Women and partners’ experiences of critical perinatal events: a qualitative study

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ABSTRACT
Objective  The aim of this study was to explore women and partners’ experiences following critical perinatal events.

Design  This is a qualitative interview study. We conducted semistructured individual interviews with women and their partners in separate rooms. Interviews were analysed thematically and validated by a transdisciplinary group of anthropologists, obstetricians and a midwife.

Setting  Department of obstetrics at a tertiary referral university hospital in Denmark.

Participants  Women and partners who had experienced a critical perinatal event within the past 3–12 months.

Results  We conducted 17 interviews and identified three main themes: (1) ambivalence towards medicalisation, (2) the extended temporality of a critical birth and (3) postnatal loss of attention from healthcare professionals. Overall, participants expressed a high degree of trust in and quality of provided healthcare during the critical perinatal events. They experienced medicalisation (obstetric interventions) as a necessity, linking them to the safety of the child and their new role as responsible parents. However, some women experienced disempowerment when healthcare professionals overlooked their ability to stay actively involved during birth events. Postnatally, women and their partners experienced shortages of healthcare professional resources, absent healthcare and lack of attention.

Conclusions  Women and their partners’ experiences of critical perinatal events begin long before and end long after the actual moment of childbirth, challenging conventional ideas about the birth as being the pivotal event in making families. In future healthcare planning, it is important to align expectations and guide parental involvement in birth events and to acknowledge the postnatal period as equally crucial.

INTRODUCTION
In Denmark, maternal mortality rates are historically low,1,2 with a significant drop over the past century due to advances in medical technology, improved knowledge and the implementation of evidence-based clinical guidelines.3 Yet, today, approximately 10% of all births in Denmark can be categorised clinically as acute or critical due to emergency caesarean sections, placenta complications, massive postpartum haemorrhage, severe pre-eclampsia and other rare complications.4

Behind the numbers of women who have undergone a critical perinatal event are stories about how people survived, how they experienced having been in need of urgent medical assistance with a potential long-term impact on their physical and mental health,5 not to mention their future reproductive decision making. Apart from a growing literature on the healthcare professional perspective6,7 and premature birth experiences,8,9 women’s stories of critical perinatal events are understudied.10 In particular, partners’ experiences with attending critical perinatal events have been largely absent in the literature.11,12

According to recent research on women’s experiences of near-loss; shock,10 loss of control,13 disempowerment and a lack of information are central concerns.14 Hinton et al identified a need for improved quality of care across the whole patient pathway including longer-term support and counselling.10 To improve future critical obstetric care there is a need to explore in-depth how women and their partners experience such critical perinatal events and pathways.
This paper presents the results of a qualitative interview study of women and their partners with critical perinatal events at a Danish tertiary obstetric department. In this study ‘critical perinatal events’ are defined as adverse events in pregnancy or childbirth with an actual or potential hazard to the health or well-being of the mother and/or fetus.

The aim of this paper is to contribute to an understanding of how women and their partners experience and make sense of such critical perinatal events and the involved presence of medical technology and professional caregiving in the field of obstetrics.

METHODS
We conducted a qualitative interview study to explore how women and their partners give meaning to their experience of critical birth events. Data from the interviews are reported in two different papers. In addition to the aim of this study, we also explored the experience of women and their partners with postnatal debriefing consultations with an obstetrician.

Setting
The study included women from the department of obstetrics at a large hospital in Denmark that had 5366 deliveries in 2018.

The inclusion criteria were women who had been referred to a postnatal debriefing consultation with an obstetrician and who had experienced a critical perinatal event. The women and their partners had to be native or English speaking. The exclusion criteria were perinatal death and lack of informed consent.

Auxiliary nurses in the outpatient clinic informed eligible study participants about the study by handing out information letters when attending the postnatal consultation. In the invitation letter women and partners were asked to give consent to be contacted for an interview and the women were also asked for consent to share their medical data. If they agreed to participate, they were contacted by telephone by the first (LEN) or second author (SH) and enrolled in the study after informed written consent had been obtained.

Data collection
The study participants were interviewed individually 3–12 months after the birth in the period from August to November 2018.

Most interviews took place in the participants’ homes, two were conducted at the hospital and one in the study participant’s workplace on request of the women or the respective partner. The first and second authors (LEN and SH), an anthropologist and a midwife conducted the interviews together. None of the interviewers had a professional or personal relation with the participants.

In order to access the women and their partners’ experiences of their pathways through pregnancy and childbirth, we used a narrative technique; opening all interviews with the question: ‘Please tell us your story about pregnancy and birth, where you think it all begins...’. Based on existing studies, interviews and participant observations of debriefing postnatal consultations with an obstetrician, a few interview themes had been identified in advance. As the women and their partners’ narration came to a ‘natural’ end, we opened a questioning phase based on the predefined interview themes (Box 1).

The interviews, which were audiotaped and transcribed ad verbatim, lasted between 30 min and 2 hours. Originally, the interviews were conducted and transcribed in Danish. Two participants were English speaking. The Danish quotes underwent forward backward translation by a professional English language service provider.

Theoretically, the study draws on a phenomenological tradition, exploring human experience and sense-making. Furthermore, using the narrative technique to open the interviews provided the interviewers access to the order and meaning that women and their partners attribute to the critical perinatal events and to their expectations and understandings of the occurred events. We paid special attention to the ways in which the women and their partners narrated their birth experience and shifted from general description of their life to specific details on social, temporal and spatial indicators and specific locations of an event.

Data analysis
We experienced thematic saturation after having conducted eight interviews with women and stopped after having conducted 10 interviews. To obtain a general comprehensive impression of the collected information, the interviews were read through and coded manually.

Box 1 Interview guide. Women’s experiences of critical births and postnatal consultations.

Introduction:
The aim of the study, voluntary participation, possible to withdraw, tape recording, anonymity, how interview data will be reported, optional reading of publication draft.

Opening question:
Please tell us your story about your pregnancy and childbirth, where you think it all begins...

Fix points
► Expectations.
► Experience.
► Social interactions and relations
  – Healthcare professionals.
  – Partner.
  – Child.
► Organisation
  Emergency, during admittance, transfers between departments (obstetrics antenatal, obstetrics postnatal, operation room, intensive care unit, neonatology, pediatrics, other).
► Reactions from family and friends.
► Postnatal consultation.
► Postrationalisations.
► Thoughts about the future—future pregnancies and births.
The transformative elements of the stories. We wanted to pay attention to the contextualisation, the chronology and publishing patterns and relations between themes and paying attention to the contextualisation, the chronology and the transformative elements of the stories. We wanted to remain open towards new themes that may have appeared in the initial interpretation. During the third reading, we related our coded themes with the predefined themes or ‘fix points’ of the second part of the interview guide. This process revealed that most of the women and partners’ began their own narratives with their expectations, followed by their concrete experiences and ending with some reflections on future pregnancies. By involving researchers from different fields in both designing the study as well as in the analysis phase, we ensured rich reflections on data as well as challenged our respective preunderstandings. In order to illuminate blind spots in the interpretive process, all authors read the transcripts and met to discuss what themes each of us had identified as central. The research group agreed on the following themes: (1) ambivalence towards medicalisation, (2) extended temporality of birth and (3) postnatal loss of attention from healthcare professionals. The authors have seen a need to bring forth the voices of women and partners as an equally important part of developing the field of medical education and improving the quality of care. Designing this study as a qualitative interview study using a narrative technique was a way for us to give room for and learn from the women and partners’ stories.

RESULTS
We conducted 17 interviews with 10 women (one of whom was a single parent) and 7 partners. All partners who agreed to participate in this study were male. The type of critical perinatal event, age, occupational status and socioeconomic status of the participants varied. Most of the women had 3–4 years of higher education or an advanced degree, were nulliparous and most were born and raised in Denmark (online supplemental table 1). The participants represented a wide range of critical events (some experiencing more than one): six of the women had emergency caesarean sections, five had a preterm birth, three experienced postpartum haemorrhage, two had pre-eclampsia, two had placental abruption and one had a perioperative bladder injury (online supplemental table 2).

Generally, the participants expressed a high degree of trust in and quality of the healthcare they received during these critical birth-related events. Moreover, the analysis identified three overall themes: (1) ambivalence towards medicalisation, (2) the extended temporality of a critical birth and (3) postnatal loss of attention from healthcare professionals.

Ambivalence towards medicalisation
A dominant narrative across the interviews was that the women and their partners viewed the availability of medical interventions during childbirth as a form of extraordinary healthcare, understood as more than expected, for the safety of the child and the mother in a situation of exceptional uncertainty, crisis and medical needs. My story began with my first child; a long birth that ended in a C-section. For my second child the midwife recommended that I try a vaginal birth, (…). But during birth the baby’s heart rate deteriorated (…) and a senior doctor recommended doing a C-section, stating: ‘Better safe than sorry.’ I just wanted him [the baby] out. For me it was like, a vaginal birth is not the most important thing, I just wanted him to come out and be fine. They took me to have a C-section, and I was all in on that. (…) The staff kept arguing in favour of a C-section. I think they saw me as, (…) I’m someone who’d really like to give birth vaginally’. They thought that I was disappointed. And it was absolutely fine, really, because they explained everything to me, the ins and outs of the decision (…). All I wanted was to have a healthy baby, right and there was nothing I could do about it myself.

(Lily (all participant names are pseudonyms))

Like many of the other interviewees Lily, stressed that surrendering control and doing whatever was needed in the interest of her child was an act of trust in clinical judgement, a realisation that one cannot act alone and a way to establish herself as a responsible parent. This woman did not expect to have a vaginal birth. Having experienced a previous caesarean section, she was mentally prepared for the fact that she might have another caesarean section and welcomed the course of events, including high levels of monitoring and urgent intervention when needed. Often the interviewees described the actual birth event as being simultaneously good and bad, safe and unsafe, and engaging and disempowering and sometimes humiliating (table 1, quote 2). Medicalised birth was described as an ambivalent experience steeped in contradictory emotions. The partner in quote 2 embraced a momentary loss of control and linked intervention to professionalism. Such ambivalent emotion towards medicalisation was a common experience shared by the majority of the
participants. The woman cited in quote 3 (table 1) experienced disempowerment along with medicalisation, which is evident in her depiction of humiliations alongside appreciative views associated with a semiacute caesarean section.

This woman acknowledged the expertise and authority of the anaesthesiologist; however, she was frustrated that her ability to participate in birth-related events was not recognised by the professionals. To this woman, as was the case for most of the women we interviewed, her ability to participate in the birth was closely linked to her ability to become a good mother.

Another woman shared what appeared to be a classic medicalisation story. She clearly expected to give birth vaginally and, as she termed it, as naturally as possible, but felt medicalised by the healthcare professionals (table 1, quote 4 and table 1, quote 5). Yet, as her story unfolds, it presents competing positions on what constitutes a good birth (table 1, quote 6). On the one hand, the notion of the body transformed into a machine indicates the woman’s resistance towards unwanted medicalisation. On the other hand, the woman described a gradual alignment with intervention when a medical reason was introduced (reduced amniotic fluids) and a change of
experience when she regained control of her own body due to the pain relief offered (epidural).

Like most of the interviewed women and partners, this woman did not tell a conventional story about a loss of control over body or actions. Rather, she simultaneously described an experience of loss of and gaining of control through interventions.

Three women with long histories of infertility treatments or chronic diseases experienced medical interventions (such as medical initiation of labour) as a consolation. To them, the experience of not being in control of their bodies was highly familiar, and medical technologies constituted necessary means to obtaining their ultimate goal of becoming a parent.

For example, one woman who had experienced many years of infertility treatments welcomed medical interventions during birth as necessary and inevitable. To her, induction of labour was a relief. Two women, with previous uncomplicated births, however, saw induction of labour as an unwelcome disruption.

**The extended temporality of a critical birth event**

In reality the birth itself was no more than a small parenthesis—to me it was at least—and then when he came out, then it all truly began. (Thomas, preterm birth week 25)

The birth itself, we’ve talked about it… in reality it’s just a … I mean it’s supposed to be the culmination of everything, but in actual fact it ended up being just a minor thing. Certainly, I feel that the birth kind of began when I was hospitalised in week 21, and then the actual birth didn’t begin until three weeks later. (Emily, preterm birth week 25)

The quotes of Thomas and Emily illustrate a particular extended temporality of experiencing a critical birth event, as identified in this study. First, the quotes show that the participants experience birth as beginning (long) before and/or continuing (long) after the actual act of giving birth. Second, the quotes demonstrate the differences in the temporality of birth as experienced by women and their partners, respectively.

In general, the women described a trajectory of healthcare that spanned the continuum from ordinary (aligned with expectations) and extraordinary (more than expected) to absent healthcare (less than expected). For the partners, the pathway of childbirth often began when the child was born. For the women, the pathway often began months, sometimes years before the actual birth.

A mother described how her story of becoming the mother of her child had begun many years earlier, with infertility treatments. After finally getting pregnant by in vitro fertilisation with oocyte donation and a near loss of the fetus, her child was born extremely prematurely (before gestational week 26). As demonstrated in the section on ambivalence towards medicalisation, her reproductive history shaped her experience of medical interventions, filling her with a sense of relief. The actual act of birth was not the pivotal moment in her memory of becoming a mother. Her eggs were not fertile and her body had resisted pregnancy in many ways. Instead, the moment she shared her first drop of milk with her son constituted the first connection between her and her new born son.

Even though this woman’s experience of birth is not representative of the predominant birth narratives, her reproductive story serves as a reminder that, for some women, the process of becoming a parent spans years of trying and failing. In the same way, many women and their partners described the act of birth not as a neatly demarcated event but as a minor part of all the other events related to becoming a parent.

The experience of women-centred care during the actual birth events made many women feel safe (table 2, quote 8). Most of the participants experienced extraordinary care and a high level of trust in the healthcare professionals during the act of giving vaginal birth or

<table>
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| **The temporality of a critical birth event** | I: Throughout the whole crazy process, the time when I felt most comfortable (…) was the actual birth. In the weeks leading up to it, the midwives said I should just lie here as long as possible and there wasn’t really much they could do for me. (…) Since then I’ve thought about how uncomfortable it actually felt for me. It was strange lying there for three weeks and being totally dependent on them and being humble towards them; now I think that there was a lack of care and attention. 
Interviewer: what do you think made you feel comfortable during the birth? 
I: ‘When I was in the prenatal ward, I felt like I was lying there alone all the time and I was really scared that something might happen. They talked a lot about me possibly going home. I don’t know what it was [during birth], the midwives, they were so nice and so good at being there and explaining all the time what was going to happen. (Emily) |
| a.I: ‘During the last third of the birth, I felt redundant and excluded; my wife was in another world.’ (Sebastien) |
| b.I: ‘During the caesarean section, I felt forgotten—just sitting there in the corner; but I wasn’t nervous. I felt that the staff was in control of the situation’ (Peter) |
| c.I: ‘No one talked to me during the C-section, until the baby was born. I felt lonesome.’ (Jessy) |
having a caesarean section. For the partners, on the other hand, the actual moment of birth was characterised by a lack of attention given or even a sense of feeling excluded (table 2, quote 9a, b and c).

The partners with premature infants, however, constituted an exception. From the moment of birth, they were granted a special and important parental role as their partners (the mothers) were often admitted to the maternity ward for more close observation in the immediate postpartum period. Partners with premature infants were the first to see, hold and feed their child. The differences in experiences between partners with preterm infants and other partners underline how not only the women, but also their partners, long to be actively involved in the process of becoming parents.

Postnatal loss of attention from healthcare professionals

It’s like, when you’ve given birth and you’ve been moved over to postnatal, it’s not really you that’s … it’s no longer about you. (Emily, preterm birth week 25)

After the birth of their child, many of the interviewed women experienced a dramatic change in scenery and a loss of the attention given by healthcare professionals. Our participants underlined how much the attention from professionals matters in the overall picture and how this is closely linked to them feeling acknowledged and to their experience of feeling competent as parents.

Postnatally, all the women described an experience of lack of maternity care due to the absence of nurses and doctors in the postnatal maternity ward. In particular, the participants experienced a lack of continuity in healthcare professionals and in the available physical space (table 3, quote 11a and b), just as they overheard healthcare professionals talking about how busy they were. Some healthcare professionals explicitly explained to the patients how they came to check on their patients, in their spare time, after their night shift was over. In the same vein, the participants interpreted such acts of kindness as extraordinary care (more than expected) and as a sign of how critical their particular clinical status was or had been. Some study participants assumed that the particular time (at night, during the weekend) at which they gave birth influenced the professionals’ level of stress (table 3, quote 12).

When all of the study participants were asked what they defined as care, they mentioned examples such as professionals asking them how they were doing, having their blood pressure checked or assistance with delivering the first drops of milk to the neonatal intensive care unit. This kind of attention was what the participants lacked on the maternity ward. For one woman, a senior doctor became her hero when he accidentally spotted her desperate need for attention in the maternity ward, 4 weeks into her admission and while her son was admitted to the neonatal special care unit (table 3, quote 13).

Other study participants described how the lack of postnatal care resulted in delayed diagnosis of a perioperative bladder trauma, medication errors, insufficient monitoring of blood pressure in chronically ill women, and in lack of consistency in breastfeeding advice (table 3, quote 14).

Most importantly, the parents expressed how a lack of attention made them feel insecure about themselves as parents. For instance, they doubted their ability to read their child’s needs, to feed their child or to take good care of it (table 3, quote 15).

Discussion

This study examined the parental experiences of critical perinatal events and resulted in various findings. First, the study demonstrates that the women and their partners felt ambivalent about the medicalisation of birth. On the one hand, they embraced interventions as a way of ensuring the safety of their child and enacting their role as responsible parents. On the other hand, the same interventions sometimes provoked feelings of disempowerment and inadequacy concerning their role as parents. Nevertheless, they generally experienced medicalisation as a necessary and timely response to critical perinatal events.

Second, we have shown how the narratives told by the women and their partners after experiencing critical birth events begin long before and end long after the actual moment of birth; comprising what we term ‘extraordinary family geneeses’ and challenging conventional obstetric ideas about the birth as the pivotal event in a family’s story of coming into being.

Third, we demonstrate that experiencing a shortage of healthcare professionals goes hand in hand with an experience of postnatal loss of healthcare attention. The absence of postnatal support and follow-up11 as well as the pressure on the hospital wards is described in previous studies.27 However, the women in this study experienced a lack of healthcare, for example, an absence of monitoring of vitals, tutoring breast feeding and personal contact provided by healthcare professionals during the hospitalisation. This postnatal experience stands out in comparison to the experienced healthcare given during the act of birth and sometimes also antenatally. Moreover, the parental experience of postnatal loss of attention and lack of healthcare offered may consequently have delayed or diminished the parents’ trust in their own abilities as parents.

Strengths and limitations

This study involved interviewing women and their partners who had recently experienced critical perinatal events; the interviews were conducted shortly after the events with a minimal risk of recall bias. The study, thus, supplements the findings of previous studies of near-loss experiences of women and their partners with interviews conducted several years after the event.10 11 Moreover, interviewing the women and their partners individually facilitated uninterrupted narratives, and gave voice to the
Table 3  Illustrative quotes representative of theme 3 (all participant names have been changed to pseudonyms)

<table>
<thead>
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<th>Theme</th>
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<tr>
<td>Loss of attention</td>
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<tr>
<td>11</td>
<td>I: ‘New doctors and new nurses again and again.’ (Victoria)</td>
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<td></td>
<td>2. I: ‘I ended up constantly moving. Altogether, I was moved around, eight different beds and three wards in five days...’ (Lauren)</td>
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<td>12</td>
<td>I: ‘I think we sort of had the impression that, you know, it was the weekend—it was a bit Saturday-like—uhh, it was all a bit quiet and low-key’ (Peter)</td>
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<td>13</td>
<td>I: ‘So I just lay there for three weeks, my cervix was too short (…) It was really tough. I gave birth in week 25 and after the birth I lost a lot of blood. I just remember thinking I was going to die. Everything felt wrong and I had no-one to talk to. No-one at all. Only family. Then I was put on the neonatal ward and the focus was completely different. They wanted me to see him [the baby], but I didn’t feel like it at all [crying]. On the neonatal ward I just sat there and stared into the incubator and tried to look like I was a mother. (…) it felt like we hadn’t actually had him until we were discharged. (…) I felt so sad and low that I didn’t even feel like living any more. Then I saw a doctor and he basically saved me. He just came in and said, I promise we won’t let you go before you can tell me face to face that you’re feeling better again.’ ‘And he kept an eye on me the whole time we stayed there. You just need some kind of continuity at such a chaotic time’. (Emily)</td>
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<td>14</td>
<td>1. I: ‘It felt like I got to see very few doctors. There was one who mostly sat in his office the whole time and looked at his screen. We felt totally ignored.’ (Jacob)</td>
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<td>2. I: ‘There’s an example that just came to mind from the maternity ward, where I sometimes didn’t feel so confident. They weren’t paying attention to us. A very concrete example was that my wife had, I think, some kind of pad inside her to stop the bleeding. And then the doctor says, ‘Don’t worry, tomorrow at 10 o’clock?—a doctor will come, they will check you and so on and so on.’ And then at 10 o’clock, nobody came. So, I think we had to ask, and then someone came, maybe, I don’t know, early afternoon or something like that. (Sebastien)</td>
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<td>3. I: ‘For me there was a big difference between being in the prenatal ward and being in the maternity ward. It felt like things were much more under control in the prenatal ward. When I was put in the maternity ward, no-one came to measure my blood pressure because they forgot. And it was like, now my baby is born, it doesn’t matter so much anymore, or what? Once I was also in the medicine room with an older nurse because I had been given some wrong medicine. They were very busy there’ (Sophie)</td>
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<td>15</td>
<td>I: ‘Lying there and aching all over, having to keep an eye on myself and also having a little mite and almost not daring to shut my eyes because I was scared, she wasn’t breathing—(…). There were all sorts of problems with feeding, she was given a bottle very early on. Just to get some food in her so she wouldn’t lose weight. … we started by giving it to her in a shot-sized glass, which was fine, but then it soon became really difficult to get her to take enough that way. Again, my experience was that I had to go out and actively try to get hold of someone, it was like ‘hey?’ There was an older nurse who looked in and said, right, if you can’t feed her more, she needs to have a bottle. And the day after it was the same thing all over again. I had to go get the nurse to come and show us what to do. But she didn’t come. Now, you’re told she should have this and this amount—but you’re not told how to work out how much she should have on your own. And if you don’t, you definitely need to come on day two, and if you don’t come on day two, well, you know … It was a bit of a stress factor actually and we were unsure whether we were doing it right.’ (Sophie)</td>
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partners, who have been silent until recently.11 The study did not include women with antenatal, intraterine or postnatal death. Our study sample was relatively small due to prioritising in-depth knowledge on lived experience over volume.24 Future studies may seek to cover more complications and a larger sample of partners. Providing patient demographics and available patient data on the participants in this study allows for healthcare professionals to compare their own patient population with this data set.

Interpretation
In the social sciences, the history of human birth is often told as a process of medicalisation touched by denaturalisation and dehumanisation,28–31 evoking feelings of disempowerment and loss of control due to the increased availability of emergency obstetric care and associated medical interventions.32 33 The stories told in the interviews provide a nuanced story of medicalisation, one that frames medicalisation as a continuum of healthcare, medical safety and clinical engagement, along with disempowerment and loss of control. This was evident in the way our participants talked about medical intervention as a necessary step in their pursuit of having a healthy child and becoming responsible parents.6 34–36 7 38 In line with such thinking, intervening
in childbirth with the aim of saving lives becomes the only morally sound position for the parents to take. Thus, the parental alignment with medicalisation represents a way of internalising responsibility and illustrates what Heisens terms “moral adherers,” underlining how the aim to save new borns and secure maternal health and survival stands as an unchallenged moral position. The position of doing nothing in a situation defined as critical could otherwise be interpreted as irresponsible or as neglect.

Implications

Based on our findings, this study points towards a need to: (1) acknowledge the postnatal period as a pivotal part of the critical birth experience and to integrate this in future healthcare planning, (2) guide active involvement of women and their partners in critical perinatal events and (3) align parental and healthcare professionals’ expectations concerning the level of postnatal care.

CONCLUSION

The study demonstrates that the women and partners feel ambivalent about the medicalisation of birth. Women and their partners’ narratives of critical birth begin long before and end long after birth, comprising what we term ‘extraordinary family geneses’ and challenging conventional ideas about the birth as the pivotal event in a family’s story of coming into being. The women and their partners experience of loss of healthcare postnatally stands out in comparison to the provided healthcare attention they experience during the act of birth and in pregnancy. This experience of postnatal loss of attention may delay or diminish the parents’ trust in their own abilities as parents. It is important to acknowledge the postnatal period as equally crucial in future healthcare planning, to align expectations and guide parental involvement. Future research should further explore what highquality early postnatal care involves according to women and their partners.

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Contributors

JLS created the idea for the project. LEN, SH, MJ, MNS and JLS designed the study. LEN and SH were responsible for conducting the interviews and main analysis. LEN drafted the manuscript, with contributions on interpretation of data and critical revision of important intellectual content from LEN, MJ, MNS and JLS. All authors reviewed and approved the final manuscript for publication.

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Disclaimer

The foundation had no influence on the design or conduct of the study.

Competing interests

None declared.

Patient consent for publication

Not required.

Ethics approval

Approvals from the Capital Region’s Committee on Health Research Ethics (no. 62217, approval date 23/2/2018) and the Danish Data Protection Agency (UD-2018–103, approval date 3/5/2018) were obtained.

Provenance and peer review

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Data availability statement

No data are available.

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