

Reviewing recordings of neonatal resuscitation with parents

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ABSTRACT

Background Recording of neonatal resuscitation, including video and respiratory parameters, was implemented for research and quality purposes at the neonatal intensive care unit (NICU) of the Leiden University Medical Center, and parents were offered to review the recording of their infant together with a neonatal care provider. We aimed to provide insight in parental experiences with reviewing the recording of the neonatal resuscitation of their premature infant.

Methods This study combined participant observations during parental review of recordings with retrospective qualitative interviews with parents.

Results Parental review of recordings of neonatal resuscitation was observed on 20 occasions, reviewing recordings of 31 children (12 singletons, 8 twins and 1 triplet), of whom 4 died during admission. Median (range) gestational age at birth was 27+5 (24+5–30+3) weeks. Subsequently, 25 parents (13 mothers and 12 fathers) were interviewed.

Parents reported many positive experiences, with special emphasis on the value for getting hold of the start of their infant's life and coping with the trauma of neonatal resuscitation. Reviewing recordings of neonatal resuscitation frequently resulted in appreciation for the child, the father and the medical team. Timing and set-up of the review contributed to positive experiences. Parents considered screenshots/copies of the recording of the resuscitation of their infant as valuable keepsakes of their NICU story and reported that having the screenshots/video comforted them, especially when their child died during admission.

Conclusion Parents consider reviewing recordings of neonatal resuscitation as valuable. These positive parental experiences could allay concerns about sharing recordings of neonatal resuscitation with parents.

INTRODUCTION

Adapting from foetal to neonatal life is a complex physiological transition. Approximately 10% of all infants require some degree of support during this transition,¹ but a lower gestational age at birth is associated with an increased need of support, with up to 85% of extremely preterm infants requiring interventions at birth.² To study and improve the quality of care delivered during neonatal transition, we implemented recording of neonatal resuscitation, including video and respiratory parameters (see [figure 1](#)) at the neonatal intensive care unit (NICU) of the Leiden University Medical Center in 2014. All neonatal resuscitations are recorded, unless parents antenatally opt out for recordings to

What is already known on this topic?

- ▶ Parental presence during neonatal resuscitation is considered beneficial; however, mothers often cannot be present.
- ▶ Premature childbirth is recognised as a traumatic experience for parents.

What this study adds?

- ▶ Parents consider reviewing recordings of the neonatal resuscitation of their very or extremely preterm infant as valuable.
- ▶ Reviewing recordings of neonatal resuscitation may contribute to getting hold of the start of their infant's life and coping with the trauma of neonatal resuscitation.
- ▶ Screenshots/copies of recordings of neonatal resuscitation are considered as valuable keepsakes, especially when the infant died during admission.

be made. Postnatally, parents may request to delete recordings. Recordings are stored as part of the medical record of the infant, and parents can request screenshots or a copy of the video recordings.

Various studies showed that parental presence during neonatal resuscitation can be beneficial.^{3–12} International guidelines on neonatal resuscitation recommend parental presence during neonatal resuscitation where possible.^{13 14} At our NICU, we encourage partners to be present during neonatal resuscitation, but mothers often cannot be present as resuscitation normally is not performed in the delivery room. We therefore offer parents to review the recording of the resuscitation of their infant together with a neonatal care provider. With this study, we aimed to explore parental experiences with reviewing recordings of very or extremely preterm infants.

METHODS

This qualitative explorative study is part of a wider project studying ethical aspects of recording and reviewing neonatal resuscitation. The study combined participant observations during parental review of recordings with retrospective semistructured interviews.



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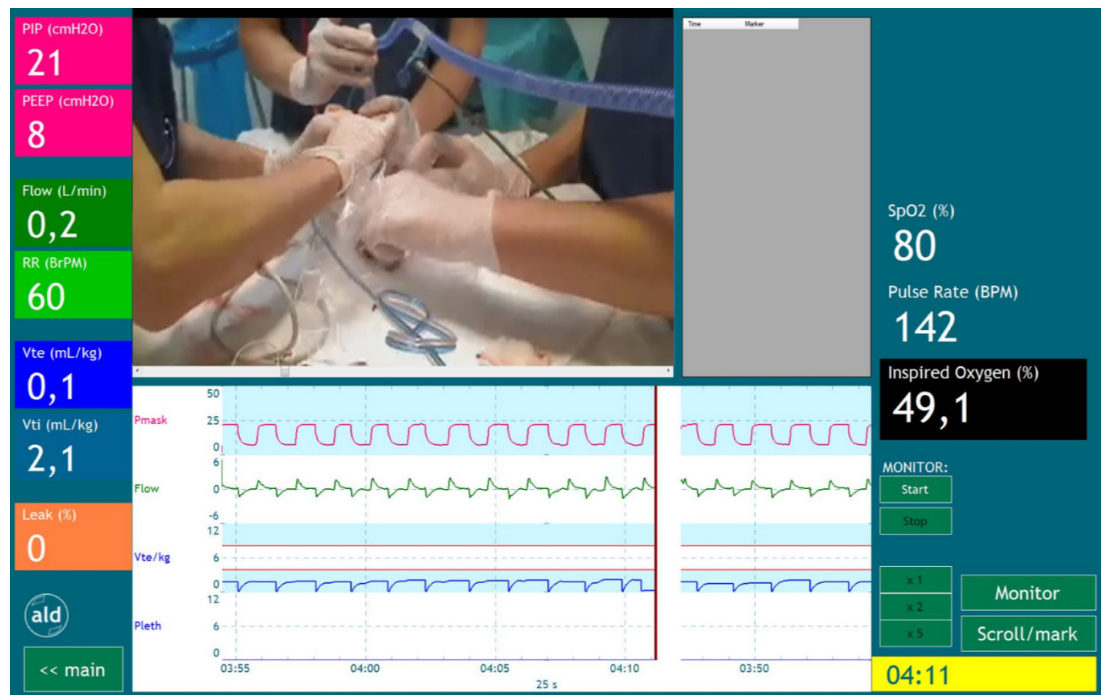


Figure 1 Recording video and vital parameters of neonatal resuscitation at the Leiden University Medical Center. PIP, peak inspiratory pressure; PEEP, positive end-expiratory pressure; RR, respiratory rate; Vte, exhaled tidal volume; Vti, inhaled tidal volume.

Reviewing recordings of neonatal resuscitation

In our NICU, to parents of each patient a primary neonatal care provider from the medical team is allocated as point of contact. This provider is responsible for the communication and has regular meetings with parents. The primary neonatal care provider informs parents about the possibility of reviewing the recording of their infant and of reviewing the recording together with parents, providing medical information and answering questions of parents.

Data collection

Data were collected between February 2018 and October 2019. In this period, all parents invited to watch the recording of their very or extremely preterm infant were approached to participate in this study, unless the primary neonatal care provider considered it inappropriate to approach parents for study participation due to emotional distress. In these cases, parents were invited to review recordings of their infant but were excluded from participation in this study. Parents orally consented to both participant observation and participation in an interview, or either observation or interview.

Participant observations and interviews were performed by MCdB. Consistent with standards in qualitative research, we reported observations in field notes¹⁵ and performed interviews using a topic list that was adapted through an iterative process to ensure that the questions captured all relevant emerging themes.¹⁶ Inclusion of participants continued until thematic saturation¹⁷ was reached.

Analysis

Interviews were audio-recorded and manually transcribed. Field notes and transcripts were deidentified. Data were first reviewed in a process of open coding by two investigators independently; subsequently, data were thematically analysed. Main themes emerged during consensus meetings. The qualitative data

analysis software programme ATLAS.ti V.8.4 was used to analyse data.

RESULTS

In the study period, recordings of neonatal resuscitation were reviewed on 27 occasions. In seven cases, parents were not approached for study participation due to emotional distress; however, the primary neonatal care providers reported positive parental experiences with reviewing recordings of their infant. All approached parents consented to participant observation during review. Parental review of recordings of neonatal resuscitation was observed on 20 occasions, reviewing recordings of 31 children, of whom four died during admission. Median (range)

Table 1 Characteristic observations	
Characteristic observations (n=20 occasions reviewing recordings of 31 infants)	
Interval between birth and review in days median (IQR)	34 (20–89)
Gestational age in weeks median (range)	27+5 (24+5–30+3)
Deceased, n infants (%)	4 (13)
Type of pregnancy, n infants (%)	
Singleton	12 (39)*
Twin	16 (52)
Triplet	3 (10)
Resuscitation, n infants (%)	
CPAP	31 (100)
PPV	26 (84)
Intubation	4 (13)
Cardiac resuscitation	1 (3)
Requested screenshots or copy video, n occasions (%)	13 (65)

*On one occasion, parents reviewed recordings of two singleton infants who were both born extremely premature.

Table 2 Characteristic interviews

Characteristic interviews (n=13 interviews with 25 parents of 19 infants)	
Fathers, n (%)	12 (48)
Bereaved, n parents (%)	2 (8)
Age (years), median (range)	
Mothers	32 (23–41)
Fathers	34 (24–45)
Present during resuscitation, n (%)	
Mothers	2 (15)
Fathers	11 (92)
Mode of birth, n infants (%)	
Caesarean section	8 (62)
Vaginal	5 (38)
Parity, n mothers (%)	
Nulliparous	9 (69)
Multiparous	4 (31)

*As infants participated in the ABC2 study (NTR7194/NL7004),³⁴ infants were resuscitated with intact umbilical cord. Mothers were therefore present during resuscitation.

gestational age at birth was 27+5 (24+5–30+3) weeks. Further characteristics are presented in [table 1](#).

On three occasions, parents declined interview participation due to emotional distress. Four times, parents consented to be interviewed; however, their infants were transferred to another hospital before the interview could be conducted. As providers tended to ask parents about their experiences during the review, experiences of most of these parents were reported in field notes of participant observation. Eventually, 25 parents of 19 infants participated in an in-depth interview. On 12 occasions, both parents participated in an interview; on one occasion, only the mother participated in the interview. Further characteristics are presented in [table 2](#).

Four main themes could be identified: impact on parents, impact on children, appreciation and set-up and timing of the review.

Impact on parents

During the study period, all approached parents except for one father agreed to review the recording of their infant. The main motivation for parental review was curiosity about the first minutes of life of their infant:

I wanted to see it because I was not there. He can be with you for two seconds, and then they take him to that other room and you only see him again on the ward. So, you don't know what happened in between. LP03, mother

Most parents, including all bereaved parents, reported positive experiences. Bereaved parents felt that reviewing supported them in their grieving process. Many parents reported that reviewing the recording helped them in coping with the trauma of premature birth:

For me, as well as for many other mothers, it was traumatic. And going through the full story helps. (...) Knowing what happened helps bonding with your child, and it helps to cope. LP11, mother

One father reported that he would have preferred not to watch the recording, but that he felt it was important to share this experience with his wife:

I would have preferred not to see it. But I wanted to watch it for my wife, you know. LP03, father

Most interviewed mothers considered the moments directly after the birth of their infant as 'the missing piece of the puzzle' and reported that reviewing the recording of their infant helped them to fill these gaps:

I was really touched. All these pieces of the puzzle fell into place, because finally I got images fitting to the words I heard before. LP19, mother

Mothers also reported that reviewing the recording helped them to create a common memory with their partner, allowing them to cope together. Coping together was also reported by fathers. Some fathers reported to consider reviewing the recording as a valuable possibility to share their experiences with their partner:

In order for her to know what happened during the resuscitation. (...) And in order for her to see what I experienced during the resuscitation. LP09, father

Many parents (65%) requested a copy or screenshots of the video recording of their infant. Parents considered the video or screenshots of their infant as a keepsake of their NICU story, and reported that having a copy or screenshots comforted them, especially when they had lost an infant:

Because we lost two children. And keepsakes, any keepsake, everything you can collect from your children, that's very valuable. (...) You don't know if you will ever do something with it, but you have it, just in case you want to watch it. LP16, father

Impact on children

Parents reported that reviewing the recording of their infant could be beneficial for their child, as they now got a better understanding of the start of the life of their infant:

It's the very first start of their life. And if they have questions about that, I can now answer them. I really appreciate that. Otherwise I would have had to tell them that I don't remember. LP02, mother

Parents furthermore reported that having a copy of the recordings may as well be valuable for their child, as this would allow their child to watch the recording in the future. Parents felt this could be beneficial for their child, for instance, when their child had questions about their birth. On two occasions, parents requested a copy in order to be able to show the recording to a surviving sibling of the deceased sibling(s):

And if our daughter is gonna make it, we have something we can show her. Look, you had a brother and a sister. They didn't make it, but this is how it all started. As such she also has an idea of how it all started. LP16, father

Appreciation

Reviewing recordings of neonatal resuscitation often resulted in appreciation. While watching the recording, parents remembered how small their infant was at birth, and they were proud of the developments their infant had made. Parents furthermore often stated to be proud of their infant during the resuscitation, especially when the provider pointed out the infant's breathing effort as visualised by the respiratory parameters:

She so much wanted to breathe, and she did! I am so proud of her! LP11, mother

Many mothers were touched by watching the first contact between father and child. Some mothers reported that seeing the father taking care of their infant resulted in appreciation for their partner:

And to see that your partner is there in these moments, that helped. (...) To see him navigating between the two boys. What do I have to do? What's going on? (...) It was such an intense experience for him. And I think it helped him too that I could tell him how much I appreciated him being there. LP19, mother

Reviewing recordings frequently resulted in parental appreciation for the providers' efforts to deliver the best care to their infant. Parents appreciated seeing the providers' professionalism:

And all care, it was so calm, and centered around her. (...) I really appreciated to see that everybody was working towards the same goal. LP07, father

Parents furthermore appreciated the efforts of providers to be open to parents by showing them the recordings. Some parents even reported that this openness would make them less likely to hold providers responsible for medical malpractice:

You're human, and humans make mistakes. And if a mistake is made, you have to be honest about it. (...) In the end, I think that is way more valuable for parents than to just keep on saying: no, I did not make a mistake. (...) When you are honest about it, I am ok with it, but if you lie about it, I will sue you. LP02, father

Set-up and timing of the review

Positive experiences with reviewing the recordings were also related with the set-up of the review. Parents frequently reported the importance of having a provider present during the review to explain the medical context:

I think it helps when somebody sits next to you and tells you this is normal. For us this is normal. (...) Someone who can really put into perspective what is normal for a premature or a newborn. LP07, mother

Parents furthermore reported that they appreciated that providers took time to sit down with them and to go through the full story:

I think that's probably the best thing, that they carefully go through what happened then. LP19, mother

Parents considered the timing of the review as the most important condition for a positive experience. Parents of surviving infants considered their infant being relatively stable as the most important precondition:

I think it is important to watch the recording when your child is stable and slowly getting better. Because you need peace of mind. Otherwise you are only worrying about your child. LP07, father

Parents of infants who died during admission normally reviewed the recordings during the follow-up meeting for parents of deceased infants. During this meeting, parents and the primary neonatal care provider reflect on the infant's stay at our NICU and the period after. Once, parents requested to review

the recording of their infant on the estimated date of delivery, as they considered reviewing the first minutes of their infant's life as a ritual to commemorate their infant.

DISCUSSION

At our centre, we consider reviewing recordings of neonatal resuscitation with parents as standard care, and parents may request screenshots or a copy of these recordings. However, concerns about sharing recordings of neonatal resuscitation with parents, for instance, because of medicolegal consequences, are also reported.¹⁸ Our study explored parental experiences with reviewing the recording of the resuscitation of their very or extremely preterm infant. Parents reported many positive experiences, with special emphasis on the value for getting hold of the start of their infant's life and coping with the trauma of neonatal resuscitation. Reviewing recordings of neonatal resuscitation frequently resulted in appreciation for the child, the father and the medical team. Timing and set-up of the review contributed to positive experiences. Parents considered screenshots or copies of the recording of their infant as valuable keepsakes of their NICU story. These positive parental experiences may reduce concerns about sharing recordings of neonatal resuscitation with parents.

Premature childbirth is recognised as a traumatic experience for parents, and various studies investigated interventions to help parents cope with this trauma.^{19 20} In our study, many parents reported considering the resuscitation of their infant as traumatic, with some fathers reporting being present during the resuscitation as a traumatic experience, and many mothers considering not knowing what had happened with their infant directly after birth as traumatic. Parents reported that reviewing the recording of the resuscitation helped them to cope with these traumas. This may be because parents are exposed to a trauma-related cue, that is, the resuscitation of their infant, in absence of danger, which is one of the most empirically validated treatments for post-traumatic stress disorder.²¹ Knowing the outcome of the resuscitation, with their infant being relatively stable, parents are exposed to the full story of the resuscitation of their infant. As parents are accompanied by their primary neonatal care provider during the review, parents receive appropriate medical information about their infant. This was also reported to reduce mental stress of parents.^{22 23}

At our NICU, partners are invited to be present during the entire neonatal resuscitation. As soon as possible, parents are talked through the interventions that are being performed. Furthermore, parents are encouraged to touch their infant as soon as the condition of the infant allows doing so. Despite these efforts to support parents during the resuscitation of their infant, some interviewed fathers considered being present during the resuscitation as traumatic. The negative impact on fathers that were present during neonatal resuscitation was also reported by Harvey and Pattison.²⁴ In their study, various fathers reported that they wanted to talk about their feelings and experiences, but that they felt this was inappropriate. The need to talk was also reported by fathers in our study, who reported the desire to share their experiences with their partner as the main reason to review the recording. Reviewing the recordings allowed fathers to share their experiences and feelings with their partner, either during the review, or afterwards, and to reflect on their experiences with their primary neonatal care provider. When reviewing the recordings, mothers frequently appraised fathers for their role during resuscitation, thus empowering fathers in their parental role. This may as well be beneficial for fathers as earlier studies

reported that fathers of preterm infants are concerned about the loss of parental role.^{25 26}

A major concern of parental presence during the resuscitation of their child is the lack of communication to parents.³ Providing parents with information during an emergency procedure can be complex, time-consuming and challenging, and even when medical information is provided, highly distressed parents may not be receptive to provided information.²⁴ In our study, parents reported that due to the timing of the review, they could be more receptive to the provided information and that they highly valued the communication during the review. Parents reported appreciation of the time efforts and dedication of providers during review. Furthermore, many parents pointed out that providers seemed not stressed during the resuscitation and that they felt a lot of personal investment. Parents also reported appreciation of the openness of providers about provided care and that this openness and transparency would make them less likely to hold providers responsible for medical errors, a mechanism that is confirmed by studies about disclosing medical errors.²⁷ As such, reviewing recordings of neonatal resuscitation with parents can be valuable for parental coping and can enhance the parent-provider relationship.

Reviewing recordings of neonatal resuscitation with parents is time-consuming and requires preparation, for example, the technical set-up of the review, which explains the relatively low number of occasions of parental review. During the study period, preparations could be done by investigators, but in the daily NICU practice, it can be challenging to offer all parents the possibility to review the recording of the resuscitation of their infant. However, given the clear benefits of parental review of these recordings reported in this study, we argue it is important to offer this possibility to all parents of very or extremely preterm infants as standard of care. Future efforts should therefore be on finding feasible ways for doing so, for instance, by appointing a dedicated provider that prepares review meetings, and establishing more evidence about the benefits of parental review of neonatal resuscitation by conducting follow-up studies, such as a quantitative questionnaire among parents, studying outcomes of this study more in-depth. Furthermore, in this study, we solely studied experiences of parents of very or extremely preterm infants. More research is needed in order to evaluate whether reviewing recordings of neonatal resuscitation is also valuable for parents of birth asphyxiated infants.

About two-thirds of the parents in our study requested screenshots or a copy of the recordings of the resuscitation of their infant. Other studies also reported that patients are interested in receiving a copy of the recording of their procedure.^{28 29} Makary *et al*^{30 31} and Joo *et al*³² argued that sharing videos of medical procedures may improve patient satisfaction, which was also reported in our study. Parents in our study highly valued copies of the recordings as keepsakes. The value of keepsakes for parents of infants admitted to the NICU was reported before.³³ Parents furthermore reported that having a copy comforted them and helped them in coping, and that they expected the recording to be valuable for commemorating infants that deceased during admission. None of the parents connected the recordings with medicolegal purposes, which may allay earlier reported concerns about medicolegal consequences of sharing recordings of neonatal resuscitation with parents.¹⁸

Based on the experiences reported by parents in our study, we argue that reviewing recordings of neonatal resuscitation with parents of very or extremely preterm infants can be recommended. Furthermore, the benefits for parental coping and enhancing the parent-provider relationship may as well apply

to reviewing recordings of the neonatal resuscitation of birth asphyxiated infants, resuscitation of older children or other intensive procedures in paediatrics. However, reviewing recordings of resuscitation should preferably not replace parental presence during the resuscitation of their child but should be considered as an additional tool to provide family-centred care.

CONCLUSION

Interviewed parents consider reviewing recordings of neonatal resuscitation of their very or extremely preterm infant as valuable. Parents reported that reviewing recordings can help them cope with the trauma of neonatal resuscitation. Reviewing recordings furthermore frequently resulted in appreciation for the child, the father and the medical team. Moreover, parents considered a copy of the video recordings of the resuscitation of their infant as a valuable keepsakes. These positive parental experiences could allay concerns about sharing recordings of neonatal resuscitation with parents.

Twitter Martine C de Vries @martinecdevries and Arjan B te Pas @None

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Competing interests None declared.

Patient consent for publication Not required.

Ethics approval This study was reviewed by the Ethics Review Committee of the LUMC (reference number P16.316). In concordance with laws and guidelines, a statement of no objection against execution of the study was issued.

Provenance and peer review Not commissioned; externally peer reviewed.

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