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Voices of experience in periviable decision-making and artificial placenta technology

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Intermezzo A:

How we handled our son's birth at the limits of viability after an unexpected pregnancy

Dirk-Jan Berken and Hiske van Dam

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Parental perspective

In this paper, Dirk-Jan and Hiske, the parents of an infant born at 24 weeks of gestation, provide an insight into their experiences of the birth and making decisions at the limit of viability. They were faced with the risk of an extremely premature birth at 22 weeks of gestation. The delivery miraculously stalled, and the limit of viability moved closer. The couple received prenatal counselling about the treatment options after birth, which were initiating intensive care treatment or comfort care. Together with physicians, they made the decision to initiate intensive care treatment if the infant was born in the grey zone. Different values were considered important in their lives during the decision-making process.

Dirk-Jan: We suddenly discovered that Hiske was 18 weeks' pregnant, even though she had been told that she was infertile. Soon after, she went into premature labour and was admitted to hospital at 22 weeks of gestation. We were told Hiske would give birth that same day and that nothing could be done for the baby. Miraculously, the birth stalled, Hiske's contractions stopped, and the limit of viability came closer. Before we could begin to process what was happening, we were meeting the neonatologist and were presented with some ethical dilemmas. How could we decide between active treatment or comfort care?

Hiske: We started with a tough, but honest, conversation with the neonatologist about our baby's chances and risks after premature birth. We had to prepare for a difficult journey with an unknown outcome. This experience was completely new to us because we did not know what was going to happen. During this period, hope and fear alternated and there were many setbacks, as well as small silver linings. We relied on ourselves and each other and stayed hopeful, even though we felt very vulnerable. We struggled through this situation as a couple and envisioned what the future would bring us. You think about what the outcome will look like and deal with the confusion of so many different emotions. It would have been so easy to drift away from each other as we went through this experience, and we had to keep on finding each other again. We both had our own fears and sorrows and our own way of dealing with them.

Dirk-Jan: During counselling we received a link to a digital information decision aid '*Keuzehulp vroeggeboorte*', where we could find additional information. Given the intensity of the conversation, we wanted to make sure we understood everything correctly. We were silently in our own world of thoughts for a brief moment of time in our hospital room, processing the given information that had been shared with us in such a short time. During this whirlwind of intense emotions and thoughts, we had to go through statistics about complications, risks of permanent damage and chances of survival. There were so many questions. How would our little boy fight this and win? Could and did we want to deal with the most severe scenarios? What would our life be like? We expressed our thoughts, fears and wishes to each other and were mostly on the same page. This was the beginning of an extremely difficult process, which could take months and we knew that our son may not

survive. We had the second appointment the next day, when we had barely pulled ourselves together and recovered from the first conversation with the neonatologist. We explained our wishes to the team, who took the time to listen and to answer all our questions.

Hiske: This big decision could only be made together, and it was emotionally overwhelming. We knew that we could not make this decision alone without discussing it with each other and without mutual support. First, we had to decide what we each wanted and then move forward together. We needed each other during this tough process. It was immediately clear to us that we wanted to go all the way and wanted all the medical help available. Becoming pregnant had initially seemed impossible, so the fact that I was pregnant was a miracle on itself. Therefore, I felt I could not deny our son a fighting chance. We had hope, as we knew that life could consist of misery, but also miracles. We knew that if there were too many complications, and it all became too much for our son, we only had one option left. As much as this would devastate us, we would be open to withdrawing intensive care if the treatment was not proportional with the prognosis anymore. However, it was not up to us to decide this for him while I was still pregnant.

Dirk-Jan: The feeling that we had to give our son a chance prevailed. We were also realistic enough to say farewell to him if his complications meant he had a prognosis of an undignified existence. Hiske was admitted to the maternity ward, and, due to our previous experiences over the weeks, we had enough confidence that the doctors would give us good advice and helping us decide if severe complications arose. We agreed with the neonatologists that we would receive clear and honest advice to withdraw intensive care if everything had been done from a medical perspective or if our son developed complications that led to such severe disabilities that it would leave him with an undignified existence. We agreed we would follow their advice. After his birth, we had multiple conversations about the chances of our son's survival in the neonatal intensive care unit. At one point he was very sick, and a positive outcome seemed unlikely. We agreed to wait two days to see if there was a chance to recovery, but if there was not, we would make a decision with the team to withdraw his treatment and say our goodbyes. Feeling part of the team and being able to discuss things openly with them helped us to make these difficult decisions together.

Our son was born at 24 weeks and 3 days of gestation. He weighed 575 grams at birth. After 107 days in the neonatal intensive care unit, he was transferred to the post intensive care unit. He came home with oxygen and tube feeding 157 days after he was born. His first year of life was dominated by the medical world: lots of checks, slowly reducing his oxygen, switching him to normal food, planned and unplanned operations and more follow-up visits. But on the positive side, he made small steps forward in his development at his own pace and required less and less input from the medical world. Meanwhile, we celebrated his first homecoming day and now our son is developing more and more. We are very grateful to experience this with him.

To parents and healthcare professionals

The principle of shared decision-making at the neonatal intensive care unit and our strong belief in our own decisions and reasoning gave us a certain empowerment. This empowerment helped us feel in control as much as possible, in a situation where control seems so often far away. It gave us the feeling of having a bit of grip on the situation, which you can hold on to during this unbelievable journey where you must remain standing till the end. We do believe we made the decision for our son, within the medical constraints and possibilities told by the neonatologist who did not influence our decision personally.

Based on these experiences, our advice to healthcare providers would be to always be honest and keep repeating information to the parents. Make sure parents feel heard and give them space to think over a tough decision and respect that choice, even if you would have made a different one. In case, time is sensitive or in the line of events, explain everything that happens, will happen and will be done, not only before birth but also directly after.

To the parents, listen to your feelings and your heart and dare to face the truth, keep asking questions repeatedly till it is clear to you. Stand strong by the decision you made and never blame yourself for anything, nor regret the choices you made.

Reference:

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