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The dilemmas of pregnant women diagnosed with lethal fetal malformation

Os dilemas de gestantes com diagnóstico de malformação fetal letal

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Abstract

This study aimed to understand the factors that influenced the decision of pregnant women diagnosed with a fetal malformation incompatible with postnatal life, to either maintain or terminate the pregnancy, as well as to assess the emotional impact of this experience. This qualitative study was conducted with 11 pregnant women at a benchmark public service on fetal medicine. Interviews were carried out to collect sociodemographic and clinical data and trigger questions were audio-recorded. The narratives were analyzed, and categories emerged from them, illustrated by excerpts from the interviews. Waiting for a miracle, the perception of motherhood and values against termination influenced the choice to keep the pregnancy. The lack of hope of having a living child, the belief that termination would bring relief from suffering and the legal right to abortion influenced the choice to terminate. Regardless of the decision, the women's perplexity at the diagnosis, as well as feelings of guilt, anguish and sadness stand out. Because this type of grief is still rarely acknowledged, it is crucial for healthcare teams to implement humanized and technically competent approaches that support women's decision-making processes, uphold their rights, and assist them in coping with the grief of their loss.

Keywords: Abortion, legal; Fetal malformations; Mental health; Pregnancy, high-risk.

Resumo

Este estudo objetivou compreender os fatores que influenciaram a decisão de gestantes com diagnóstico de malformação fetal incompatível com a vida pós-natal, para manter ou solicitar a interrupção da gestação e avaliar o impacto emocional dessa vivência. Estudo qualitativo, realizado com 11 gestantes em serviço público de referência em medicina fetal. Foram efetuadas entrevistas com levantamento de dados sociodemográficos e clínicos e perguntas disparadoras audiogravadas.

As narrativas foram analisadas e delas emergiram categorias, ilustradas por trechos de entrevistas. A espera por um milagre, a percepção da vivência de maternidade e valores contrários à interrupção influenciaram a opção por manter a gestação. A falta de esperança de ter um filho com vida, a crença de que a interrupção traria alívio para o sofrimento e o direito legal ao aborto influenciaram na escolha pela interrupção. Independentemente da decisão, destacam-se a perplexidade diante do diagnóstico, sentimentos de culpa, angústia e tristeza. Por se tratar de uma dor ainda pouco reconhecida, é importante que as equipes de saúde tenham estratégias de abordagem humanizadas e tecnicamente qualificadas, que apoiem o processo decisório da mulher, garantam os seus direitos e auxiliem na elaboração do luto pela perda sofrida.

Palavras-chave: Aborto legal; Malformações fetais; Saúde mental; Gravidez de alto risco.

With the growing advancement of medical technology, early detection of fetal malformations is becoming increasingly common (Zhang et al., 2023). In Brazil, fetal malformations account for 11.2% of infant deaths, making them the second leading cause of neonatal mortality (Nunes & Abrahão, 2016). Data from the Nascidos Vivos Information System indicate that, in 2019, there were 24,838 births with congenital malformations in the country (Ministério da Saúde, 2020).

Among the fetal malformations incompatible with life due to high prenatal and postnatal lethality rates are anencephaly, body-stalk syndrome, bilateral renal agenesis, neural tube defects, skeletal dysplasias, trisomy 13 (Patau syndrome), and trisomy 18 (Edwards syndrome) (Atienza-Carrasco et al., 2020).

In 2012, the Brazilian Federal Supreme Court decriminalized termination of pregnancy in confirmed cases of anencephaly, broadening the debate on other fetal malformations incompatible with postnatal life (Leite et al., 2020). Although national scientific production on this topic remains scarce, the number of judicial requests for pregnancy termination increases every year (Leite et al., 2020).

Choosing whether to continue or terminate a pregnancy is an extremely sensitive decision, and the manner in which the diagnosis is communicated, as well as the emotional support provided, can either facilitate or hinder decision-making (Atienza-Carrasco et al., 2020).

Given these considerations, this study sought to understand the factors influencing the decision-making process of women carrying fetuses with malformations incompatible with postnatal life – whether to continue the pregnancy or to seek judicial authorization for termination – and the emotional impacts involved. The aim was to provide information that could assist healthcare services in developing approaches that are sensitive to this type of suffering and capable of alleviating it.

Method

This was a qualitative study involving interviews with 11 pregnant women, aged 18 years or older, who had received confirmation of a diagnosis of fetal malformation incompatible with postnatal life at the specialized Fetal Medicine prenatal care clinic of the Women's Hospital Prof. Dr. José Aristodemo Pinotti located at the *Centro de Atenção Integral à Saúde da Mulher* (CAISM, Women's Comprehensive Health Care Center), a part of the Universidade Estadual de Campinas (Unicamp, State University of Campinas).

Based on verification of the fetal diagnosis in the participant's prenatal care record, each woman was invited to participate in the study in a private room at the same clinic, after her prenatal appointment. Data collection and interviews were conducted only after providing clarifications, reading, and signing the Informed Consent Form, drafted in accordance with Resolution nº 466/2012 of the National Health Council (Conselho Nacional da Saúde, 2012).

Data collection occurred between October 2022 and October 2023. Because this was a qualitative study using a convenience sample, no sample size calculation was performed. Recruitment concluded when data saturation was reached (Faria-Schützer et al., 2021).

Semi-structured, audio-recorded interviews were conducted, each lasting approximately 1 hour and 15 minutes. The interviews began with the collection of sociodemographic, obstetric, and mental health information. Subsequently, the following guiding questions were posed: “How have you been feeling emotionally since receiving the diagnosis?”; “What factors are influencing your decision to continue or terminate the pregnancy?” and “What are your expectations for the period following delivery?”

The interviews were manually transcribed without software assistance. Data analysis followed the Clinical-Qualitative Method, which seeks to interpret the meanings conveyed in reports obtained through interviews or individual testimonies (Faria-Schützer et al., 2021). Two authors independently read and analyzed the transcripts in detail, aiming to capture narratives emerging from the guiding questions. Discrepancies were resolved by consensus, leading to the definition of categories illustrated with excerpts from participants’ statements, selected based on relevance and recurrence criteria (Faria-Schützer et al., 2021). Objective data were tabulated for descriptive presentation and analysis.

The project was approved by the Research Committee of CAISM/Unicamp and by the Research Ethics Committee (CAAE: 43802521.5.0000.5404), opinion number 4.908.577. To ensure confidentiality and anonymity, participants were classified as having either Continued the Pregnancy (CP) or Terminated the Pregnancy (TP) and assigned Roman numerals from I to XI.

Participants

The study included 11 pregnant women aged 18 years or older who, at the specialized Fetal Medicine prenatal care clinic of CAISM/Unicamp, received confirmation of a diagnosis of fetal malformation incompatible with postnatal life.

Instruments

First, the Data Collection Form, specifically developed for this study, was administered to obtain sociodemographic, obstetric, and mental health information.

Next, a semi-structured interview was conducted, using open-ended prompting questions to explore the factors influencing the woman’s decision to continue the pregnancy or to seek judicial authorization for termination.

Procedures

Interviews were conducted at the specialized Fetal Medicine prenatal care clinic of CAISM/Unicamp between October 2022 and October 2023. Once the fetal diagnosis was confirmed in the participant’s prenatal care record, she was invited to take part in the study in a private room at the same clinic, after her prenatal appointment. Following a joint reading and signing of the Informed Consent Form, the interview began with the Data Collection Form, followed by the semi-structured interview script.

Results

Of the 11 pregnant women interviewed, 7 were under 30 years old, all lived with their partners, and most (8 women) had completed at least high school. All participants reported having a religion; however, fewer than half (4 participants) reported active religious practice. Six of the 11 women received confirmation of the diagnosis during the second trimester of pregnancy. None of the multiparous women had received a diagnosis of fetal malformation in a previous pregnancy, and most (8 women) had not planned the current pregnancy. Among the diagnoses of fetal malformations, body-stalk syndrome was the most frequent, followed by Edwards syndrome (Table 1).

Table 1

Characteristics of the pregnant women interviewed and the fetal diagnosis received (n = 11). Campinas (Brazil), 2023

Participant	Age	GA at diagnosis	Religion	Educational level	Living children	Fetal diagnosis
TP-I	32	12 weeks	Non-practicing Catholic	Incomplete Elementary School	Yes	Microcephaly
CP-II	41	22 weeks	Non-practicing Evangelical	Postgraduate	Yes	Trisomy 13
CP-III	25	22 weeks	Practicing Evangelical	Complete High School	No	Trisomy 13
TP-IV	36	12 weeks	Practicing Evangelical	Complete Higher Education	No	Holoprosencephaly
TP-V	27	20 weeks	Non-practicing Catholic	Incomplete High School	Yes	Bilateral renal agenesis
CP-VI	24	14 weeks	Practicing Spiritist	Complete High School	No	Body Stalk Syndrome
TP-VII	29	13 weeks	Practicing Evangelical	Complete Higher Education	No	Body Stalk Syndrome
CP-VIII	28	12 weeks	Non-practicing Evangelical	Complete Elementary School	Yes	Trisomy 18
CP-IX	19	22 weeks	Non-practicing Evangelical	Complete High School	No	Body Stalk Syndrome
TP-X	40	20 weeks	Non-practicing Evangelical	Complete High School	Yes	Trisomy 13
CP-XI	24	24 weeks	Non-practicing Catholic	Complete High School	Yes	Body Stalk Syndrome

Note: CP: Continued Pregnancy; GA: Gestational Age; TP: Terminated Pregnancy.

Regarding the decision about the pregnancy, 6 women chose to continue the pregnancy, while 5 opted for legal termination. All participants who requested termination had their requests granted by judges and underwent the procedure at CAISM.

When asked about mental health support and treatment, all participants reported having shared the diagnosis and prognosis with someone close to them and feeling welcomed and supported. Of the 11 women, 3 had received psychological care prior to the diagnosis of fetal malformation, and 7 were undergoing psychological follow-up after the diagnosis. Most participants (8 women) were not using medication for the treatment of mental disorders.

Analysis of the interviews revealed five thematic categories: (a) Emotional reactions to the diagnosis of fetal malformation incompatible with postnatal life, (b) Prenatal care as a facilitator in coping with the situation, (c) Factors influencing the decision to continue the pregnancy, (d) Factors influencing the decision to terminate the pregnancy, and (e) Expectations regarding the postpartum period.

Emotional Reactions to the Diagnosis of Fetal Malformation Incompatible with Postnatal Life

Regardless of whether they chose to continue or terminate the pregnancy, participants reported intense emotional suffering, particularly feelings of shock, sadness, and questioning about guilt, as illustrated by their statements:

It was such a shock; I could never imagine this would happen. (TP-I)

It's been a roller coaster, some days I'm fine, other days I cry... I even thought it was my fault, that it was something I had done. (TP-IV)

It's a crazy kind of pain, a pain I had never felt in my life, it's so hard for me. Emotionally, I'm really fragile, worried, but when I got the diagnosis, I was even more scared. I was devastated, crying for more than a week. (CP-VI)

I was very sad, very debilitated, afraid of falling into depression, it's complicated. Only those who go through it know the pain. It's such a hard decision. Talking about it makes it sound like we're fine, but we suffer a lot. (TP-VII)

At first, I didn't quite get it; I was kind of paralyzed. (CP-VIII)

Prenatal Care as a Facilitator in Coping with the Situation

Although the quality of care was not part of the guiding questions, it emerged spontaneously in participants' accounts – both when describing their emotions and when discussing the decision to continue or terminate the pregnancy. Participants reported that being referred from their hometowns to a specialized hospital, receiving care from an experienced team, and being given clear guidance provided them with greater security. They emphasized the comfort brought by compassionate care at this difficult time:

The doctors in my town gave me a lot of support, but my concern was not having the resources or a hospital. When I found out I would deliver here, I was relieved. Thank God it worked out. (CP-II)

The fetal medicine clinic team was great; they treated me very well. I have nothing to complain about, we're getting a lot of support. (TP-IV)

I got more guidance here at Unicamp. I also got support at the clinic [Primary Health Unit], but here there are more people to explain things, and they understand more. So, with their support, I'm not going to say I'm calm, but I'm trying to be. (TP-X)

Thank God everyone was very kind, and they explained everything clearly in a way we could understand. (CP-XI)

Factors Influencing the Decision to Continue the Pregnancy

After receiving counseling regarding the diagnosis and prognosis, including the high likelihood of the baby's death shortly after birth, 6 of the 11 participants chose to continue the pregnancy. Some participants relied on their faith and belief in God, hoping for a miracle:

I am not God, and that's why I will not terminate under any circumstances. When she wants to be born, she will decide. (CP-II)

God gives life, God gives death, and God also keeps me strong, there is no one else. If I take her out early, she might not have any chance at all. (CP-III)

Whatever has to happen is in God's hands. I have faith that nothing is impossible for God. (CP-VIII)

If I terminate, I'll be left thinking, 'What if I had waited? What if something had changed?' Even though we know the reality, I don't know... I think the feeling of guilt would be different, so I said, 'I'll wait'. (CP-XI)

Perceptions of motherhood and the idea of the womb as a place of protection were also expressed:

I'm going to take out a child who is inside me, who, for better or worse, is safe in there. (CP-II)

There's a heart here, it's a person. From the moment we find out we're going to be mothers, we already start being mothers. I have to keep loving him just the same, keep living my pregnancy just the same, he's my son, and I will do everything for him. (CP-VI)

I'm doing my part as a mother, it doesn't matter how he comes into the world; we're still mothers. Just as I was responsible for conceiving him, I have to be responsible for caring for him. (CP-VIII)

The desire to spend more time with the baby, even if only in the womb, the feelings associated with fetal movements, and the hope of meeting the baby alive after birth were mentioned as reasons for continuing the pregnancy:

We talk to her, and she responds, we just put our hand there, and she moves, she jumps. I want to be with her until the end. (CP-III)

He is my son, I won't give up now. Whether he will live for half an hour or a day, he's my son. I'll go until the end, I won't give up now. (CP-VI)

The only thing I want is to meet her alive. (CP-VIII)

I think it's that was it, feeling him move. I do some simple things that I know I may not be able to do with him as a child, so I take my phone and play a little lullaby as if he were right there. (CP-IX)

For 5 participants, termination was perceived as something they could not do due to their values regarding abortion:

I don't have the courage, I don't think it's up to me to make that decision. (CP-II)

I don't want to take her out and kill her. (CP-III)

When I had the ultrasound, I was already 18 weeks along, how can you terminate after all that? In the ultrasound, the doctor said his heart and head were perfect, his hands... everything looked perfect. (CP-VI)

I can't decide the life of a child, who am I to decide someone's life, especially my own child inside me?. (CP-VIII)

Because whether we like it or not, he's alive. What comes after is another matter. (CP-IX)

Factors Influencing the Decision to Terminate the Pregnancy

Among the 5 participants who chose termination, trust in the medical team's information and the lack of hope following confirmation of anomalies incompatible with life after birth were highlighted as reasons for their decision:

The doctor said the baby could be born and not survive, maybe just for a few hours, so I decided it was better. (TP-I)

I asked for another ultrasound, and if it confirmed the diagnosis, then that's it, let's not be irrational, we can't have that irrational faith. (TP-IV)

Once we saw there was really nothing to be done, they always kept me well informed about the prognosis, that it would be the same whether I terminated or not. (TP-V)

Either I keep living and watch my child die right afterward, or I have the legal option to terminate, since it's a malformation, we have that right. Unfortunately, there's nothing I can do. If there were some surgery that could be done in the uterus, I wouldn't think twice for my daughter's well-being, but it's not up to me. (TP-VII)

Once the karyotype result came back confirming Edwards syndrome, and I saw there was absolutely no chance of taking him home, I decided to terminate. (TP-X)

Although it was a very difficult decision, some participants believed that ending the pregnancy sooner would alleviate the suffering they were experiencing, making the negative emotions more bearable:

You grow attached, you know? Once the baby is born and you're close, you get even more attached, and it would be worse, so I decided right away. (TP-I)

Trying to block out this hardship we're in, this suffering we're going through, trying to end the suffering. (TP-V)

I think if you wait until the end, it's worse for us, for the family, for the baby too, you know? It's a greater suffering. (TP-X)

For 3 participants, the thought of seeing their child pass away shortly after birth – and the fear that the baby might suffer pain or discomfort – caused anguish and reinforced their decision to terminate:

I don't want to see her suffocate to death when she's born. (TP-IV)

I don't want to see the baby, he will be born, and I don't want to have contact. I don't want that last image in my mind, and I'm afraid of him dying in my arms. (TP-X)

I can't imagine watching my daughter die, I think I would die with her, because seeing your child die like that is terrifying. (TP-VII)

Confidence that God was in control of the situation and guiding their decisions provided comfort and reassurance for proceeding with termination:

It's as if God were saying: 'Look, you're on the right path'. (TP-IV)

God has a purpose in this, whether it's a good or bad lesson, God will still be God. (TP-VII)

It's God's purpose, and we may not understand it all now, God knows everything, and He doesn't give someone a burden they can't carry. For me, it's God's purpose. (TP-X)

Expectations Regarding the Postpartum Period

Because it is an unfamiliar context, the postpartum period of a baby with malformations so limiting to life can make it difficult for pregnant women to understand what to expect from this painful experience, generating doubt and intense anguish:

I'm tired of imagining, I've thought about it, but there's no use suffering; every time I think about it, it's a lot of suffering. (CP-II)

I don't know (crying), I don't know. (CP-III)

I really don't know, I wasn't sure whether I would be able to bury her, whether I would be able to stay with her, something like that. (TP-IV)

I don't know, it's something I believe will be very hard. While we're decided, we're strong and steady, and we want everything to be resolved, but we don't know how it will be. We'll try to carry on, but how it will be, I can't even imagine. (TP-V)

It's very scary, right? And afterward, if she really does pass away, I also don't know how I'm going to deal with that. (CP-VIII)

Nothing, I can't... it's as if I just see a wall, nothing behind it; I can't see anything, nothing. (CP-IX)

Discussion

The accounts provided by the women interviewed indicate that, regardless of whether they chose to continue or terminate the pregnancy, receiving a diagnosis of a fetal malformation incompatible with postnatal life is experienced with intense emotional suffering, marked by perplexity, fear of the unknown, sadness, guilt, and ambivalence.

In this study, most participants were under 30 years of age, a finding corroborated by other Brazilian studies and one that contradicts the commonly held association between advanced maternal age and the diagnosis of fetal malformation (Borges & Petean, 2018; Ramos et al., 2009). All participants reported having a partner with whom they shared the burden of the situation and reported receiving support from the healthcare team. The literature emphasizes that support from the social network and care providers fosters maternal well-being and facilitates coping (Borges & Petean, 2018).

It is noteworthy that the participants in this study had completed at least high school. For some authors, educational level may influence how pregnant women understand and assimilate information regarding fetal malformations (Borges & Petean, 2018). Nevertheless, maintaining clear, accessible, individualized language, without technical jargon, helps women and their support networks comprehend the situation, increases their sense of security, and facilitates decision-making.

Participants underscored that being appropriately referred from their place of origin to a referral hospital and receiving care from experienced professionals brought greater security and comfort. Conversely, the literature indicates that lack of support throughout the process and the invalidation of maternal feelings can further intensify emotional suffering (Lotto et al., 2018).

The diverse, individualized factors that influenced participants to continue or terminate the pregnancy underscore the importance of an individualized approach to each woman's needs. Faced with such a delicate situation, healthcare teams should maintain a welcoming and neutral stance to avoid moral judgment or undue influence on women's decisions. This can be challenging for some professionals, who may feel deeply affected by the difficulty of dealing with the topic (Santos et al., 2014). Accordingly, it is essential that this issue be addressed within healthcare services, that professionals working in this context have opportunities for continuing education, and that they receive support for their own distress (Patricio et al., 2019).

Although most participants reported no active religious practice, all stated they had a religion, and many identified their religious beliefs as shaping how they were coping with the situation. This finding is supported by the literature, which highlights religion and moral beliefs as influential in decision-making, whether to terminate or continue the pregnancy (Blakeley et al., 2019; Hjort-Pedersen et al., 2022).

While some women requested termination in an effort to mitigate suffering (their own, that of family members, or even that of the fetus), others expressed the desire to continue the pregnancy to have more contact with their baby, whether in utero or in the postpartum period. Given that some mothers consider termination the best way to cope with their distress, while others wish to hold their babies, even after death, to spend more time and say goodbye (Marc-Aurele, 2020), support and care networks must be sensitive to these different needs and to enabling them, thereby contributing positively to the next step: the grieving process.

Perinatal grief is often regarded as unusual, unrecognized, and misunderstood in our society, which creates obstacles that hinder this experience and the healthy elaboration of loss (Iaconeli, 2007). A recent study on grief following abortion found that the death of a baby, regardless of

gestational age or how it occurred, is a source of pain and should be regarded as a loss akin to that of any loved one (Oliveira et al., 2022). Recognizing the importance of mourning rituals and offering mothers who lose their babies due to fetal malformations the possibility of farewell rituals may promote mental health by fostering a more positive grieving experience and facilitating acceptance of the child's passing (Oliveira et al., 2022). Denying the possibility of rituals and farewells at this time is to deny the mother's pain over the loss of her child, invalidating the maternal relationship and the bond established during pregnancy (Iaconeli, 2007).

In this study, it can be observed that terminating the child's natural course of life was, for some participants, perceived as something they could not do because of their religious and moral beliefs and the emotional significance attributed to the maternal role. In this sense, the literature indicates that a baby's death may be experienced by the woman as an inability to exercise motherhood, a "maternal failure", which can generate conflicts regarding the woman's role in society and her feminine identity, given the strong idealization of motherhood (Duarte, 2008).

On the other hand, both in this study and in another on the topic, confirmation of a diagnosis that makes life after birth unfeasible, regardless of gestational age at delivery, provided reassurance and influenced some women's decision to terminate the pregnancy (Kamranpour et al., 2021). This underscores the importance of safeguarding current rights and considering their expansion regarding the legal right to terminate pregnancy in cases of fetal inviability.

It is important to emphasize that emotional reactions were similar regardless of choice – guilt, sadness, fear, anguish, anxiety, despair, and love. These feelings have been reported in other studies and may be explained by the clash between the idealized healthy, perfect child and the reality of a diagnosis indicating life cannot be sustained after birth (Blakeley et al., 2019; Patricio et al., 2019).

Still with respect to the idealization of the child, participants' accounts revealed difficulty in imagining the postpartum period. Because losing a baby contradicts what is psychically construed as the natural order of life, it can have a devastating impact with multiple negative repercussions for women's mental health, especially when the loss is permeated by fantasies about the baby's bodily condition and by a lack of physical and visual contact (Ladino et al., 2023). Thus, professionals caring for these women should provide clear information about procedures, remain available to address questions, and extend support into the postpartum period.

A 2019 systematic review showed that few studies have focused on clarifying the factors that influence decision-making among women carrying nonviable fetuses and highlighted the need for further clarification to ensure quality health care for this population at both individual and social levels (Blakeley et al., 2019). Another international study likewise reflects on the paucity of discussions and care provision in this complex area (Lotto et al., 2018). Brazilian studies that delve into the dilemmas and suffering experienced by women in this situation remain scarce.

In this sense, we hope that the present findings contribute Brazilian data to the field and encourage care practices with the potential to minimize the emotional trauma stemming from this overwhelming experience, thereby helping to prevent adverse mental health outcomes in these women.

Although we have presented and discussed multiple aspects of this complex experience, some limitations must be acknowledged. First, the study was conducted in a university-based fetal medicine referral service staffed by a specialized, highly trained team; therefore, the findings may not be fully generalizable to other public or private healthcare contexts. Second, the study reflects only a brief snapshot of the experiences of 11 women whose dreams were abruptly interrupted by a traumatic event. Even though data saturation was used as a criterion, it is important to recognize

the inherent difficulty in attempting to generalize the influence of any factor on a woman's decision to terminate or continue a pregnancy, as such decisions are deeply individual and subjective, shaped by personal life contexts and coping resources. The interview data should therefore be seen as part of a broader mosaic, to be continuously enriched by diverse studies and perspectives, ultimately fostering a more comprehensive understanding of the situation and strengthening the emotional support and care provided to these women.

Final Consideration

Receiving a diagnosis of a fetal malformation incompatible with postnatal life is profoundly distressing. Because this form of suffering is still insufficiently recognized, often confined to the mother's experience and, in some cases, the people who are closest to her, there is a pressing need to improve obstetric and maternity services to support these women through humanized, technically competent, woman-centered care.

Welcoming attitudes, assertive and compassionate communication, and sustained emotional support should be present throughout the process, from the moment of diagnosis and decision-making through delivery and the postpartum period, in order to mitigate adverse impacts and promote these women's mental health.

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