

How parents feel about blood transfusions in the NICU and what they would like to know

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Background:

Blood component transfusion, occurring commonly in NICU, is a high-risk activity and can be associated with adverse events. Parents make decisions for their babies in NICU. There is limited research into parents understanding and experiences of blood component transfusion in NICU. Decision-making around blood transfusion has been identified as being an area of NICU decision making that is important to parents. In Weiss et al’s qualitative study about parental decision making in NICU, parents varied with their opinion of who should make the decision for their baby to have a blood transfusion, based on their approximation of potential risk and potential urgency. Information provided to parents on blood transfusion has not been assessed by parents.

Objectives: The aim of this study was to explore parents’ understandings and experiences of blood transfusion in the neonatal unit.

Methods:

A ‘low-inference’ design of this qualitative descriptive semi-structured interview-based study was chosen. A sample size of six to twelve interviews was chosen, as suggested by Guest, Bunce, and Johnson, for research aiming to understand common perceptions and experiences. Informed consent was obtained and confirmed. Interviews were held in-person with PPE or via video-link, and audio-recorded and transcribed. Grounded theory was used to analyse the interviews, using inductive thematic analysis. NVivo (QSR International, MA, USA) was used to record codes. As data collection continued, codes were combined and refined and themes were identified.

Results:

Seventeen parents of eight singletons and three sets of twins (fourteen babies) took part in 11 interviews, between February 2021 and March 2022. Interviews lasted between 06:35 and 25:11 (median 18:25). Seven interviews were in person, and four were over video. Four babies were born at term, ten babies were preterm. Two babies died in NICU. The main themes elicited by the interviews were parents’ expectations and outcomes of transfusion, parents’ prior and current opinions of transfusion, parents trust in healthcare professionals and how parents would like to get information about transfusions in the NICU.

Conclusion:

Parents in our study trust information from the healthcare professionals caring for their baby, and would like more specific information about how blood transfusion will impact their baby, in a variety of means. Parents felt that blood transfusions were beneficial for their babies in NICU. These findings can be used to improve information provision to parents about blood transfusion in NICU.

Themes and subthemes	Topic	Quotation
Theme 1: Expectations and outcomes of transfusion		
Baby before transfusion		“you’re watching her get paler” i1 “my baby needed it” i2 “because there was a couple of days [baby] was particularly pale so we knew his haemoglobin is going to be checked and he might need it” i4 “he was unstable and that you were trying to stabilise him and that he may need a blood transfusion” “I knew the whole situation was serious—you do whatever you need to do to get him okay” –i9 “I thought that transfusion was a big deal and a hard thing to go through and I was so surprised that Monday that she was going to have to get one—I was quite upset over it” –i8
Opinion about transfusion		“The benefits completely outweigh that” –i1 “It scared the living daylight out of me to be honest, I didn’t know anything about it... way less scary, way less daunting... the first time that I heard about it I was like they are going to hook her up to a machine that is going to pump her through with blood—it wasn’t the experience I thought it would be, but seeing it” i10 “I always thought blood transfusions were I suppose a huge deal a very big deal for anyone who is getting a blood transfusion it’s serious... It was all so stressful” –i3 “associated needing blood with being really unwell... you wonder what has gone wrong like” -i4 “people do think that having a blood transfusion is an awful thing, like the way that I thought you know that you must be very sick if you need it” -i8 “To be honest the blood transfusion was just a form of treatment... I know for [Partner] we weren’t concerned about the blood transfusion, we were concerned that he was so sick” -i9
Memory of transfusion		“The first time that I heard about it I was like they are going to hook her up to a machine that is going to pump her through with blood—after it was explained and seeing it—it took the edge off it to be honest—it wasn’t the experience I thought it would be” -i10 “all that is a huge kind of a blur” -i2 “I didn’t appreciate that it actually takes four hours” -i3 “I think the second one was much easier because we already done the first one... We were there for one of them, it wasn’t scary at all” –i5 “I was surprised at how easy it was... it just seemed really straightforward” –i7
Outcome of transfusion		“The benefits completely outweigh that... the next day she is like a new baby... it’s amazing” –i1 “the day after she was a lot more active”–i10 “he got well, so quickly” -i11 “it seemed to work brilliantly” -i2 “Boost up... it was brilliant... Perked her up no end. She needed it” -i3 “You could see the difference in their colour” –i4 “it was kind of like a booster for her” –i5 “they [transfusions] are really good how they help them out a lot—it makes a big difference” –i6 “it was a great thing that she had got the transfusion... she was so alert and pink and bright” –i8 “Things started to improve when he got the transfusion” –i9
Theme 2: Consent and trust in professionals		
Consent		“I remember signing the paper while I was in recovery I just felt like it was necessary. Like, I just know that that’s paperwork you have to do” -i11 “I was aware they needed a blood transfusion, I was aware I had to consent for it” -i4 “Yeah, just getting the phone call was scary—it was just to give consent for the transfusion” -i6 “I was shown a factsheet or—I was really well explained on each occasions—obviously I had to consent to it” –i7
Trust in professionals		“have unwavering faith... Our job is to be her mum and dad” -i1 “I kinda just felt like it needed to be done” -i10 “I had full trust... You’re the professional” –i11 “it’s for her benefit—so obviously I go with whatever the doctors—say that she needs and required”–i3 “we’re taking it in good faith that we are being guided in the right direction” –i4 “we were always going to give it to her because she needed it” –i5 “we trusted everything that you guys told us, it was very straight and we knew exactly what was happening so we were happy enough that you guys knew that he needed a transfusion and whatever you guys knew that he needed we were happy to go with” –i9
Theme 3: Information about transfusion		
Information provision		“The amount of information and the content of information that we got throughout all of this was the right balance... I think that it’s important to understand how your head is about to explode, and all of the medical terminology is quite scary, so you’re told what you need to know, but not more that you need to know, which is good... You do need to be protected as a parent, in order for you to keep your head in the game... we got told—I feel - everything we need to know” –i1 “I remember whoever spoke to us, explained it to us... It’s kinda reassuring that we were told how it works... I prefer face to face explanation... I know you give us the paper and everything, sometimes I don’t read them and you’re so preoccupied—I find it better face to face with one of the doctors in NICU and you can ask questions then and understand it better” –i10 “what really worked well for me is that you use layman’s terms, like so it wasn’t confusing language...the kindness is a huge part, so friendly, and so reassuring and really encouraging... made the process so much more relatable, because it was so unrelatable to us, like we had no idea- [RE the leaflet] I don’t feel like it was related to what I was going through, you know, the weight or what he was going to really do you know what I mean? It was too generic”–i11 “keeping it as simple as possible so they can take it on board...if you give too much it can be overwhelming—in an already overwhelming situation... The basic information on a sheet like.. why does my baby need a blood transfusion” -i2 “It would have been nice to know what is actually involved in it... they just wanted to give her blood and rise her oxygen levels in her blood... [RE information provision] it would be nice to get it in advance, well in advance... I would like it as a link, but obviously other parents may like it as a leaflet” –i3 “I think parents need it in plain English—black and white... things need to be plain and simple” -i4 “Probably by an email or on my phone... having something that you can see on an easy to use website...it was explained very well” –i5 “I was shown a factsheet, it was really well explained on each occasion... at the moment you want to talk to the doctor you want it explained, you want the opportunity to ask questions... that explanation in person is the main thing I think it gives you comfort and the opportunity to ask questions... a digital copy that you can refer back to if you needed to if you had any questions if you lose the leaflet, I think we were really well informed all along”-i7 “The part that makes me feel a little bit uncomfortable... was explaining the risks, I suppose that they have to be explained” i8 “But for me personally—paper – [Partner] took it all in auditory—he didn’t get the leaflet and he didn’t look at it—I had it in my room and I had it in [baby’s] medical file—I know [Partner] never saw it -he heard what people had said to him and he took it up that way—he recalled that when I talked about it—that’s ten weeks later” i9
Information Leaflet		“think I read a leaflet... I know you give us the paper and everything- sometimes I don’t read them and you’re so preoccupied” i10 “I wasn’t in a headspace to start reading a leaflet... it was so generic, it felt more like it was it felt more like it was directed towards adults... it was actually for what you’re going through right there and then like to know that way. I know like, for a baby, a newborn?...I don’t feel like it was related to what I was going through” i11 “The basic information on a sheet like you know - why does my baby need a blood transfusion and a paragraph on when the blood is missing: ...the possible reasons why this is gone” i2 “I mean if I want to know something I look it up on my phone so yeah that might be the way to go... Having a leaflet if you don’t have an email address” i4 “how it’s being done, what way it helps, stuff like that that” i6 “you’re given stuff in the hospital, it can get stuffed into a bag or lost—if you had it digitally to hand that would be really good too” i7 “The morning that she had it—we got a leaflet” i8 “I remember I got a kind of a leaflet, I don’t know who gave it to me, about blood transfusion in Holles street” -i9
Information about transfusions		“well how long it takes, h— why did [baby] need it in each case. There were different reasons” i3 “Well just to say the good things about it, how it’s being done, what way it helps, stuff like that that” i6 “I was shown a factsheet or—I was really well explained on each occasions—obviously I had to consent to it... I think a leaflet would be good—at the moment you want to talk to the doctor you want it explained you want the opportunity to ask questions...-”i7