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## **Improving care for red blood cell alloimmunized pregnant women**

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# Chapter 8

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**When a pregnancy is complicated by red blood cell alloimmunization:** the importance of sincere information – a qualitative study of women's experiences

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*In preparation*

## Abstract

**Background:** In the Netherlands Red blood cell (RBC) alloimmunization occurs in approximately every 300 pregnancies, 80/year caused by Rhesus-D-antibodies of which 25% have severe hemolytic disease of fetus and newborn (HDFN). No research examining women's experiences of this condition has been published.

**Objectives:** to describe women's experience of a pregnancy complicated with RBC alloimmunization. **Methods:** A descriptive study was conducted using in-depth interviews. A convenience sample of 10 pregnant women with RBC alloimmunization and at risk for HDFN were interviewed during their complicated pregnancy or a few to several years after giving birth. Women were recruited from another cohort study on women with RhD alloimmunization (OPZI 2.0 study). Transcripts of the interviews were analyzed using content analysis to describe their experience.

**Findings:** The severity of the RBC alloimmunization during pregnancy varied from RBC alloimmunization without risk for HDFN to severe HDFN and perinatal death. Five themes were identified from the descriptions of the experience as related by the participants. They encompassed the experience of the moment they first heard about the RBC alloimmunization, experience of care, knowledge about HDFN by obstetric care workers and patients, impact of pregnancy turning from physiologic to pathologic and the impact on family planning.

**Applications:** The key word in all the themes was confidence; the trust in the pregnancy and well-being of the fetus and/or newborn has decreased. The experience of care and the way of providing information about the risks and possible treatments can break or increase the trust in the pregnancy and neonatal period.

## Introduction

Hemolytic disease of the fetus and newborn (HDFN) is nowadays a rare disease, affecting approximately 290–410 pregnant women per 100,000. It is caused by red blood cell (RBC) alloantibodies, developed by the mother and transferred to the fetus trans placentally. Without treatment, HDFN may result in progressive fetal anemia, fetal hydrops, asphyxia and perinatal death. After birth, neonatal hyperbilirubinemia may lead to 'kernicterus', causing neurodevelopmental impairment with athetoid cerebral palsy, hearing problems and psychomotor handicaps.(3, 4, 6-9, 20)

Several preventive measures, such as administration of anti-D Ig to RhD-negative women with an RhD-positive child and preventive matching of blood transfusions, have substantially reduced the prevalence of RBC alloimmunization in pregnancy, resulting in an even lower risk of severe HDFN. Routine RBC antibody screening in pregnancy has provided the means for timely referral and treatment in secondary or tertiary care centers.

In general, pregnancies at risk for HDFN, as indicated by laboratory investigation, need frequent monitoring with ultrasound and Doppler middle cerebral artery (MCA) peak systolic velocity (PSV) measurements, to reliably predict the development of severe fetal anemia.(18, 29, 143) Fetal anemia is treated with intrauterine transfusions (IUT). Depending on gestational age, it may alternatively be decided to induce (preterm) labor, followed by neonatal phototherapy or (exchange) transfusions if necessary.

Because of the low current prevalence of alloimmunization in pregnancy, obstetric care providers (OCP) rarely encounter alloimmunized women and hardly ever women with a pregnancy at risk for HDFN. OCP's may become unaccustomed to managing these complicated pregnancies and properly counselling the parents on treatment policy and associated risks. In our previous study we found that Dutch OCP's showed a lack of knowledge regarding maternal RBC alloimmunization and were not aware of this lack of knowledge.(174) Furthermore, women showed only moderate satisfaction with the information provided about the screening program concerning RBC antibodies.(63) We did not find other reports specifically describing the experiences of RBC alloimmunized women with a risk of HDFN. During focus group interviews undertaken to gain insight into barriers and motivators of women to becoming anti-D plasma donors after RhD alloimmunization during pregnancy, we observed that women shared other aspects of their experience in relation to the counselling received during the pregnancy in which RBC alloimmunization was detected first and often had difficult memories even years afterward.(175)

However, there are studies available about the experiences of women with a complicated pregnancy due to other causes. A recent qualitative study, interviewing 12 women with a complicated pregnancy, showed that they often felt out of control, fearful and confused.(176) The authors suggest that midwives can play a key role in translating medical jargon and providing emotional guidance and support. Two cross-sectional observational questionnaire studies showed high-risk pregnancies and/or those complicated by a medical disorder to be anxiety provoking and to increase the likelihood of depression, as well as causing stress and distress in the pregnant woman.(177, 178) Côté-Arsenault et al. showed that parents of a neonate with a lethal diagnosis valued receiving intensive psychological guidance,(179) and this contributed to a positive experience of received care.

The present study was designed to gain more insight into the experience of women and their partners regarding the care currently provided during a pregnancy involving RBC alloimmunization, with a risk for HDFN. Our aim was to describe the perceived and desired guidance for a complicated pregnancy and to formulate recommendations for potential improvement of care and at the level of communication.

## **Methods**

### **Design**

We conducted an explorative study with a qualitative descriptive design, following the principles of 'Abbreviated Grounded Theory' (Glaser and Strauss).(180) Semi-structured interviews were conducted based on a topic list.

The study followed an interpretive approach using sensitizing concepts – that is, concepts that might be related to the experience of care. The concepts were not used as interview questions but kept in mind as possible dimensions. The sensitizing concepts were derived from the literature and from our own experience of care for this group of patients.

### **Data collection**

#### *Study sample*

Alloimmunized women with a pregnancy at risk for HDFN were invited for interview. Data were collected between 2011 and 2018. If the woman was accompanied by her partner, the partner could also participate in the interview. Women were selected

via purposive sampling with the intention of ensuring a heterogeneous group of participants. We attempted to have variation in the following characteristics: timing of interview either during or after the alloimmunized pregnancy; antenatal care in primary, secondary or tertiary care; Dutch or non-Dutch ethnicity; and disease severity.

Most participants were enrolled in the OPZI 2.0 study, a nationwide cohort study on D immunization in pregnancy. When giving consent for the OPZI 2.0 study, the participants also gave permission to be approached for further research. A minority of women were recruited via their obstetrician at the Leiden University Medical Center (LUMC), the tertiary care center for alloimmunization in pregnancy in the Netherlands. Women were informed that they could decide not to participate or withdraw from participation at any time without explanation. Interviews were conducted until data saturation was achieved and no new information emerged.

### **Topic list**

The topic list was based on the clinical experience of YM and JK and sensitizing concepts such as: received information (knowledge); fear/anxiety surrounding pregnancy complication and coping mechanisms (behavior); expectations of care (norms and values); and suggestions for improvement of care (intention). The topic list was prepared by YS and refined by JK.

### **Interviews**

The interviews were conducted by YS and two midwifery students, CV and IT, who used the data for their bachelor's thesis. Semi-structured interviews were conducted either in the participant's home or in a quiet room at the hospital. Each interview lasted approximately 30–45 minutes. The interviews began with general questions about the participant's (obstetric) background. Subsequently, the woman was asked to tell her personal story concerning the alloimmunized pregnancy. Follow-up questions were asked to give the woman the opportunity to clarify relevant aspects of her initial answers. The interviews were recorded on audio tape and were transcribed verbatim by a secretary who had signed a binding agreement to secure confidentiality.

## Analysis

Thematic analysis was undertaken, with the aim of formulating relatively broad themes that summarize the content of the data. First, the transcript was read several times, for the purposes of data familiarization. The transcripts were then open, axially and selectively coded; so that the main themes became visible. These main themes were captured in phrases, described as expressed by the participant. Finally, links were made between the different themes and a core theme/category was established. The interview transcripts were analyzed by YS and JK, who both reviewed the findings and came to a consensus. The themes were confirmed by repeatedly returning to the original data and ensuring transparency in data processing; all results can readily be traced to the underpinning data.

## Results

### Participants

We carried out eight interviews, after which data saturation was reached. Half of the women were accompanied by their partner during the interview. In all interviews the woman mainly spoke and was supported on some points by her partner. The findings and quotations therefore relate to the women participants. Two women participated in the study during their first alloimmunized pregnancy. Both received tertiary care in the LUMC. One of them underwent an intrauterine transfusion (IUT) (Table 1). The other six women were interviewed 9–36 months after giving birth; two of these received care at the LUMC. The other four women never received tertiary care. All participants received primary or secondary care at some point in their first pregnancy at risk for HDFN or during the pregnancy before the one at risk. Seven women had RhD immunization with or without additional antibodies and one woman had K immunization. One of the babies did not require a RBC transfusion or phototherapy for HDFN.



**Table 1.** Overview of participants

Participant number	GPA*	Line of care	Intra-uterine transfusion	Neonatal transfusion	Photo-therapy	Ethnicity	Gestational age	Months post-partum <sup>#</sup>	Year of interview
1	G4P3	Tertiary (LUMC)	No	-	-	Caucasian	27	NA	2011
2	G2P1	Tertiary (LUMC)	Yes	-	-	Caucasian	34	NA	2011
3	G3P3M2	Tertiary (LUMC)	Yes	Yes	Yes	Arab	NA	9	2018
4	G2P2	Secondary	No	No	No	Mediterranean	NA	36	2017
5	G3P3	Secondary	No	Yes	Yes	Caucasian	NA	28	2016
6	G1P1	Secondary/ tertiary	No	Yes	Yes	Caucasian	NA	16	2016
7	G2P2	Tertiary (LUMC)	No	Yes	Yes	Caucasian	NA	36	2016
8	G3P3	Secondary	No	No	Yes	Caucasian	NA	36	2017

\*Gravity and parity and (if applicable) number of children alive (M); #NA = not applicable

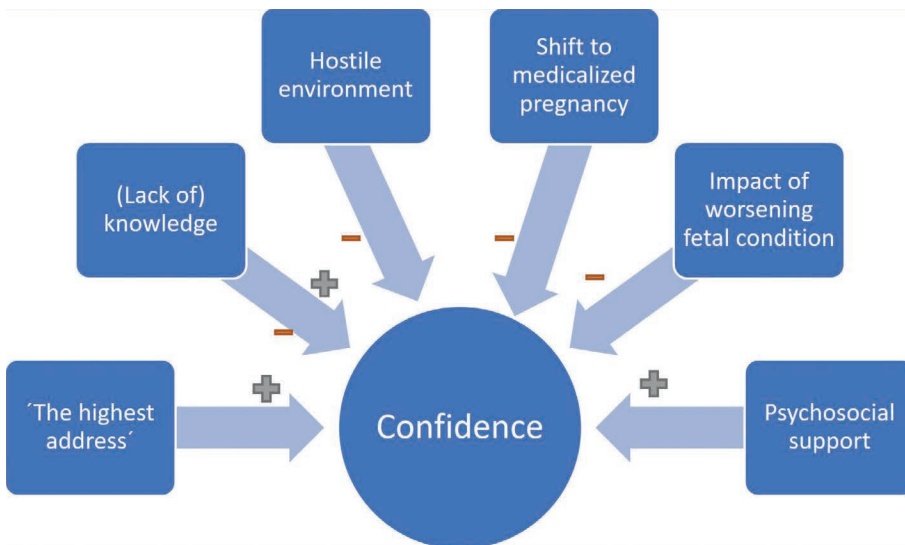


## Themes

After analysis of the transcript and codes, six main themes could be formulated. These were: shifting from having a normal pregnancy to one with a potential medical complication; experiencing the impact of worsening of the fetal situation; experiencing the body as a hostile environment for the baby; experiencing needing psychological support; experiencing lack of knowledge; and experiences if the woman reached the LUMC center for fetal therapy, the 'highest address' of knowledge/skills.

**The core theme, to which these six themes are related, is 'confidence'.**

Figure 1 shows the core theme and main themes and their mutual relationship. Knowledge of RBC alloimmunization and its risks and possible complications plays a role in the woman's confidence in the pregnancy, and when knowledge is lacking or not properly communicated, this creates unease. When the problem suddenly deteriorates (impact of worsening fetal condition) confidence in a successful outcome decline, but as soon as the pregnant woman arrives at the LUMC (the 'highest address') and receives the best available care, confidence in a successful outcome of the pregnancy increases again. Furthermore, the pregnant woman loses confidence in her body when there is erythrocyte immunization, which is further explained under the theme 'hostile environment'. Confidence in a normal course of pregnancy has disappeared and a shift from non-medical to top medical care is experienced as drastic.



### **(Lack of) knowledge**

#### *Difficult subject matter for both OCP and patient*

Within the theme 'lack of knowledge', one participant described the issue of RBC alloimmunization as 'a difficult topic'. Most participants found the problem difficult to understand and said that they fully relied on the gynecologists in their decisions. On the other hand, according to the participants, the primary or secondary OCP seemed not always to have sufficient and complete knowledge about the problem. This resulted in providing too little or even incorrect information at crucial moments. In the interview excerpt below, a participant received the result by telephone that RBC antibodies had been detected. Little information was given about what this result meant for the pregnant woman, and it was mostly emphasized that she should not be concerned. When asked what information she received by telephone, the participant said:

*"She said what it was, but she also said to us, don't worry because the pregnancy has been going throughout, so don't search the internet. When you come to the gynecologist you will get all the information."*

Later, the same participant said: *"In the beginning we were quite calm until a few weeks ago when we got the most recent laboratory test result and this result was 80% [YM: result of ADCC test], then it all went very quickly, and we were very shocked."*

In this context, it seems as though the pregnant woman has consistently held on to reassuring thoughts in order to deal with the uncertain situation, possibly fueled by reassurances from the OCP.

Another participant indicated that she was always reassured, and the seriousness of the situation downplayed. This led to distress after the birth of the child, when the baby was nevertheless born very ill. She would rather have been able to prepare for this.

One participant, who had had three pregnancies, received the result that she had RBC alloantibodies after the birth of her second child, when it was found that he had severe anemia. She had the results from the gynecologist and was not satisfied with the communication. The way in which she received the results was one reason she changed to obstetric care in another hospital for her next pregnancy. *"The way it was told to me was the reason I would never want to give birth in that hospital again. The guidance was very poor, and I was told: 'Antibodies have been found in your blood and from now on every pregnancy is dangerous, but the good news is you can become a blood donor.' [...] This was a lot to process at that time."* When asked

what additional information was given at that time, the participant said: *"I felt that they actually didn't understand much of it themselves. [...] Afterwards I learned more myself through the internet."*

Various participants stated that they would have preferred the OCP to be honest about their gap in knowledge and to consult an expert or refer to a reliable source of information, if their own knowledge was inadequate to explain the risks of the situation. This would have been better than giving information that could be misinterpreted.

When the OCP indicated the limits of his or her ability straight away and referred the pregnant woman to secondary or tertiary care for more information, participants were very satisfied with the way they had received the bad news.

If the pregnant woman was not satisfied with the information obtained, or if this information was not provided with the help of an interpreter, for example, she looked for information herself. In some women this initially led to fear. This feeling diminished when they received information from an expert or if someone around them with a medical background could explain this to them a little more.

### **Hostile environment**

#### *The child is in danger because antibodies from the mother destroy the child's RBC's*

One of the participants referred to the womb as a "hostile environment". For example, she recalled that after the gynecologist explained the problem of RBC alloimmunization, her partner commented: *"It is a very nice idea that at the moment the umbilical cord is cut, the enemy is gone."* The participant stated that the idea of being an "enemy" and at the same time taking care of the growth and maturation of the child was incomprehensible. She said: *"Sometimes I am suddenly really scared; then I think soon she will die and they cannot get her out right now."*

Because of the uncertainty and the unpredictable course of this condition, the quoted pregnant woman above has less confidence in her body to protect her child sufficiently and allow it to grow and be well. At any time, the child could be requiring intervention. Participants indicated that they experienced anxiety about losing their child. This fear was also felt looking back, realizing what could have gone wrong if timely action had not been taken. One participant said: *"If we had waited a week more, he would have been born dead. Yes, that thought..."*

## Shift from a normal to a medically complicated pregnancy

### *"The pink cloud is gone"*

Two participants had had a previous pregnancy in which no complications occurred, and they gave birth at home. These participants indicated that they felt more tense during the subsequent pregnancy. They referred to the pregnancy as no longer "carefree", "living from week to week", and involving "practical hassle". One participant indicated that she felt more appreciation during this pregnancy when she felt fetal movements. Participants also indicate that they were dependent on their relatives to care for their other children because of visits to or delivery at the tertiary care center, which might be a long distance away. Three of the participants also had to reassure and prepare their family and relatives for the period after birth. There were also participants who found the idea that the baby could be born ill very difficult. Furthermore, two participants indicated that they were sorry that the delivery would be induced and could not give birth at home in their own environment. Additionally, they were worried about their ability to breastfeed normally. What also emerged clearly were the considerations for a subsequent pregnancy. Almost all participants mentioned that they did not dare to plan a subsequent pregnancy. One participant put it like this: "What is also quite a big thing is that your next pregnancy, if it comes, will already start with a percentage of antibodies. [...] I think it will be very long months." Another participant said, in relation to a possible next pregnancy: "But now it is done. I hope this all goes well. I will soon have four children; it will also stop at some point. You shouldn't be defying luck. The body has shown that it clearly has more trouble with pregnancy."

In contrast, participants were very pleased that they had regular check-ups in secondary or tertiary care, which restored their confidence in a successful outcome for the pregnancy. The feeling that they were taken seriously and getting expert information also contributed to the feeling of confidence, although this balance was very unstable: when a result was communicated by a person with little substantive knowledge, or when the doctor or midwife was not well informed about the patient file, this again caused tension. Confidence in and surrender to the expertise of the OCP was then more difficult for the pregnant woman and her partner.

There was a clear need among the participants to know the different scenarios during that could arise during pregnancy, delivery, and the neonatal period. The participants indicated that better preparation provided peace in a stressful situation.

## Impact of worsening fetal condition, rapid referral and intervention

### *No time to think about it*

One participant was referred to the tertiary care center to determine whether intrauterine transfusion was necessary, and this was done immediately the very next day. She said: *"It all went very quickly; we had not taken it [intrauterine transfusion] into account anymore. Especially because we were a little naïve about it until then. We were already in the 31st week, so we hoped that with a bit of luck it would all be fine."* The participant indicated that she was upset and overwhelmed by the speed with which the examinations and intervention took place. She didn't have time to think about this and therefore followed the doctors in what they thought was best. When asked what her role was in the decision to give the intrauterine transfusion, she said: *"My opinion wasn't asked, but that is also irrelevant because it was simply necessary."* Another participant said, in relation to the moment she was referred to the tertiary care center: *"You always keep it in mind, but it still scares you. I thought: 'It is getting serious now. It's serious.' And then I felt quite anxious. [...] I did not know what they could do there [YM: in the LUMC], and then I deepened my knowledge on that myself and I became a bit calmer."* The woman indicated that at that time she felt the need to get more information about the possible treatments at the LUMC. She could find this on the LUMC website, and this gave her more peace of mind.

The potentially sudden need for induction of labor and the course of the disease after the birth of the baby were not always clear to participants in advance of these events. Some participants reported experiencing difficulty bonding with their baby due to the fear of losing the child. Participants who had experienced good guidance from the pediatrician indicated that they had confidence in the doctors and treatment. Empathy and calm explanation were again important here. For two of the participants, the child fell seriously ill after discharge. By trusting their own instinct and daring to ask for help, they ensured that their child received the right care promptly. In one case this meant asking for a second opinion in a crucial situation.

### The "highest address"

#### *The tertiary care center, the LUMC, is the last link in the case of a complicated alloimmunized pregnancy*

Participants indicated that they received a great deal of information and explanation about the examinations and treatments at the LUMC. The information also matched their level of understanding well. They felt good about the investigations being carried out and had confidence in the doctors. One participant said: *"When I heard during the check-up at the LUMC that the baby was doing well, I was always relieved, on to next week."* Another participant indicated that she did not feel "small" and that there

was room for emotions, which she experienced as positive. She went on to say: *“You have the feeling in terms of knowledge and skills that you are at the highest address here.”* On the other hand, when asked whether there was also room for personal questions, the same participant said: *“In the other hospital we knew all the doctors, so you also have a bond. [...] It would have been nice to have had the possibility of discussing some practical things about the delivery.”*

Despite the predominantly positive ratings for the care at the LUMC, participants indicated that they missed the practical information about induction of labor and the neonatal care immediately after birth. One participant, originally from Syria, missed the use of an interpreter when giving important results and information about therapy.

### Psychosocial support

Several participants indicated that they experienced feelings of fear and anxiousness during pregnancy or after the baby was born. They were afraid to lose their child. In addition to obtaining information about the expected course of the condition and need for frequent check-ups, participants also indicated that empathy for the situation, a sense of being taken seriously, and the ability to share emotions and experiences contributed to their confidence in the pregnancy. If these aspects were not experienced in the care they had, feelings of anxiousness were still apparent during the interviews. When these aspects were adequately addressed, the participant could put their story in more perspective.

One participant said: *“but just think what tone you use, what words you use. It is very important to someone who has just given birth and is experiencing an uncertain time.”*

Participants valued the continuity of one OCP, especially when attended by primary or secondary care. The need to be aware of the situation and the course of the disease was felt and appreciated. When the primary care midwife remained involved during the pregnancy, even when the pregnant woman had already been referred to secondary or tertiary care, this was also appreciated. The midwife can translate medical jargon and help to ask the right questions, for example about the expected course of the disease or practical matters such as childbirth in this situation.

### Discussion

The concept of 'confidence' plays a central role in the experience of women with a pregnancy complicated by RBC alloimmunization. The issue of confidence covers three domains: confidence in one's own body, during the pregnancy, and in the care

providers. Circumstances can influence the experience of pregnant women positively or negatively. In particular, the provision of sincere, open, correct and complete information, and support decisive moments, can positively influence confidence. It is clear from this study that when information is given by persons with considerable experience in relation to RBC alloimmunization, this provides more confidence to the patient.

This study provides a clear picture of participants' experiences. The pregnancy is no longer experienced as carefree, and the pregnant woman regularly finds herself in an uncertain situation, due to the jeopardized fetal condition. To deal with this uncertainty, women use various coping strategies, such as seeking social support, seeking more insight and information, and trying to have faith in a positive outcome. In relation to treatment by intrauterine transfusion, the pregnant woman must rely completely on the knowledge and skills of the doctors, and she and her partner seem to play only a minor role in the decision-making process. Everything is done for the benefit of the baby, suffering from the maternal alloimmunization.

What also emerged from this study is the influence of RBC alloimmunization on opting for a further pregnancy. The participants indicated that their choice is influenced by the course of this pregnancy. Even women who did not have a sick child at the end understood that this can be totally different in a future pregnancy. They do not want to take that risk, or do not want to go through what they experienced in the current pregnancy.

### **Strength and limitations**

To the best of our knowledge, this is the first study concerning the care experiences of women at risk for HDFN. We interviewed eight women, heterogeneous in gestational age or time after the birth of their last child, severity of HDFN (ranging from none to life-threateningly ill), ethnicity, and attendant level of care. Data saturation was reached when comparable experiences were found in relation to the care provided, especially the expressed need for clear, correct and complete information, and the relationship between the information and participants' confidence in the care provider and course of pregnancy. In our opinion, the results of this study are therefore generalizable to all pregnant women with RBC alloimmunization in the Netherlands. The relatively broad time period during which the interviews were conducted (2011–2018) allows us to show that the experiences of care did not change over time.

The participants who received care at the LUMC were made aware that a midwife based at the LUMC was one of the interviewers (YM), and this may have caused participants to reflect more positively on care received at the LUMC. Nevertheless,



those participants also felt sufficiently free to suggest improvements in care at the LUMC.

## Previous findings and interpretation

Poorly provided or incomplete information after detection of RBC alloantibodies, or during follow-up, influenced confidence in a positive pregnancy outcome and caused feelings of anxiety in alloimmunized pregnant women. From evaluation of similar situations, such as informing parents of a positive test result for any of the diseases tested for during newborn screening, Moody et al. advised arranging direct face-to-face contact between the specialist team and the family, continuous support and the availability of accessible condition-specific information.(169) In our previous research we found that the knowledge of OCP's about RBC alloimmunization and HDFN was frequently insufficient, and they were often not aware of these gaps in their knowledge.(174) From the perspective of the women in the current study, a lack of knowledge on the part of the OCP should best be shared with her; otherwise this causes feelings of anxiety and insecurity in the pregnant woman and her partner. As described in the results, when the doctor or midwife is aware of the limits his or her abilities and refers for a second opinion from the specialized team, this shortcoming is quite surmountable. This finding is also applicable in other high-risk pregnancies or rare conditions. A study of pregnant women in which twin-to-twin transfusion syndrome was diagnosed showed that patients received limited information about the consequences following the diagnosis.(181) As a result, they started looking for information themselves. We also found this to be a coping mechanism, and Fischbein et al. indicated that this helps families deal with the unpredictability and emotional adjustment.(181) Nonetheless, in our study women and partners indicated that they wanted more information from an expert at these crucial moments. This may also point to a difficulty in readily finding and accessing high-level knowledge via the internet for pregnant alloimmunized women. The tertiary care center (LUMC) has readily accessible information on its website, and it is worthwhile for both pregnant women and OCP's to refer to this information.

Various studies of parents' recommendations on how to inform them in relation to a newborn screening result that indicates a disease suggest that it is important to offer realistic reassurance and hope, to address and support parents through the moments of anxiety and to keep content simple, clear and actionable.(169-172) The same emerges from this study. The pregnant women and their partners also indicated that they wanted honest information about the risks of RBC alloimmunization, and that knowing what might happen and what to expect is very important. In addition, giving the opportunity to share their emotions, and guidance in dealing with their emotions, is appreciated.

## Recommendations

Based on this research, we recommend that when RBC alloantibodies are found, this result is communicated face-to-face and that the risks and possible scenarios in relation to the course of the pregnancy are shared. Consulting an expert on this topic before sharing the risks and scenarios is recommended. It is important that the message is clear and contains realistic reassurance, and that the opportunity is offered for sharing emotions. Continuity in the guidance of the pregnant woman is appreciated, and she should be well prepared for any interventions during pregnancy and for having a child who may be or become ill shortly after birth. Prenatal counselling by a neonatologist should be involved, to prepare women and partners for the anticipated neonatal therapy. Furthermore, a preconception consultation should be offered to give women the opportunity to make an informed choice about a subsequent pregnancy. The themes found in this study can form the basis for a quantitative questionnaire to design further improvements in communication with alloimmunized women and provision of knowledge in the rare event of RBC alloimmunization in pregnancy.