Ingela Rådestad - My story

When I gave birth to my first child, a little girl who was dead before she left my womb, I was young and knew little about grief. I had not previously experienced any major crises and sorely needed some guidance. However, no such guidance was offered. My husband and I tried to process what had happened as best we could and life continued, with few memories of our daughter. Two siblings were born. It was not until five years later that I could write down the story of my experience. The article was published in the journal of the Swedish Association of Midwives and contained an important message: Do not ignore and destroy the positive aspects of a stillborn child. It is a child that is born, even if the child is dead. Writing about it contributed to making my grief less of a heavy daily burden. The grief came to rest as quiet melancholy in my heart.

A midwife who had read the article introduced me to a group of mothers who had lost their children and whose deliveries she had facilitated. Deeply moved by the stories told by these mothers, of how they had met their children, I started reflecting on whether the care offered in connection with the death of a child may affect how you feel in the longer term. I did not know at the time that this was a possible issue for research and study.

I gave birth to my fourth child and led an intense life as a mother, at the same time as I was working as a midwife. My thoughts about the care provided in connection with a stillbirth were present all along. Fourteen years after the birth of my first child I had the opportunity to initiate a research project, together with an obstetrician, a psychiatrist and an epidemiologist - all experienced researchers - to try to find answers to my questions. We approached all women who had lost a child before birth in Sweden at the beginning of the 1990s and asked them to complete a questionnaire three years after the delivery. The results confirmed my hypothesis. The women who had been given the opportunity to develop their motherhood, who had spent time with their dead baby after the delivery, been given time to say farewell and who had memories of their child, had fewer symptoms of anxiety and depression than the women who had not met their baby. In 1998, I defended my dissertation.

Since my disputation I have been able, through participation in different projects, to contribute to the continued development of knowledge concerning care in association with stillbirths. Several of the research issues dealt with in my dissertation have been further studied. We can now safely claim that the previous regime, when parents were prevented from seeing and holding their

stillborn child, led to greater psychological pain. If, instead, parents are supported and encouraged to see, hold and take pictures of their child, this helps them grieve and carry on with their lives, despite the great loss.

Throughout my research work, I have focused on the care offered after a stillbirth. In the autumn of 2009 something happened that made my interest shift to include also the possible prevention of stillbirths. I became a grandmother under dramatic circumstances. My daughter was going to give birth to her first child and my husband and I travelled to see her and be close to her before the planned induction. The evening before the induction we had dinner together and the following day, our daughter and her husband went to the hospital, full of hope and expectations. They promised to send us text messages so that we could follow the progress of the delivery. The reports described a calm and peaceful situation, nothing much happened but they felt comfortable at the maternity clinic. Then, all of a sudden, my daughter went into intensive labour. The midwife who was going to decide on when to transfer my daughter to the delivery ward was late and in the meantime a student midwife arrived and started CTG recording. After 20 minutes of normal foetal heart sounds but with frequent contractions, the child's heart rate suddenly dropped. The student midwife understood the seriousness of the situation, alerted the ward and ran with the bed the 100 steps to the theatre. Gabriel was born within ten minutes, he was exhausted but cried and the attending surgeon told us with tears in his eyes that is was a close call - the baby could have died. The separation of the placenta led to significant blood loss and my daughter also had a major haemorrhage after the Caesarean section, necessitating another operation. Later on, a third operation had to be carried out. My daughter's coagulation system had by now collapsed and her kidneys had stopped working, turning her first hours and days of motherhood into a fight for her life with intensive care and dialysis. Sitting by her bedside one week after the surgery I was thrown 27 years back in time. My first child died as a result of pre-eclampsia - would I now lose my second child to the same complication; however, now as grandmother?

On this occasion, the seconds, the medical resources and the competence were in our favour, and I realised that we had been incredibly lucky when, three months later, we could celebrate Christmas with the wonderful baby Gabriel and my fully recovered daughter. Gratitude is perhaps the word that best describes my feeling; gratitude that my daughter gave birth in a country where women have access to advanced medical treatment and care.

More than three million children die in the world every year before they are even born, but stillbirths are largely invisible in global public health programmes.

To prevent stillbirths during the latter part of pregnancies, these children also have to be included in the statistics and goals formulated in all countries for how to reduce this form of infant mortality. In low and medium-income countries, where 98 per cent of all stillbirths happen, it is a matter of allocating more resources to improve treatment and care. Approximately one million children die in connection with the delivery, one reason being the lack of access to emergency Caesarean sections. Another reason is the lack of transportation, which makes it impossible for women with delivery complications to travel to a hospital for help. Infections, malnutrition and anaemia are other factors that contribute to the high mortality rate.

The risk factors are different in high-income countries and other measures to reduce mortality rates are thus needed. A clear relationship has been found in several studies between the pregnant woman's perception of decreased foetal movement and stillbirths during the latter part of the pregnancy. Through better information to pregnant women, encouraging them to seek medical attention if they experience reduced foetal movements, some of these deaths could most likely be avoided. Supporting smoking cessation during pregnancy and helping overweight women lose weight could probably also contribute to preventing foetal death during the latter part of the pregnancy. The percentage of children who die before birth has been more or less stable in many high-income countries over the past 30 years. In Sweden, four out of 1000 born children die during the latter part of the pregnancy. It must be possible to lower this number.

For many years I have been active in the Swedish SIDS Society, a support organisation for parents who have lost a child. I have lead counselling groups for mothers and fathers who have recently lost a baby. We meet during one term to talk about grief, the future and how they feel about another pregnancy. In each group, there are always a few stories told by couples that raise questions about whether the death of their child could have been prevented. It is painful to see their grief, knowing that if someone had reacted a bit sooner or had taken a more overall approach to their pregnancy and delivery, they may have been able to see the smile of a baby instead. These parents with an acute sense of loss and grief, as well as my own loss 36 years ago and the knowledge that I almost lost my child and grandchild are strong drivers for me to try to contribute to preventing the death of children.

Every child's death is a disaster. Not only for the parents but also for their siblings who are waiting to welcome a little sister or brother, for grandparents and other friends and relations. It is my vision that this form of infant mortality be taken seriously and global objectives formulated to reduce the number of children who die during the latter part of pregnancies.

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About Ingela Rådestad

Ingela Rådestad is a Swedish midwife and defended her dissertation "Giving birth to a dead child" at Karolinska Institute in 1998. She has also written some 80 scientific articles, three books, several book chapters and popular scientific articles. Ingela Rådestad is Professor of Caring Science at Sophiahemmet University.