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This birth is difficult but beautiful — parents' experience of giving birth to a baby with a lethal foetal diagnosis

Abstract

Introduction: The experience of childbirth, during which parents welcome and say goodbye to their child at the same time, is an unimaginably difficult/traumatic experience. This study aims to explore parents' experiences following the birth of a terminally ill baby.

Material and methods: Semi-structured, in-depth interviews were conducted in this qualitative study. The interviews were developed using content analysis, by coding and constructing themes in iterative, collaborative meetings, using the MAXQDA tool. Thirteen parents took part in the study: nine women following a prenatal diagnosis with a lethal prognosis for their child and four fathers of those children.

Results: Content analysis revealed two main themes and two sub-themes. The first theme is "Embracing bad news during pregnancy" and the second theme is "This birth is difficult but beautiful", within which the following sub-themes were identified: "Joy of meeting the baby" and "Saying goodbye to your child is important".

Conclusions: For parents who were preparing for childbirth after prenatal diagnosis with a lethal prognosis for their child, the experience of childbirth had positive implications. Meeting their newborn child was an important moment for them, an affirmation of their parenthood. Parents emphasised that the time to say goodbye to their child was a celebration of their brief parenthood.

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Introduction

According to researchers, childbirth is a profound psychological experience that affects a woman's physical, psychological, social and existential being [1, 2]. The birth of a child, especially the first one, is a pivotal event both in the short and long term, leaving women with "engraved memories" [3]. Childbirth is a psychological experience with positive or negative connotations [4]. For some women, it is one of the most beautiful events, while for others it is a confrontation with fear of pain. A traumatic birth experience can have a long-term impact on a woman's health and well-being [5, 6].

The experience of childbirth affects a woman's personal development. This process can be "empowering" or "debilitating", depriving the woman of her strength. The midwife plays a significant role in the experience of childbirth, as her "being with the woman" during labour, based on ensuring emotional, physical, spiritual, and psychological support, increases the woman's sense of control, self-confidence, and trust in others [7, 8]. Research shows that care based on compassionate midwifery, subjective treatment and delivery on the woman's terms are key to a positive birth experience [9–11].

Stillbirth is described in the literature as a paradoxical coalescence of life and death. It is impossible to rejoice at the birth of a newborn and its death at the same time. It is a paradox that lingers in the minds of many parents who have experienced the loss of a child [12]. Researchers emphasise that despite the loss of a child, parents can have positive birth memories thanks to empathetic care and high medical standards [13]. At the same time, studies show that contact with the newborn and holding the baby are associated with fewer symptoms of anxiety and depression for mothers of stillborn children [14–17].

Even though over the past 40 years the philosophy and approach to care for parents who experience the death of their unborn or newborn child have changed, there is still a lack of social acceptance for stillbirth [16]. The taboo associated with death increases parental suffering, loneliness and social isolation [14, 18]. In 2011, three articles were published on stillbirths. According to them, stillbirth is one of the most neglected areas of public health and is omitted in global health programmes [19–21]. This article fills the lack of qualitative research on the experience of parents who, in the delivery room, experience the death of their baby in utero or shortly after birth, welcoming and saying goodbye to their child at the same time. This study aims to explore mothers' and fathers' experiences related to the birth of a fatally-ill baby.

Material and methods

Given the different emotional reactions of parents experiencing the birth of a stillborn child or one who dies soon after birth, a methodology was sought to reflect the subtle differences in the way information is communicated. A qualitative descriptive approach was chosen as the best methodology to capture the experience and emotions of parents who experienced the birth of a fatally-ill baby without relying on pre-existing theories [22, 23].

Recruitment of study participants began in January 2022 and was completed in February 2023. Study participants were recruited from the perinatology outpatient clinic of the specialist hospital and the district hospital group. Inclusion criteria for the study included a diagnosis of a lethal foetal anomaly, stillbirth, or a neonate who lived for several hours to several days after delivery. Fourteen mothers and five fathers were offered participation in the study. Three mothers and one father declined to participate in the study, citing a lack of readiness to share painful memories associated with the loss of their child; one mother did not meet the criteria due to the length of time her child had lived. Finally, nine mothers and four fathers took part in the study. All parents consented to take part in the study and were provided with comprehensive information regarding the purpose and procedures of the research. The youngest mother was 25 years old and the oldest was 40 years old. Eight women met with a midwife before delivery to prepare for childbirth. Seven women gave birth vaginally, while two women had a caesarean section. The shortest interview time was three months and the longest was twelve months postpartum. The characteristics of the study group are shown in Table 1.

Eight interviews were recorded using the Zoom platform. They took place in the participants' homes at the most convenient time for the interviewees. Two interviews were conducted using a dictaphone during a face-to-face interview at a location indicated by the parents. The recordings were recorded by the first author of this article, who is an experienced midwife. The research was based on a pre-determined set of themes concerning the antenatal period, the birth experience and the time to say goodbye to the baby. When more details were needed, the author asked additional questions such as: "Can you tell me more about this?". The author's many years of professional experience allowed her to empathise with the world of the participants as much as possible. In this type of sensitive research, empathy is particularly important [24].

If both parents expressed the desire to participate in the study, the interview was recorded once with

the participation of the child's father. Each interview lasted between 45 and 70 minutes. After each interview, notes were made regarding the interviewer's observations and reflections. The interviews were then transcribed and analysed. Each interview was read at the outset to extract the overall meaning. Then semantic units, i.e. smaller text fragments that are relevant to a given phenomenon, were determined. Three independent midwives performed the coding using MAXQDA software. Throughout the data analysis process, the authors held regular meetings to review the coding to ensure the accuracy of the coding template [25]. The paper was written based on the Standards for Reporting Qualitative Research (SRQR) [26]. Ethical approval for the study was obtained from the Bioethics Committee of the Centre of Postgraduate Medical Education No. 75/2021. The study was conducted in accordance with the Declaration of Helsinki.

Results

The main part of the analysis was the parents' experience of giving birth to a baby with or without vital signs. When analysing the statements obtained, two themes and two sub-themes were identified (Fig. 1):

1. Embracing bad news during pregnancy.
2. This birth is difficult but beautiful:
   a. The joy of meeting the baby;
   b. Saying goodbye to your child is important.

The main theme was the experience of childbirth for parents whose child had been diagnosed with lethal foetal anomalies during the prenatal phase. In this experience, an important role was played by the time from receiving the devastating diagnosis to the moment of delivery. All parents emphasised the important role of the health professionals who accompanied them during their pregnancy. They particularly emphasised the role of the midwife, who prepared them for the birth of their sick child by familiarising them with bad news.

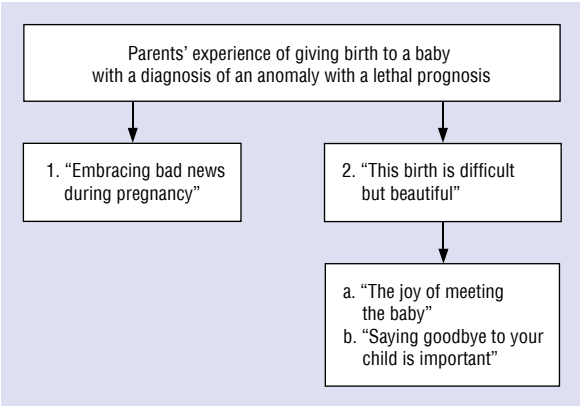

Figure 1. Diagram of parents' experience following the birth of a baby with a diagnosis of an anomaly with a lethal prognosis

Embracing bad news during pregnancy

Parents stressed that it is difficult to prepare for the birth of their child who needs to be said goodbye shortly after birth. At the same time, they described with gratitude meetings with health professionals who helped them to come to terms with the difficult subject of giving birth to a fatally-ill baby before the birth:

— "[…] that meeting really opened our eyes and there are probably some things we wouldn't even be able to read about on the internet, but that meeting helped us a lot because we knew first-hand what we needed to prepare for, what we needed to determine, how we wanted it to look like. The issue of some kind of farewell, the issue of mementoes […], or burial issues" (F2).

After the initial shock of learning that their unborn child had been diagnosed with an anomaly with a lethal prognosis, parents appreciated the regular meetings with the midwife who helped them accept the lethal diagnosis for their child:

— "I would say that, despite the circumstances, we were very well prepared for it and we also wanted to prepare ourselves for it, because we had to accept that it happened […], and because of the good preparation, I didn't feel any difficulty at all" (F1).

The interviewed mothers emphasised that the information provided during pregnancy helped them in the process of adapting to the diagnosis of a lethal foetal anomaly and adjusting to the irreversible situation. They emphasised that the issue of "time" was important, which helped them to come to terms with all the difficult scenarios of the pregnancy outcome:

— "I definitely prefer to know more, I prefer the truth, whatever it is, to prepare myself, adjust, have time… I think the more we know, the easier it is for us to prepare, especially if we have sick children and it can end differently" (M8).

Four women and three fathers emphasised that discussing their needs before the birth of their child was an important part of embracing the bad news. Their expectations, written down in the form of a "birth plan", helped them to identify their preferences, structure their actions and reduce the stress of the unknown. Naming their needs gave them a sense of control over the situation:

— "[…] once we sat down and definitely wrote down those tips — what to pack, what is needed, even food… And thanks to the fact that we both had some kind of an outline, a plan of what should be taken, we actually managed to pack everything" (F1).

— "If there had been a stillbirth, I would have been completely unprepared, and thanks to this plan I had everything written down what needs to be done…" (M1).

This birth is difficult but beautiful

Another category that emerged from the analysis of the interviews concerned the subject of the experience of childbirth. For parents who gave birth despite a lethal diagnosis for their child, the experience was difficult but beautiful. The desire to be a parent and give birth on their own and the prospect of meeting their child regardless of their condition gave the parents temporary joy. All the interviewed parents described their childbirth as a positive experience after a dramatic pregnancy period. Although childbirth was a very difficult experience for them due to the fact of physical pain and emotional suffering, it contained elements of beauty, happiness and blessing:

— "[…] this birth, although very difficult, was beautiful" (M6).
— "[…] when the birth finally happened, there was certainly some joy, satisfaction that we did it, that it's behind us, we could see him together, be with him. And we were happy; it was a difficult moment but it was also happiness for sure" (F1).
— "[…] I feel like I experienced the birth in such a state of bliss, and it was also the fact that I could see Alicja, and see that she had a beautiful face" (M9).
— "Contrary to appearances, the final stage — pushing the baby out — was difficult for me personally from a technical point of view" (M9).

Most parents said that the birth of their sick child marked the end of the painful stage of pregnancy, which was associated with fear not only due to the lethal diagnosis but also due to the lack of information about where to seek help. The experience of childbirth concluded a dramatic pregnancy story in which anxiety and fears for her health and her baby were compounded by a lack of social support. In this perspective, childbirth appeared to be the end of a painful story:

— "Childbirth is not a drama because the drama was six months ago when we found out about his illness".
— "Honestly, what gave me motivation during childbirth was the fact that my nightmare, our nightmare, would be over, the fact that someone finally took care of me, the fact that I could give birth, I could see my baby, say goodbye the way it should be. And the fact that there is a second son waiting at home and you just have to finish the story gave me such the greatest strength" (M4).

A positive aspect for all parents was the treatment by the team of health professionals in the delivery room of this birth as if it were a natural, normal birth. Both fathers and mothers appreciated all the actions of the medical staff that "normalised" this difficult experience:

— "However, to actually treat this birth as normal and not think about what will happen next […], the most important thing is just to treat it in such a normal way and not to show that it is something different; it is just something that simply happens" (M6).
— "And she was with us (daughter) and I even took her in my arms afterwards, so it was in no way different from a normal birth" (F2).

Parents appreciated every gesture from the delivery room team that gave them the status of "normal" parents. The presence of the husband during delivery, a friendly atmosphere, providing peace of mind and the opportunity to hold the baby in my arms contributed to giving a sense of "normalcy" to the experience:

— "The fact that we could spend this time together, maybe it wasn't the ideal time, but we could be… we were for a moment those parents, we have this child in our arms" (M4).
— "[…] for women giving birth, the atmosphere that gives them peace and motivation to give birth on their own and still have something normal is very important…" (F3).
— "The calmness of the midwives helped; there was just one other midwife who had such a calm voice, and I remember when the anaesthetist came to give the anaesthetic, she sort of put me in such a trance, and I was calmed down… And I was acting so task-oriented then, it calmed me down that such an atmosphere was there that nobody was rushing me, no one was shouting at me" (M4).

Seven women, recounting their birth stories, appreciated the fact that they were able to give birth naturally. In their statements, they expressed gratitude and joy that they gave birth on their own. It was very important for them in the context of experiencing "normal" motherhood. One mother reported that it was her dream to give birth naturally:

— "And this may sound silly, and someone might think that I'm saying such (silly) things in such a situation, but this is the only thing I am happy about in the situation of this birth that I was able to fulfil this little dream to give birth naturally…" (M4).
— "I remember how everything was there and I remember how painful and hard it was for me, but I wanted to hold on until the end… and I just wanted to give birth on my own…" (M3).

All the interviewed women appreciated the non-directive care of the midwives. Sensitive and empathetic care, both during and after delivery, gave them a sense of security and peace of mind:

— "It was very important for me how those people approached me and which midwife would be with me during the delivery, whether she would talk to me, whether she would understand how hard it was for me." I thought a lot about it and when I saw the midwife for the first time, I calmed down. That lady would definitely help me, it was already visible" (M3).

— "But there were also nice moments, for example, when one of the midwives in the maternity ward said she had read my story… And she came to ask if she could hug me, just like that. She sat for a while, cried with me and left" (M2).

The joy of meeting the baby

All the mothers in this study perceived meeting their newborn child as special. Regardless of the newborn's health and condition, the mothers were happy with this first meeting, admired the appearance of their child, and celebrated every moment, knowing that their meeting could be very short:

— "I felt good, despite some pain and discomfort, I was very happy that we could be together for a while. I didn't know how long it would last, but that moment was rather joyful. I didn't feel anxious then, it was a rather positive experience of that first meeting, very positive…" (M7).

— "I think that when I saw Krzysiek, it was the most beautiful thing and later, when I talked to my husband, I said: 'Did you ever imagine that we would have such a beautiful child?' It was just perfect" (M8).

— "The motivation for giving birth was actually to see him as soon as possible, just to see him, and hug him, and really, just to see him… Just to greet him and also tell him everything that was most important to me…" (M1).

The birth of a child, meeting with them and seeing them was an important moment for the parents. Two mothers reported that their greatest happiness was that they could tell their newborn child everything that was important to them, even when the child could no longer hear it:

— "When I gave birth to my child, a very important piece of information for me was that there were two hours after the birth that I had to say goodbye." And in fact, when I heard that, that's when I felt so lucky that I could tell my son what was important. Admittedly, he couldn't hear it anymore, but it was the fact that I could tell him that" (M1).

Parents appreciated the "time" they received in the delivery room to enjoy the meeting with their child. Holding and cuddling the baby, and saying goodbye in an intimate setting gave them a sense that they did everything they could for their child:

— "We could hug her, even when her heart had stopped beating. We could hug her and say everything we wanted to in that moment, we had that time. Because we could have as much time as we needed… Even though she was with us for a short time, I felt that we did everything we could for her, we could say goodbye to her with dignity and that's probably the most important thing" (M6).

Saying goodbye to your child is important

The birth experience was a period of ambivalent feelings for the child's parents. The happiness and joy of "meeting" and seeing the baby were mixed with the pain of separation and saying goodbye. One mother reported that she did not want to infect this first meeting with her sadness. She wanted to fill the short time she had for her newborn with emotions of happiness and delight:

— "And now I'm glad that it wasn't the time of sadness that I had for her but it was the time of saturation with what I had at that moment, when I could look at her not through tears, because after all, it's happiness because it's also a new life, and here is our child" (M7).

The most difficult part for the parents was the separation from their newborn. Interrupting the time of the meeting and handing over the baby was a traumatic experience for the parents. One mother said that she did not agree internally with the idea of her child being gone. This experience remained in her memory for a long time:

— "And actually the hardest thing is to let the child go. I couldn't talk about it for a very long time, I was only able to talk about it when it was Easter… The worst thing was still that I had to say goodbye" (M1).

Mothers considered it very important to who they would hand their stillborn child over and in what form this would be done. The trust they had in the midwife who looked after them during the birth played a key role. One mother said that she could only entrust her daughter to a trusted midwife; only to her could she hand over her stillborn child:

— "I had no reservations about handing Ania over to the midwife because I trusted her. The midwife bathed her and dressed her. I didn't expect that we would have an hour together" (M9).

Another mother recounted the last moments spent with her child after his death. She appreciated every

gesture of respect towards her deceased son's body. She was left with negative memories of the black bag in which she saw her child for the last time:

— "The midwife who was present at the birth was also present at the death, which was very important and good for me. So together with her, I was able to bathe Marcin, so that was also for me… that was very important. So she removed all sticking plasters, prepared the bathtub, and I just bathed my child posthumously, and we dressed Marcin… Unfortunately, after those two hours, I had to say goodbye to his body, and the girls packed him in a black bag. This is such a negative memory for me, I wish there were white bags" (M7).

Discussion

The two themes identified in the study emphasise that the period of pregnancy, birth and the time after the birth of a fatally-ill baby is an experience of ambivalent feelings of pain and suffering for parents, and at the same time the joy and happiness of meeting a newborn child, whether it is born alive or stillborn. The interviewed parents emphasised that receiving an unfavourable diagnosis was a devastating piece of information for them, which turned the pregnancy into a difficult emotional experience. However, this painful diagnosis was crucial in terms of emotional preparation for childbirth. The interviewed parents said that embracing bad news allowed them to put it aside and focus on the task of preparing for the birth of their child. This is consistent with other studies that confirm that parents go from a period of sadness and grief to a period of active planning between diagnosis and birth [27]. Other studies emphasise that prognostic certainty about the lethal prognosis for the child to be born has a strong influence on parents' progression, focusing their attention on what they can do at the moment for themselves and their unborn child [28]. Lalor et al. [29] emphasise that women cope by giving meaning to the prenatal diagnosis with a lethal prognosis for their child, trying to make sense of this negative event, and accepting the new reality in which there is no future for the child.

The interviewed parents emphasised that naming their needs, discussing different scenarios of the pregnancy outcome, and expectations about how they want to spend their last minutes, hours, or days with their child helped embrace difficult topics. Writing down all their needs and expectations with the midwife gave the parents a sense of control over the situation. The birth plan was a helpful tool that structured actions at a time of stress associated with childbirth. This is corroborated by other studies, in which birth planning helps to fulfil the parental role, develop parental competencies, and is an important tool to establish a trusting relationship with the interdisciplinary medical team [30–33].

The results of the study revealed that for parents who give birth to a fatally-ill baby, despite the pain and suffering associated with the loss of the baby, this experience has positive implications. This is in line with previous studies that have reported that parents may have positive memories after stillbirth as a result of the caring attitude of medical staff and high-quality medical procedures [13]. The experience of giving birth (to a healthy baby) is a life-changing event, a transformation that implies long-term consequences, and an opportunity for a woman to discover her strengths [34, 35].

In the study conducted, the experience of giving birth to a baby who dies during or shortly after birth was very difficult and traumatic for the parents. At the same time, women emphasized the beauty of this experience, which was a meeting with their baby that gave them the status of a mother, and the fact that the personal relationship with the midwife contributed to positive emotions, despite the pain and suffering associated with the delivery of a fatally-ill baby. Sensitive care brought relief and a sense of security in this difficult experience.

The empathetic care of the midwife in the delivery room plays a key role in a positive birth experience for the parturient woman, especially in the case of giving birth to a baby with lethal anomalies. Care based on "compassionate midwifery", effective intervention by medical caregivers to relieve physical and emotional suffering, is crucial for women in labour to go through the difficult experience of childbirth [11, 36, 37]. The study found that meeting their newborn baby and the time they were given to say goodbye to them was important to the parents. Parents celebrated every moment spent with their child, knowing they had little time for each other.

Regardless of how short the baby's life may be, parents want to meet with their child and hold them in their arms. The sensitive care of medical staff, which acknowledges the humanity of a stillborn baby or a newborn who dies shortly after birth, is an affirmation of the mother's brief motherhood. The mother should be allowed to be a mother by enabling her to meet, see and hold the dead baby in her arms, and participate in the creation of memories [16, 30, 38].

Limitations of the study

One limitation is the selection of the study group. The study only included parents who were willing to share their experiences, so it is not possible to describe

the experiences of parents who did not want to share them. The study included only women for whom the motivation to continue the pregnancy was their own decision, not legal regulations in Poland. Therefore, the experiences of women who gave birth to their fatally-ill babies solely because of the applicable law are not known.

Conclusions

Embracing bad news related to a prenatal diagnosis with a lethal prognosis for their child is crucial for parents in the process of adapting during the difficult period of waiting for the birth of the child. The empathetic care of the midwife in the delivery room, the affirmation of the parents' identity by treating their birth experience as "normal" and allowing them to say goodbye to their newborn appear to be key to a positive childbirth experience and better coping with the loss of the child.

Article information and declarations

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Author contributions

All the authors contributed equally.

Conflict of interest

The authors declare no conflict of interest.

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