

Fetal movements & Mindfetalness talk in Adelaide 3 November 2017

Presentation

I am 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. I hold a position as professor at Sophiahemmet University; you can see my workplace down to the right in this picture.

Thesis

Let me first give you some background to my research concerning fetal movements. As a PhD student 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. 314 women are included in this study and the main focus was to investigate if the care given were associated with long term psychological complications. We found a strong association between the care the woman received and later psychological health.

In the questionnaire we also asked if the women had had any feeling that the baby could have been dead before the diagnose was made. Almost one fourth of the women stated they had a very strong feeling that the baby could be dead.

12 mothers till stillborn babies

Some years later, I once again came in contact with the concept of premonition. This time in a small qualitative study including 12 women with stillbirths. They reported having a feeling that something was not right before they were told that their baby had died in utero. But their feelings were difficult to convey to other including to health care professionals. I can say, that the two next studies I will present for you, changes my research focus from raising questions about best practice when a baby is stillborn, to questions about how can we prevent stillbirth.

Staircase of insight

In an interview study with 26 mothers we got a deeper understanding about how mothers to stillborn babies handled their feelings that something might be wrong and we describe this with a theoretical model that we named *The staircase of insight*. The women experienced losing contact with their unborn baby when the fetus began to move less or even to not move all. However, they were calmed by others or 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 the baby was well; for many it was impossible to take in and understand that a baby can die before birth.

Web survey

In the other study that made me focus on preventing stillbirth, we used a web-based questionnaire and gathered information from 614 women who had lost their baby before birth. Of this 64% had a feeling that something could be wrong, often because the baby was moving less. Seventy percent of them contacted the birth clinic, but it was too late, the baby had already died. Twenty-two percent did not contact health-care even though they felt worried; they held off until the next scheduled to the antenatal clinic 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.

Quotes

Here you can read quotes from two women in the study.

Different studies not only the studies I have done, have shown that many women who have lost their baby before birth have had a feeling that something might be wrong before they learned that it was so. Becoming aware of this led me to the thought that pregnant women perhaps had been given incorrect information concerning how the fetus normally moves. Thus, several studies indicate 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. I decided to investigate what midwives in Sweden based their information on when they informed women about fetal movements.

Text book for midwives

At that time the in most recent edition of the Swedish text Book for Midwives, you could read: "Many women react to a pattern of fetal movement at the end of pregnancy. Normally fetal movement decreases from week 32 onward due to the decrease in space available in the uterus. Women should be informed about this."

Literature review

I started to search for evidence concerning the normal pattern of fetal movements. My conclusion after attempting to understand the scientific literature in this area was that there is no evidence for saying that the frequency of fetal movements decreases in the third trimester. Further, giving misleading information about decreased frequencies of fetal movements poses a threat to the unborn baby's life.

The Royal Colleague

I was so happy when I could read The Royal College of Obstetricians and Gynecologists guideline about fetal movements, published in February 2011, The message in the guidelines were totally in line with my literature review, there is no evidence that the fetal movements decrease in the third trimester.

Daily news paper

Inspired by the guideline, I wrote a debate article in the largest National Daily paper in Sweden.

My message was: There is a potential for the proportion of intrauterine deaths to be reduced by employing evidence-based information concerning normal variation in fetal movement

Commercial info

Actually, not much did happen after the debate article, or even after I wrote two articles for health care professionals one for the national Midwifery journal and one for the professional journal for physicians. The Textbook for midwives were still the only one for all midwifery students in Sweden and commercial actors frequently gave non-evident messages to pregnant women. Both in brochures but also by apps directly to the women's smartphones. The myth that the fetal movements decrease in the third trimester seemed very difficult to get rid of.

Television

However, I became aware of the potential that television has, when a journalist picked up the message in my debate article. She did a couple of very emotional strong interviews with women who had lost their babies and they could witness about misleading information about fetal movements from health care professionals. The program was broadcasted October 7 in 2011.

Total change

The day after the program was broadcasted the publisher of the textbook stopped selling it, and a correction was communicated to all universities with a midwifery program. Further, the commercial companies published press releases where they apologized for their misleading information. I know also that midwives rapidly

changed their information to pregnant women, now they encourage women to seek care if they experience a decrease in their unborn baby's movement's pattern.

National Board

Also, The National Board of health and welfare has published guidelines about how to give information about fetal movements to support health care professionals in their work.

Today's questions

So, if we can give all pregnant women evidence based information about fetal movements pattern and when to seek care if they have concerns about the movements, what can we do more to strengthening women's ability to be aware of fetal movements? Further, should we support structured observation of fetal movements?

40 pregnant women at term

Before we talk about a method to observe fetal movements let me first present some data from a study we performed with 40 women in late pregnancy. We asked them: Can you describe how your baby has moved this week. All women were at term and they all gave birth to a healthy child, some of them just days after the interview others just one or two weeks after. Almost all described strong and powerful movements and all related to the strength of the movements more than the frequency. No one of the women said that the movement had become less at term. Here you can read some of their descriptions

Quote

Quote

Quote

Decreased fetal movements

We now that there is a connection between reduced fetal movements and stillbirth, Further, we know that sometimes women wait rather long before they seek health care when they have concerns due to the fetal movement pattern

However, we also know that experiences of reduced fetal movements is a common reason for consulting health care in late pregnancy. In the study I now will present we wanted to explore why women decide to consult health care due to reduced fetal movements at a specific point of time and investigate reasons for delay a consultation?

A questionnaire was distributed in all seven delivery wards in Stockholm during one year, 2014, to women seeking care due to decreased fetal movements. The questionnaire was only given to women who after a check-up could go home again. There were at the time no signs of a compromised fetus.

Prevalence

In total, 3058 questionnaires were collected and it correspond to around 10 % of all women giving birth in Stockholm in 2014.

Gestational week

Here you can see that half of the women were at term when they sought care.

How long they had felt DFM

Here you can see that almost half of the women waited 2 days or more before they decided to seek care.

Open ended question

Some of the questions in the questionnaire were

Open-ended and so was the question concerning *why the women decide to consult health care at a specific point of time*. We found that affected the time-point for consulting care were that the woman stated they had reached dead line for

waiting and couldn't handle the worry any longer. The most common answer why not consulting care earlier was that decreased fetal movement was a new experience for them and that they thought it was temporary. Some women stated that they not wanted to burden the health care system unnecessarily, they did not want to feel that they were annoying, or was perceived as stupid.

Want to communicate

Let me also present results from another open ended question in this questionnaire. The women's responses to the open ended question: "Is there something you want to communicate to health care professionals who take care of women with decreased fetal movement or to women who experience decreased fetal movements?"

The women's requests to health care professionals were:

Pay attention to the woman and take her seriously

Rapid and adequate care and Improve information on fetal movements.

Want to communicate

Regarding what the women want to communicate to other pregnant women, they wanted to encourage them to:

Contact health care for check-up, and

Pay attention to fetal movement.

The main message was the importance of consulting care once too often rather than one time too few.

Today's questions

So, what can we do more to strengthening women's ability to be aware of fetal movements? Further, should we support structured observation of fetal movements?

Mindfetalness

Pregnant women have varying degrees of awareness of fetal movements. A challenge for midwives is to strengthen awareness and use the information from the unborn baby's mother to increase the possibility for a healthy baby to be born. I will now present an ongoing study where we want to investigate if information about a method for structured observation of fetal movements called *Mindfetalness* can be a help for women to be aware of fetal movements and if the method has any effect on perinatal outcome.

Mindfetalness is just a concept describing what most women already do, but here we ask them to be aware in a more structured way. We encourage women in late pregnancy to devote 15 minutes daily from gestational week 28 until birth, in an effort to focus on how their baby is moving. The period during which the mother should practice Mindfetalness should be when their baby is wakeful. Further, we encourage her to lay down on her left side when she practicing Mindfetalness.

Aim

The main aim is to study if stillbirths can be reduced. Further we want to investigate if *Mindfetalness* increases or decreases the number of women who unnecessarily (from a medical perspective) seek health care due to decreased fetal movements.

Method

We have randomized about 40 000 women to receive information about *Mindfetalness* from her midwife or to routine care.

Map

In practice, we have randomized all 64 antenatal birth clinics in Stockholm, half of them gives the women a brochure about the method and information about a web site with information on how to practice Mindfetalness. The other antenatal clinics do not give information about the method. The study has been on-going since September 2016 and we will stop the implementation of Mindfetalness in January 2018. After that we will from register study if there is any differences concerning Apgar score among the babies born by mothers who received information about Mindfetalness and those who did not, as well as women's seeking behavioral for decrease fetal movements in each group.

Brochures

The information is given in several languages

Pilot study positive response

Before we started this large RCT we performed a pilot study. Pregnant women were informed about Mindfetalness by their midwife. We found that 90% gave positive response concerning the method Mindfetalness. Those who used the method daily said:

"I feel that I build a relation to my baby"

"I get to know my baby better"

"A good support and useful tool"

"I feel safe and are not so worried anymore"

The compliance to the method was high.

Negative response

However, 10% gave negative response to the method, usually they stated they had: Lack of time or no need for a method. One woman did not like structured way to observe fetal movements and one woman thought the method create more concerns for her.

Midwives

We also asked the midwives what they thought about giving the information about the method to the women: They were all very positive and said:

"The woman gets to know her unborn baby better"

"It is a good method for stressed women so they take time on daily basis to their unborn baby"

"I have become better to talk about fetal movements with the woman and in a more structured way now"

Data RCT

I am of course now very curious about the results of the RCT and hopefully we can present preliminary data in June 2018.

Thank you!