Contact with stillborn babies – a talk given in 2013

I´m a nurse midwife, and during the last 20 years I've been doing research, mainly focused on how to improve care after a stillbirth.
I live in Stockholm, the capital of Sweden; A town surrounded by water, with about one million inhabitants and I hold a position as professor at Sophiahemmet University.

My first scientific contact with the topic for today's talk was when I was a doctoral student and worked with the data collection for my thesis. I did a follow up study in 1994, where I asked all the women who had given birth to a stillborn baby in Sweden in 1991, to fill out
a questionnaire. The questionnaire ended with this sentence:

"If you wish, please write down what you consider most important for staff who meet parents of stillborn babies to think about." Almost all the women had some suggestion. Their responses were sorted into different categories.

The largest category by far, consisted of appeals to the staff:
Help the parents to see and to hold the baby!

In this study, fourteen women, only four per cent of over three hundred women, had **NOT** seen their baby. Half of the women who didn't see their child – regretted it. They wished the staff had tried to persuade them to look at the baby. **Not ONE** of the women who **DID** see their child regretted it. There were only four women, One per cent of all women in this study, who was content with their decision not to see their baby.

The women who had **not** seen their baby had symptoms of depression more frequently than women who **had** seen their child. Of those who did **not** see, 62 per cent had symptoms of depression over the average, as compared with those who **did** see, where 37 per cent had symptoms over the average, on the depression scale we used in this study. The differences between mothers that had held their babies and those who had **not**, were not as pronounced as for the ones **seeing** the baby.

In this study we also asked the women: Did you spend as much time as you wished with your baby after birth? The women that had **not** done this showed more signs of depression. The relative risk of being at the top of the depression scale, scoring over the 90 per cent percentile, was four point one for those who had **not** spent as much time with their child as they would have liked.

That is, they were four times more likely to have many symptoms of depression if they had **not** been with their child as long as they wanted.This difference was statistically significant.

We also investigated **predictors** of having held the baby. We found that mothers were more likely to **hold** their baby if they perceived that the staff encouraged them by showing tenderness and respect for the baby, or incorporating the encounter as part of their routine.

I defended my thesis in 1998 and the results favor the care in Sweden, where the approach since the end of the 1980´s has been to receive a stillborn child in the same way as a liveborn. That could also be seen in my thesis.

When we compared **how mothers in the control group** in this study, mothers to **healthy liveborn babies**, experienced the staff's **attitude** to their child, we found that the figures for staff showing the baby tenderness and respect were almost the same as for how mothers to stillborn babies experienced staffs attitude to their child.

So, if I summarize the contact the mothers to stillborn babies had in this nationwide population based study, ninety-six percent of the women had seen their baby. Eighty percent had touched. About seventy percent had held and almost half of the women had kissed their baby's cheek.

Most of the mothers also stated that the staff had adequate ROUTINES for taking care of the parents of stillborns. But, at the same time, they wished the staff had made more suggestions to things they could do to have **more contact** with their baby.

Four years after my dissertation, The Lancet, a scientific journal with high impact factor, published the paper "Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth". The article drew a lot of attention. In Sweden, one physician referred to the article in the journal of the Swedish Medical Association. He stated: "It is better for women **NOT TO** SEE, their baby." And he expressed doubts about the practice of encouraging parents to see and hold their baby.

Health care professionals started wondering if they had been misguided for the past twenty years. Intuitively, they felt they had been doing the right thing, but the physician´s interpretation of the article in The Lancet set off a debate.

The authors of the article in the Lancet said: "Our findings do not support good-practice guidelines, which state that **failure to SEE and hold** the dead child, have adverse effects on parents' mourning."

The authors drew conclusions about the effect of both SEEING and HOLDING the child. This article has had a major impact on guidelines for the care after a stillbirth. I would like to take some minutes of this talk and go back and see how **evidence based** their conclusion is.

Data from the one year follow up presented in the article; you can see that two of the women who had not seen their baby show symptoms of depression. Of the women who saw their baby **but did not hold**, only one shows signs of depression, which corresponds to eight percent. That means depressive symptoms were **LESS** common among women who **HAD** SEEN their baby. Seven per cent **FEWER**, with signs of depression among the women who **HAD** SEEN their baby. For symptoms of anxiety the number is two: two women who had **not** seen their baby, eighteen per cent have symptoms of anxiety, but **NONE** of the women who **HAD** SEEN showed symptoms of anxiety. That means anxiety symptoms are more common among the women who **HAVE NOT** seen their baby.

So I do **NOT** find that they have evidence for their conclusion on seeing. In fact, their data reveal adverse effects of NOT seeing the baby. Now let's see if their conclusions hold true for the women who had **HELD** their child.

The data do not show any statistically significant differences between holding the baby and seeing it. But I make note of the fact that the risk difference for anxiety at the one year follow up were 26 per cent, and it **may** reflect a true difference.

After this critical examination of the article in The Lancet I could conclude that for **seeing** the baby and the outcome anxiety and depression symptoms, the results were in line with those in my thesis. That means, **that it is better to see the baby than not**.

But, **what if** Hughe´s data about holding reflect a **true difference?**
I have searched for explanations for this and did some re-analyses of the data in my thesis. Before I present my results I want to show you the difference between my study and the study presented in The Lancet.

They studied sixty women who lost their baby as compared with sixty women who gave birth to a living child. They recruited patients from three district

general hospitals. My study was based on a nationwide survey and includes in total 636 women. They measured the effect of stillbirth anywhere from about one year, to over fifteen years after the baby's birth.

One important difference between their study and my own is that their study measures the effects of losing a baby very early in pregnancy, after eighteen weeks. At that point, the child weighs about four hundred kilograms and is around 20 centimeters long. You can hold it in one hand.

To **understand** if gestational week could explain the difference between Hughes and my results concerning holding the baby I included all outcomes in my thesis and compared the outcomes for mothers holding a full-term stillborn baby with mothers holding a baby born in gestational week 28 to 37.

Among mothers who did not hold their baby, a relative risk above 1.0 was obtained for 23 of 28 measured outcomes indicating harm; that could be symptoms of anxiety, depression, low satisfaction with quality of life and well-being. However, most of these associations were not statistically significant. But in this cohort holding a stillborn baby implied on average a **beneficial effect**.

However, the increased risk of long- term outcomes associated with **not** holding was less pronounced for women who gave birth at gestational week 28–37 compared with women who gave birth at term.

My study only included stillbirths after 28 gestational weeks, thus in 1991, only stillborn babies after 28 gestational weeks was registered in the national birth registry, that is now changed to 22 weeks.

The results from my study indicate that **one explanation** for Hughes results is that it mirrors the fact that more than 60 per cent of the participating mothers in their study lost their baby in gestational 18-27.

What if Hughes and co-workers data about holding reflect a true? How can we then understand it? **These** are my thoughts about this:

A mother at term has had longer time for bonding with her unborn child and has had time to prepare to meet her baby after birth.
If your baby is born dead in gestational week 18 your pregnancy has been interrupted less than halfway to term.

Some women may need support to understand that they have become mothers

before they can take the baby in their arms. That is sometimes also true for mothers to prematurely live born babies.
If you are forced by a rigorous protocol to do something you are not prepared for, it can be another trauma. We do not know from Hughes data how the baby was presented to the mothers, and we do not know if the baby died during the delivery or if the mother had some time to prepare herself for meeting with her child. These are facts that can explain data. **Not knowing** these, I would be very careful in drawing any conclusions from their study.

The study was published in The Lancet, and I dont know if it was merely the fact that it was published in this high impact journal, or if it was their controversial results who called for all the attention. I can conclude that this study has had a **very negative effect** on the care after stillbirth and many mothers and fathers have probably have had **less contact** with their baby after birth, just because of how the study was interpreted.

It is a problem when a study is interpreted incorrectly and when you dont consider the methodological limitation of a study. Also, lack of clinical experience in the research group makes you **less skilled** to see possibly confounding factors that might explain your results.
The National Institute for Health and Care Excellence in the UK interpreted the conclusion from the study in their own way and in 2007 the institute stated "Do not routinely encourage mothers of infants who are stillborn or dead soon after birth to see and hold the dead infant.

NICE guidelines are aimed to support healthcare professionals to make sure that the care they provide is of best possible quality."
This statement was of course a shock for parents who had lost a baby, and I know that SANDS have worked **very hard** to change this statement and a clarification came in 2010:

Their first statement was: "Not intended to suggest that women should not be given the choice of seeing and holding their baby but rather that they should not be routinely encouraged to make the choice if they do not wish to."

Later in this talk I will come back to the concept of "given the choice of seeing and holding" but let me first present some more data from studies of seeing and holding:

We collected data via a questionnaire posted on the homepage of the Swedish National Infant Foundation. Over a thousand mothers answered the

questionnaire. Among 100 questions we asked:
"Are you grateful for anything that health care professionals did in connection with the birth of your child?" We used a method called content analysis and sorted all statements from the mothers into categories and codes.

The category "Health care professionals supported contact with the baby" comprised 198 codes. The mothers were thankful that health care professionals gave them the time to be with the baby and they expressed gratitude that the health care professionals encouraged them to see and hold their baby.

You can read some of their statements here.

"They let us have our little girl with us for as long as we liked after the delivery, and they encouraged us to do so."

"They let me hold my child straight away, and I had her with me all the time I was on the delivery ward".

"They insisted that it was good for me to see the child".

"They encouraged us to hold him"

The category "Health care professionals supported motherhood" consisted of 191 codes. In this category the women described their thankfulness for health care professionals treating their baby as if it was alive. Health care professionals also supported motherhood by seeing the mother and father as the parents of their child. This was demonstrated by making positive comments about their baby to the parents. Here you can read some of the statements.

"The midwives had wrapped up our son so beautifully, and carried him as if he was a living child."

"They got me to connect with my child, treated her as a person, arranged her so beautifully, and even put a nappy on her".

"They told us that she was beautiful, and congratulated us that, in spite of everything, we had become parents to this wonderful little girl".

I can also present data concerning mothers feelings in relation to how their baby was presented to them after birth. In this study we wanted to determine if the

way caregivers offer opportunities to see and hold a stillborn baby impacts a mother´s feeling about her experience.

The data I now will present come from the same data collection I mentioned earlier. The participants were self-recruited after being informed about the study through newspapers and social media. In all, 1034 mothers answered the questionnaire, and of those 840 had a stillbirth after the 22nd gestational week and answered the question: How was the baby presented to you?

668 (80%) of the mothers in this study saw their baby, 54 per cent of them was **asked** by the staff if they wanted to see their baby after birth. 32 per cent of the mothers stated that the staff just offered the baby **without asking** them. 12 per cent of the mothers asked the staff if they could see their baby. Only 3, 0.4 per cent of all participating mothers stated that they felt pressured by staff to see their baby.

The results point in one direction – It is better to give the baby directly to the mother. That means that the baby is simply and naturally presented to the mother without asking her to choose. If the staff showed the baby without asking, more often the mothers stated that it felt natural to see the baby. Also, feeling good when seeing the baby was in favor of mothers who were **not** asked.

Statistically significant figures in favor for not asking was found for mothers who stated that seeing the baby felt **NOT AT ALL** frightening and not at all uncomfortable.

547 (65%) of the mothers in this study held their baby. For 51 per cent of them, the staff **asked if** the mother wanted to hold her baby after birth.

26 per cent of the mothers stated that the staff just offered the baby **without asking** them. 15 per cent of the mothers asked if they could hold their baby, and 11 per cent of the mothers took their baby in their arms on their own initiative.

Only 2, 0.4 per cent of all participating mothers stated that they felt pressured by staff to hold their baby.

We saw a trend towards mothers feeling naturally good, less frightened and less uncomfortable when staff offered the baby without asking.

Fewer of those who gave birth before 1990, saw and held their babies as compared to mothers who gave birth after 1990. It was two times more common

to see and almost four times more common to hold the baby if the mother gave birth after 1990.

I fully agree that being able to make choices is a **fundamental** principle of health care. If you look at this the other way around, **why** should only mothers to stillborn babies have the opportunity to **make choices** whether or not they want to see their newborn baby? If it is a **fundamental** principle, why should you not give this opportunity to mothers to live born babies?

So let me explain why I do not think that the care we provide is of the best possible quality if we ask mothers to stillborn babies if they want to see and hold their child.

Stillbirth is an **exceedingly traumatic** event, and of course any mother is unprepared to manage a stillbirth: she will often defer to the advice of providers, simply doing whatever the providers advise her to do.

Asking mothers this crucial and **irreversible** question may imply that some mothers would not want to see or hold the baby. A spontaneous reaction under the emotional traumatic state just after the birth may be to reply with a refusal.

Additionally, often a spontaneous refusal to see the baby usually changes later when the mother has had the opportunity to think more clearly and is offered subsequent opportunities for meeting her baby.

During the interval between the refusal and a change of mind, a dead body undergoes changes. For the first 30 minutes, a stillborn baby feels soft and warm, much like a live baby, and parents have later noted that contact during this initial period is invaluable.

Our findings indicate that the mother's natural instincts to have contact with her baby can be supported if providers respond to a stillborn baby with the same care as a live born baby.

Mothers of babies born alive **are not** routinely asked if they want to see their baby, asking parents to stillborn babies can be seen as an **intervention** that questions their parenthood.

Health care professionals should support motherhood by treating the stillborn baby as a new-born child, and the woman who has just given birth as the child's

mother.

A mother and a father need guidance during meeting and saying farewell to their baby. The challenge for developing clinical skill in this field, as well as for obtaining scientific knowledge, is to define the boundary between beneficial guidance and harmful persuasion.

If the mother and the father in a sensitive way are guided by staff to hold their baby the holding will possibly be beneficial for them in the long term. We have much to learn about this encounter and how healthcare professionals can support parents in their meeting and parting.

What can we do to better prepare mothers and fathers for their meeting with a stillborn baby, a still-warm but silent child?

Let me use the last few minutes of this talk to focus on the child, the stillborn baby. This is a quote from Elin, a mother to a little girl who died in late pregnancy:

> " Many people think that the worst thing that can happen is to give birth to a dead child, but it was not so bad. The worst thing was to leave her there in the hospital."

I have heard many mothers and fathers saying "The worst thing was to leave the baby in the hospital". Just like parents to live born babies, parents to stillborn babies wish the best for their child.

If the parents stay at the hospital a couples of days after birth, it is **not unusual** in Sweden that the baby is taken from the parents at night. The baby is transferred to the pathology department and placed in a cold room or, the baby is placed in a refridgerator at the delivery ward. The newborn baby has to share the space with placentas, blood and urin samples.

From the web questionnaire I talked about earlier, we also have data on how common it is to take the baby home. About 2.5 % of the stillborn babies in Sweden are brought home, but more babies would have been brought home if the parents had known that this was a possibility.

On the basis of research and the fact that dead babies are placed in a refridgerator at the hospital, I have developed a tool that can improve the dignity for the child and the childs family. We chosed a simple cooling technique.

Cooling blocks ensure that the temperature is kept low, they are a total of 12 and easy to change when necessary.

It can maintain the baby at below room temperature and it is not necessary for the parents to be separated from their child. It can also be used if the parents want to take their baby home before the funderal. And be used as a coffin.

Thanks to a generous donation I have had the opportunity to produce 50 of this and can now, as a non-profit project, donate one to all birth clinics in Sweden. The staff do not longer place dead babies in the refrigerator, something they never found dignified in the first place. The longest time a family have had their baby at home in a *Cubitus baby* is 11 days.

My motivation for my work in this field is all the mothers and fathers I have met in the support groups that I have led through Swedish National Infant Foundation and also all the parents I have met through different research projects.

I am a mother and a grandmother. I can describe myself as a very happy person with three lovely children and a family where we all like to get together. But, at those gatherings there is one child missing, a child that I never got the chance to see grow up. My firstborn daughter died in late pregnancy.

The care for parents to stillborns in 1981 was radically different from the care today. **Let's not go back to that time!**

Conferences like this are important. If we can learn more about what causes stillbirth, and maybe reduce the number of children who die, then we can reduce a lot of pain. If the tragedy is there, then we also know that there is a lot we can do to help the parents meet and mourn for the child, a child they will never forget.

Thank you!