

IT'S A BEAUTIFUL CHILD. WHY DID HE DIE?

After the stillbirth of their son, journalists Jop de Vrieze and Zvezdana Vukojevic are in search of answers within the Dutch system of natal care. Gynecologist: "Could we have saved him? Maybe, yes."

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"Couldn't you have called sooner?" Fifteen minutes earlier I stepped into our midwife practice, because I couldn't remember the last time I had felt my unborn son moving in my belly. At first, I almost got sent home, both consultation rooms were occupied. "Just lie down for an hour at home", I was told. "Call our emergency number if you don't feel him while resting." I insisted they would examine me, even if it had to be in their little kitchen. This happened, on a blanket on the floor. "Are you sure you're 34 weeks along? You lie down so easily." The midwife puts her hands on my belly and she grabs a hold of the baby: "It feels small!" Just a week before another midwife had told me the size of my baby was okay. With use of a doptone she had let me hear his heartbeat. Now the same device is going left and right, up and down over my baby bump, but all we hear is my own slow heartbeat. "Maybe my colleague can find something." Again the doptone goes over my belly, to no avail. "Couldn't you have called sooner?"

Was this my fault? "Call your husband."

Two days later, on the 27th of August 2015, our first son Mikki de Vrieze is born at the Amsterdam hospital Onze Lieve Vrouwe Gasthuis (OLVG). In silence. He's small, his rib cage is somewhat sunken, but everything appears fine – except his tiny heart isn't beating. "It's a beautiful child", nurse Margo says. Why, for the love of God, did he die?

Risk selection

Out of every 500 babies born in the Netherlands every day, counting from 22 weeks of pregnancy onward, four pass away. That's more than 1.400 babies every year. Sixty-five percent of these babies die in the mother's womb. A 2003 study based on numbers from the year 2000 showed that out of all of the EU countries examined the Netherlands had the highest infant mortality rate. After this study came out the subject has been on the political

agenda and the Dutch antenatal care system has been under close scrutiny. It's customary that the midwives (primary care) guide healthy pregnant women through their pregnancy and refer them to the medically trained OB/GYN (secondary care) if they deem medical care necessary. This 'risk selection' by midwives has been heavily criticized. Since then progress has been made. The number of stillbirths decreased from 7,7 out of every 1000 in 2000, to 5,3 out of 1000 in 2013. Collaborations entailing regular consultations between midwives and gynecologists have been set up. Yet, according to Jan-Jaap Erwich, professor of Perinatal Mortality prevention at the University of Groningen, a fifth of stillbirths are still avoidable.

It's a painful question to ask but we do want to know: was this the case for our Mikki?

Three weeks after his birth gynecologist Lukas Uittenbogaard at the OLVG produces graphics accompanied by the words "With his 1378 grams Mikki was more than a kilogram underweight for the gestational age. "He probably suffered from what we call intrauterine growth restriction– one the most important risk factors for stillbirths. The placenta was too small to keep providing him energy during his growth. He became malnourished. Initially it stunted Mikki's growth. After that his movements decreased and more bodily functions started to shut down. His heart was last to give out.

More than two weeks prior to that fatal day I, already quite worried, sought out my midwife. For several days now I've noticed a significant decrease in our son's movements. "Don't worry" the midwife said, "he's getting bigger, so he has less room. Moreover, your placenta is on the front and acts like a cushion. Also he's turned in such a matter that he isn't kicking you in the belly, but in your back." Using the doptone she let us hear his heartbeat.

HOW THIS ARTICLE CAME TO BE

Last year we, the authors of this article, lost our son even before he was born. Like every parent would, we started looking for answers on the internet. What was the cause? What could have been done? Writing an article wasn't yet considered at this point. But during our search we encountered all sorts of issues. A guideline heavily under discussion. A British professor involved with these matters repeatedly refusing to speak to us. A similarly reticent professional association of midwives. The story started to transcend that of our son. The question arose if we were the right ones to write about this? We engaged in lengthy

discussions amongst ourselves and with colleagues. Yes, we finally concluded. The perspective of affected parent is what's so often missing in news coverage on this subject. From this perspective we could write a story, thoroughly researched and balanced. We delved into scientific articles, guidelines, policy documents, parliamentary papers and internal documents and spoke over 30 sources. All of them we approached as journalists. The midwives and gynecologist Uittenbogaard, we spoke initially to as parents. They were informed at a later moment and their reactions were included. The midwives declined to be mentioned by name in the newspaper.

A week later I returned with the same symptoms. “How often do you feel the baby move?” I couldn’t provide an exact number. “Just keep a tally for three days.” If you’re still worried then, you should call”. Faithfully, for the following three days, I kept tally in a notebook with every movement I felt. “Weakly”, I wrote down, “but yeah, he’s getting bigger, probably kicking in my back”. A leaflet from the midwives practice provided similar reassuring arguments. Nothing in there about the risks of reduced fetal movement.

“She didn’t tell me this could happen”, I told the gynecologist. Quiet for a moment, he replied: “Do we want midwives to trace instances like Mikki’s? Yes. Could we have saved him if we knew what affected him? Maybe we could’ve.”

Stupefied we left the hospital. Slowly the rest of what he said started to seep through: “If you were referred for an ultrasound, it’s possible we would’ve noticed Mikki was too small. We could’ve monitored his growth and condition, possibly prepared his lungs with corticosteroids and have him delivered the moment being inside the womb would be less pleasant than outside it.”

Measuring tape

Detecting growth restriction is mostly done manually by midwives. In 2004 gynecologist Joke Bais showed that by using this method almost 80 percent of the alarmingly small babies go undetected – weight estimates deviate on average fifty percent. Furthermore, some babies are just bigger or smaller by nature. Not every small baby is growth restricted and not all babies that suffer from growth restriction are small. Growth restricted babies have a 5 to 10 times higher chance to be stillborn. And an astonishing 40 percent of stillborn children turn out to be growth restricted.

The professional association for midwives KNOV introduced a new guideline: ‘Detecting fetal growth restriction. Midwives had to follow a method developed in England called GROW. Following this method, the belly of pregnant women has to be systematically measured with a measuring tape from week 26 up to week 40. The different measurements were put in a personal growth curve. Costs are about 60 euro cents per pregnancy. I was never measured systematically and we’ve never seen such a growth curve. How is this possible?’

Three weeks after Mikki’s is cremation we have a debriefing at the midwives practice. They assure us we didn’t do anything wrong: “You alerted us twice. Alas it still went wrong. Tragic for you, but for us as well. We overlooked a small baby. It was a concurrence of vague symptoms and circumstances put together...”

We ask why there wasn’t a growth curve. “Oh, that method is heavily debated. The curves were shown to be too unreliable, so the method was withdrawn.” When requested the KNOV informs us by mail that there is indeed discussion on this matter but that “within the scientific community there are always different perspectives” and that the method is “still being rolled out”. The KNOV implemented the method without input of the NVOG, the professional association for gynecologists, despite intentions of both associations to seek more collaboration. The NVOG regrets this course of events, according to spokeswoman Anneke Kwee. “There’s not enough scientific evidence.” In England the GROW method barely decreased the high infant mortality rate. “All studies show that the measuring tape method detects very small amounts of growth restricted infants”, says Aris Papageorghiou, professor of obstetrics at the University of Oxford. Taking all of this into consideration a lot of midwives, including ours, abandoned this method.

WHAT IS THE CAUSE OF STILLBIRTH?

When a fetus dies in the womb after a gestational age of at least 22 weeks it is defined as stillbirth. If the child is born alive yet passes away in the subsequent week it is called neonatal death. These perinatal fatalities combined are referred to as infant mortality. In some countries these deaths are only registered from a 24 or even 28 weeks gestational age or more (late fetal death). Thereby when drawing comparisons that last definition is often used. Stillbirths are relatively more common with women who smoke or drink and those that are overweight. Relatively often it concerns a first pregnancy and women who’ve had

miscarriages before. Chances increase after the mothers 35th and in particular after her 40th year. Women from low social-economic standings, in particular those from non-western descent, have a fifty percent higher risk of stillbirth. Often this is blamed on language difficulties, an unhealthy lifestyle and seeking out midwives only late in the pregnancy, but presumably deficient communication between healthcare provider and the pregnant also plays a part. Most stillbirths however occur amongst women with zero or only one of these risk factors, who, until the infant dies, are considered as having low-risk pregnancies. Both stillbirth and premature birth are oftentimes caused by poorly perfused placenta. Pregnancy poisoning (pre-eclampsia) is also a result of this: when the fetus produces blood pressure increasing substances to ensure its adequate oxygen and nutrient supply. In many cases the cause of this 'placental syndrome' is not found. Part of the research focuses on finding biomarkers; signal substances in the mother's urine or her bloodstream. Identifying these markers would greatly improve early recognition of placental problems.

Growth ultrasound

If it was up to pensioned midwife Paul de Reu, the detection of fetal growth restriction would already happen otherwise: using ultrasounds. In the eighties De Rue purchased an ultrasound device, the first midwife in the Netherlands to do so. For years he performed one or two growth ultrasounds in the third semester of every pregnant woman in his care. By doing so he managed to detect 53% of the critically small fetuses; almost three times of those detected 'by hand'. He concluded that by using his method one third of stillbirths by growth restriction are avoidable. In 2010 he earned his Ph.D with his research. In response to that former Secretary for Health Ab Klink allocated 24 million euros in 2010 to introduce the standardized 30 weeks ultrasound (one ultrasound costs 36 euros and 32 cents). But before Klink could follow through the government fell. His successor, Edith Schippers, decided more research was required. Ultrasounds are, according to critics like midwife researcher Ank de Jonge of the VUmc, "less of an exact science than one would think". The growth ultrasounds could lead to more incorrect diagnoses and more unnecessary medical interventions. Besides, one ultrasound would be insufficient. "The question is how much costs and premature births would you risk to prevent one child's death" according to professor Jan-Jaap Erwich. According to De Jonge a Cochrane review study from 2015 shows that growth ultrasounds do not reduce infant mortality. But when we contacted British gynecologist Leanne Bricker, who

wrote the article, she shines a different light on this conclusion. “Almost all of the studies were conducted with outdated ultrasound equipment. Furthermore in almost every study only one ultrasound was conducted and none of the studies were large enough to be able to indicate a decrease in mortality. Without a doubt measuring by ultrasounds is more accurate than measuring by hand from the outside, but the studies to definitively prove that it reduces infant mortality have simply just not yet been done.”

Also it’s hard to carry out. In the ambitious Iris-study currently being conducted in the Netherlands and co-initiated by De Jonge, 7.500 pregnant women receive the standardized controls in the third trimester and another 7.500 receive an additional two growth ultrasounds. Researchers are trying to determine if a possible decrease of mortality and severe ailments outweighs the downside of growth ultrasounds like costs, unnecessary medical interventions and parent anxiety. But according to an article by the medical journal *The Lancet* in January, the study isn’t large enough to determine that. Because infant mortality is as rare as it is, at least 130.000 pregnancies are needed to determine any decrease.

“The Iris-study is entirely purposed to further the interest of midwives” according to Jan Nijhuis, Professor of Gynecology at the University of Maastricht. “Their aim is to prove that obstetrics can be performed without ultrasounds just fine.” He has no doubt about what the best detection method is: measuring the growth curve using multiple ultrasounds between week 20 and 40. “We in the Netherlands are an arch conservative country. This has always bothered me where it comes to natal care. It’s more a game of interests than it is about the well-being of mother and child.” Paul de Reu –honorary member of the KNOV – gets agitated about the anti-technological attitude of his professional association. “All we do is check the wrapping of the parcel to determine how well the content is doing”, he says. “While we have the technology at our disposal to look inside the womb without any health risk to the involved.”

Three days of tallying

Why wasn’t I referred to a gynecologist when I mentioned I didn’t feel my son move as he did before? Exactly three months after Mikki was born we walked into the office of gynecologist Uittenbogaard once again for a second debriefing with our midwives. They repeat their conclusion: “We just overlooked a small baby.” But in the meanwhile, we’ve become familiar with the guideline ‘reduced fetal movements’ that states the subjective

perception of the mother should be leading. The first time I mentioned I felt our baby move less there should have been excluded that there was something seriously wrong. The midwife should have referred to the gynecologist for an ultrasound. The instruction to tally for three days can't be traced to any guidelines.

Why didn't they tell us how important it is to take reduced fetal movement serious? After all a Norwegian study proved providing this kind of information leads to a decline in stillbirths, without an increase of unjust referrals. "When you provide this information, you get vastly differing reactions", our midwife said. "You're pregnant and vulnerable. Some women will leave with tears in their eyes saying 'I won't ever return to your practice'." "That's very patronizing, isn't it?", we say. Uittenbogaard: "Rather a tear than a dead child." He makes the remark that we feel "unfairly reassured" and we affirm this. Midwife: "We are sorry you feel that way." The midwives mention they will replace their reassuring folder. And that they will give referrals sooner next time when there are signs of decreased fetal movements.

"Would you do things the same way again?", Uittenbogaard asks the most experienced midwife. "Well eh yeah, if I don't have a clear picture I can't establish if there really is reduced baby movement.."

"Insane! That's life threatening!", we shout over each other.

Positive framing

Was this an incident, we finally ask ourselves. Did we by chance encounter a midwife that wasn't knowledgeable enough about the guidelines, or is there more at play? In a 2012 analyses the Dutch Health care Inspectorate concluded that in 80 percent of deaths or severe complications occurring in 'primary care', "insufficient recognition of pathology" was the case. In 2015 systematic evaluations of infant mortality cases after 37 weeks of gestation between 2010 and 2012 revealed that in 20 percent of the cases obstetric care had failed, amongst other things because women weren't being referred in time or at all, or because no ultrasound was conducted when suspicions of growth restriction arose. Gynecologists too, in 20 percent of the cases, fell short.

Midwives are trained to see a pregnancy as something normal. The KNOV encourages a 'watchful waiting policy'. Midwives also have a financial interest in this. A midwife who assists a pregnant woman until the 29th week of gestation earns about 400 euros, if the assistance lasts until birth the midwife earns more than 1300 euros (even if there's a referral during delivery). We requested the KNOV several times for an interview about infant mortality. To no avail; appointments are canceled and questions are routinely dealt with by mail due to "busy schedules". Records of the General Members Assembly of June 12th 2015 shed a different light on this, we read: "The KNOV's decision to not commit ourselves to media attention concerning infant mortality seems to be paying off". "Instead the KNOV focuses on positive *framing*."

In 2011 Minister Schippers instated the College of Perinatal Care to reform natal care in a manner that would decrease infant mortality. Together with representatives of all the professions chairman Chiel Bos (former chairman of the Dutch Health Insurance association) drew up a system in which midwives and gynecologists work together on risk selection in 'birth centers' which are closely aligned with hospitals. As to remove 'perverse financial incentives' from the system every health care provider receives a fixed amount per pregnancy. This system of 'Integral Natal Care' is to be introduced in 2017. The midwives professional association has also signed off on this.

But the midwives withdrew their support. The KNOV states in an email in an answer to our questions that the midwife should stay responsible when it comes to risk selection because "a lot of studies show" that it's in the best interest of mother and child. Of course they discuss

“high risk pregnancies” with other health care providers. “But if we have to discuss every woman that’s expecting in a maternity care team, unnecessary medicalization will increase and freedom of choice for the pregnant women will decrease. A GP doesn’t discuss all of his patients with specialists in the hospital now does he?”

“When push comes to shove, the interests of the obstetric professionals aren’t that of the pregnant women but their own”, says Chiel Bos, “and of course they will go to great lengths to turn the tide.” Action group Geboortebeweging (Birth Movement), that highly values ‘natural’ birth, dismisses the attention for infant mortality as “pulling the dead baby card.” Last September, the KNOV hired an advisor for public affairs: Arjen van Berkel from lobbying firm EPPA, who, amongst other things is active in the tobacco lobby. Within four months after being appointed the Dutch Parliament (with 148 of the 175 votes) passed three motions to implement the integral maternal care “careful and in phases” and against medicalization.

At the General Meeting on the 31st of March, KNOV members voted against the new system in large numbers. Last week the KNOV withdrew confidence in the College of Perinatal Care and stepped out. Direct motivation was an interview where chairman Bos, as stated in a press release, “blames stillbirth on the midwives”. The professional association of midwives declares “to keep in dialogue with our partners in natal care.” The association of gynecologists NVOG called upon the midwives to reverse their decision: “We understand the emotions concerning the unfortunate statements of the CPZ chairman. Gynecologists have a shared responsibility when it comes to our relatively high rate of perinatal death. Walking away from the table doesn’t solve the problem, increases emotions and in the end will adversely affect pregnant women.”

In the consulting room

Since the end of March The United Kingdom, another country in which infant mortality is relatively high, has made stillbirth negotiable in the consulting room. The National Health Services published an action package called ‘Saving babies lives’ for professionals and pregnant women. The British flyer for women expecting clearly conveys the importance of feeling a baby move in the womb: “*Around half of women who had a stillbirth noticed their baby’s movement had slowed down or stopped.*”

In Dutch flyers and consulting rooms the word ‘stillbirth’ is still carefully avoided. “Reduced baby movement could mean all sorts of things”, the KNOV spokesperson states. “You wouldn’t want to unnecessarily worry expecting mothers.”

Children like Mikki suffer the costs. Eight months old he would have been, instead we burn candles next to a tiny urn with his little mint green footprints on it, filled with three teaspoons of ash. Instead, we're publishing this story. In the words of Paul de Reu: "Still too many babies die of the things-will-work-out syndrome."

In a response our midwives stated: "The stillbirth of your son impacted us greatly and has been on our minds a lot the last few months. We consider your decision to share your experience a positive one. We support it because, like you, we serve the interest of reducing infant mortality. [...] Due to our professional confidentiality we cannot react substantively."

HOW DO YOU DETECT IT?

The big challenge when detecting growth restriction is to distinguish between small fetuses who are healthy and those who are growth restricted. At the end of 2015 a British research group published (in The Lancet) a promising way to do this: by using ultrasounds to not only monitor the weight of the fetus but also the abdominal circumference of the unborn child - because a relative decrease of circumference indicates emaciation. Using this method they managed to cut the 'false-positive' diagnoses by half: for every correct diagnoses there's only one incorrect one. This would greatly alleviate concerns pertaining to over-treatment and unnecessary premature births. The research group wants to make haste setting up a comparative study to confirm if their method actually does reduce infant mortality due to growth restriction.

BIRTHS ARE OFTEN PAID FOR TWICE

If a midwife refers a woman to a gynecologist during labor, both caregivers will be paid for the delivery. This measure was introduced in 1962 to prevent midwives postponing referrals. Downside to this is that midwives have a financial incentive to keep pregnant women under their care until these women go in to labor and only referring at that time. The referral rate during labor is around and about 39 percent these last few years (from 31 percent in 2000). Figures from the Dutch Health Authority (October 2015) show that midwives and gynecologists declare about 215.000 deliveries on a yearly basis when there are only 170.000 births. This means there are 45.000 deliveries being declared twice. Midwife Pien Offerhaus shows in her thesis from 2015 that the increase in referrals did not lead to a decrease in infant mortality or complication occurring with mother or child. Most significant reasons for referral are requests for anesthesia, meconium in the amniotic fluid

and non-progressing dilation. Offerhaus names growing fear for complications as an explanation.

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