

Ingela Rådestad