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MATERNAL ANXIETIES AND PERSPECTIVES DURING HOSPITALIZATION: THE VIEW OF A PREMATURE BABY/PHYSIOTHERAPIST

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Abstract: INTRODUCTION: Preterm infants involuntarily carry with them the experience of their mothers and the stigma of prematurity, which can have an impact on their entire lives, including their professional lives. OBJECTIVE: The aim of this study was to find out about maternal anxieties and perspectives during hospitalization from the point of view of a premature baby/physiotherapist. METHODOLOGY: This was a qualitative study carried out in the neonatal units of the Assis Chateaubriand Maternity School with 7 mothers who were accompanying their premature babies who were hospitalized. RESULTS: The mothers revealed a great deal of disruption surrounding the birth of their babies and the hospital routine was described as exhausting and painful. However, it was seen that by identifying themselves as premature and as physiotherapy students, the participants supported each other in this scenario, in order to reduce their anxieties and increase their prospects.CONCLUSION: It is important that the whole experience of prematurity is supported by all the professionals on the team, in order to reduce its future negative effects as much as possible.
Keywords: Prematurity; hospitalization; mothers; analysis of feelings; physiotherapy.

INTRODUCTION

A newborn born at less than 37 weeks gestational age (GA) or less than 259 days is considered a preterm newborn (PTNB). Prematurity can be described as a complex clinical syndrome, of multifactorial etiology, associated with a broad spectrum of clinical conditions that impact the survival, growth and development of the neonate (Sacramento; Lopes, 2022).

The anatomical and physiological immaturity of PTNBs, the numerous complications resulting from multiple disorders, the need for clinical interventions and specialized care, and the use of invasive devices and medications, prolong the period of hospitalization of these neonates. This process often begins in the Neonatal Intensive Care Unit (NICU), the environment in which premature infants usually spend the first few months of their lives (Szewczyk *et al*.,2021).

Although the NICU is a place that promotes the survival of premature neonates, the environment can be impacting and frightening for families. When parents see their newborn being admitted to the NICU, they experience fear because they believe that this environment is for neonates in a serious condition and at imminent risk of death. This context generates numerous anxieties and concerns (Santos, 2022; Exequiel *et al*., 2019).

Mothers tend to suffer the greatest impact from prematurity, as they have carried the child and had many expectations and dreams for the birth of their child. The breakdown of the mother-child relationship and the absence of this contact during long periods of hospitalization can cause damage to the child's psychological and motor development, as well as generating feelings of incapacity in the mother (Silva; Carvalho; Mathiolli, 2022;Teixeira, 2022).

The choice of this topic is justified by the researchers' personal, academic and professional experience with prematurity. This patient/professional relationship is reflected in the personal experience described here:

> *"I was born at 28 weeks, weighing 1295g and I spent 45 days in the NICU. My mother says that I was "very small, very little" and that when everyone saw me they feared for my survival, which still has repercussions in my life today.*

Based on the above, the aim of this study was to find out about mothers' anxieties and perspectives during their hospitalization due to prematurity from the point of view of a premature mother/physiotherapist. This was done by describing the mothers' sociodemographic, gestational and parity characteristics, capturing their main experiences and their perception of the hospitalization process.

By studying and exploring the speeches of these mothers, strategies can be devised to improve the monitoring of families and the work of the multidisciplinary team in the trajectory of prematurity, which makes this study relevant.

METHODOLOGY

This was a field, observational, descriptive and qualitative study carried out in the NICU of the Assis Chateaubriand Maternity School (MEAC), which is a teaching and research institution, a guideline for public health policies and a hospital unit that is an accredited institution, a regional reference in research in the area of women's and perinatal health (Brazil, 2022).

Data collection took place from January to June 2024 and investigated 7 mothers who were accompanying their children in the NICU and agreed to take part in the research, being informed about the study and giving their consent through the Free and Informed Consent Form (FICF). The study was approved by the Ethics and Research Committee (CEP) of the study hospital, located at Rua Cel. Nunes de Melo, s/n Fortaleza - CE, with Opinion: 6.844.738.

The research instruments used were a structured questionnaire that covered the mother's sociodemographic, gestational and childbirth characteristics, and a semi-structured interview script that highlighted the guiding question of the research and sought to understand the mother's anxieties and perspectives during her hospitalization due to prematurity.

The interview was divided into three axes: prematurity, hospitalization and the mother's aspirations and perspectives. The mothers' answers were recorded using the "iPhone call recording" feature, transcribed verbatim using "Word 2010" and described in this study in quotation marks, so as to take the participants' exact words into account, including linguistic errors. The main points expressed were noted down and read out at the end of the interview so that the participants could agree with their content, complete it or correct it.

Rodrigues, Oliveira and Santos (2021) describe that qualitative research is "entangled in the subjectivity of the researcher" because it interprets the problem and "explains the phenomena meaningfully and appropriately", so the researchers chose to identify them according to fragments of the song Hymn of Prematurity to represent the research participants and also to safeguard their anonymity: So tiny, So immense, Intense journey, Caress with your fingertips, It's not a wait, Great struggle, Love that fits in an embrace.

According to Paiva, Oliveira and Hillesheim (2021), in order to carry out a study, it is important to plan, and one of the most decisive stages is the exact definition of the data collection and analysis techniques. According to Minayo (2013), the "content analysis" approach is the one chosen by researchers, as it answers particular questions, is concerned with the social sciences and with a level of reality that cannot be quantified.

In order to carry out this research, all the ethical precepts of research with human beings that govern confidentiality, secrecy, anonymity, autonomy, beneficence, non-maleficence, justice and equity, regulated by Resolution 466/12 of the National Health Council / Ministry of Health / MS (Brazil, 2013), were obeyed.

RESULTS AND DISCUSSION

When we entered the NICU, the responsibility of welcoming these mothers permeated us and even though we weren't part of the team, the essence of being health professionals led us to get involved in the care. As we listened to seven mothers, who shared their stories in an empowered way, we realized how hard and exhausting the interruption of the pregnancy/puerperal cycle due to prematurity is for them. Before starting the interviews, the researcher responsible for the collection sha-

red her story of prematurity, which helped to reduce maternal anxieties, bringing hope and strengthening their prospects for the future.

In order to get to know the characteristics of the study population, sociodemographic, gestational and parity aspects of the mothers interviewed were investigated (Figure 1).

The predominant route of birth was cesarean section. Among the interviewees, one reported that her pregnancy was not the first to be terminated early, representing her fourth experience of premature birth. For the others, it was their first experience of prematurity and contact with the NICU. The clinical characteristics of the neonates are listed in Table 2.

The analysis of the participants' speeches extracted from the interviews, exploration of the material and interpretation of the speech resulted in the identification of 3 thematic axes for the discussion of the study: motherhood interrupted or anticipated by prematurity, the trajectory of hospitalization, maternal desires and perspectives.

MATERNITY INTERRUPTED OR ANTICIPATED BY PREMATURITY

The first axis sought to understand how mothers experienced the whole process of prematurity. Aspects such as knowledge about the reasons for premature birth, whether the pregnancy was planned and desired, the perception of interruption or anticipation of the maternal process, and expectations about what the pregnancy would be like were explored.

When investigating the reason for the premature birth, 5 mothers described the reasons in their own words, while 1 didn't know about the prematurity because her son was born at 36s and 1 said she didn't know the real reason, but believed it was due to an "infection". The explanation given by the team about the reasons for the premature birth was implicit in the mothers' speeches. Below are the accounts that illustrate this perception:

> ***So small**: "Because I had complications... I had... eclampsia. I had all the follow-up here, I came in with high blood pressure, gestational diabetes... then I thought I was already showing symptoms of eclampsia... but the team, the team that attended to me very well, from the beginning when I came in to the end. They explained it to me, the care was great, it was very good of them, they gave me a lot of attention, and talked to me, they were always with me and when it was the fourteenth... there was a "rush", they did my "cesarean section", and I am grateful mainly to God, and all the team, all of them here for their attention, and everything they did, especially for my little warrior and for me".*

> ***So immense**: "You spoke! Yeah... he was born prematurely because of my pressure, which altered the uterine veins, right? Intrauterine. And then the placenta matured to a level... 2, and I had to be hospitalized, I spent a month beforehand, so I could prevent it, taking medication, and my and the baby's vital signs were checked. When the placenta changed to grade 3, they had to deliver me. And it was clear, right? From the moment I was born, right through to hospitalization and delivery".*

> ***Intense journey**: "He was born prematurely because he was suffocating in the 'amyiotic' fluid, and I was also getting tired, I was also getting suffocated, right?".*

> *"Because of the pyelonephritis, I had a urinary infection, right, which affected my kidneys, and that's why she was born prematurely.*

> ***It's a big struggle**: "So... I didn't think he was born prematurely, but the doctors explained to me that he... that up to 36 weeks he's still premature in itself and at 37 weeks he's not anymore, so that's why I think he was born prematurely. Yes, the team told me why.*

> ***Love that fits in a hug**: "No, it hasn't been said yet. I think it must have been due to the infection I had in my uterus, which must have...expelled me, you know? for a premature birth, but it wasn't anything I said, that's it!".*

In their study, Lind, Loureiro and Rocha (2024) identified several risk factors related to prematurity, such as previous premature bir-

Mothers	Age	Marital status	Income (SM)	Education	Occupation	Type of home
So Small	38	Stable union	Up to 1 MW	Elementary school incomplete	Home	Own home
So immense	37	Stable union	Up to 2 to 3 MW	University degree completed	Psychologist	Own home
Intense journey	32	Married	Up to 2 to 3 MW	Elementary school incomplete	Hair	Own home
Fondness at your fingertips	21	Single	Up to 2 to 3 MW	High School Incomplete	Home	Rented house
It's not a wait	20	Single	Up to 1 MW	High School Incomplete	Unemployment	Own home
It's a big fight	28	Married	Up to 1 MW	Complete high school	Home	Own home
Love that fits in a hug	39	Divorced	Up to 2 to 3 MW	High School Incomplete	Home	Own home

TABLE 1: Sociodemographic Characteristics of the Mothers
Source: Self-employed

Mothers	Gestational age	Gender	Days of hospitalization
So tiny	36 weeks	Female	16 days
So immense	30 weeks	Male	39 days
Intense journey	32 weeks	Male	30 days
Fondness at your fingertips	30 weeks	Female	30 days
It's not a wait	36 weeks	Female	----------
It's a big fight	36 weeks	Male	6 days
Love that fits in a hug	24 weeks	Male	130 days

TABLE 2: Clinical Characteristics of Neonates
Source: Author

th, oligohydramnios, diabetes mellitus prior to pregnancy, twin pregnancies, autoimmune diseases, stress during pregnancy, urinary infection, pre-eclampsia, gestational bleeding, an interval between pregnancies of less than six months and pregnancies resulting from in vitro fertilization, respectively, and these factors were also observed in this study.

When asked about their planning and desire for pregnancy, 4 said they had planned the pregnancy and all said they had wanted it. Regarding their perception of the moment of delivery and their expectations of the pregnancy, they reported:

> ***So small****: "No... I don't think about what happened, it was because it had to happen, it ended up happening, but... I don't have anything to say about them, to complain, I just have to thank them for everything they did, for my little warrior, especially for my little warrior and for me".*

> ***So immense****:"It was very fast, because I was wanted, so I wanted a more peaceful pregnancy, right? To take photos of the pregnancy, to have that diaper party, right? So all of that was interrupted, I had to buy layettes while I was in hospital. And it was very embarrassing because... I couldn't take those belly photos, right? And... I was hospitalized and undergoing treatment, right? So that I wouldn't have a..., it's not even that I wouldn't have a premature birth, because it was going to be a premature birth! Because when the... degree of the placenta was grade 3, it's irreversible, it's as if the... the baby's blood, the mother's blood no longer passes to the baby and it returns to the mother, right? So that's why".*

> ***Intense journey****:"I think...it's...for me, in my view, it was the right time, God's time, that I couldn't bear to carry him in my womb anymore, because it was very exhausting, because I couldn't breathe, I didn't feel well, I couldn't sleep, I couldn't do simple things, like talking, everything, I was tired, short of breath, I stopped my whole life, you know! I couldn't work, I couldn't do anything else, everything tired me out.*

***Caressing my fingertips**:"So, from her, from the last one, I thought it would be the same as the other pregnancies, right? Because she'd have to stay in hospital, in the ICU, she'd have to be seen, right? Because of the weight, the pacifier, waiting for breastfeeding, everything was going to take a long time, right? Everything was going to take a long time, right?".*

***It's a big struggle**: "Like this, right? Since I had a short cervix, right? My doctor warned me right from the start that the sac could rupture before I was nine months along, right? So I was already aware of this, right?! And... I always imagined it, I never did, did I? I never ruled out the possibility that it could rupture before, and that it could come earlier, right? But...it's...it's, as I said, it's...my doctor had already warned me and everything was fine, right? There was nothing out of the ordinary, right?".*

***Love that fits in a hug**:"Yes, it was. Because when I started to enjoy the pregnancy, I already had him... I took a while to find out I was pregnant, and when I did, he was born in no time at all. Then I couldn't breastfeed, I couldn't hold him, I couldn't have skin-to-skin contact, I couldn't even do many things, it was taken away from me".*

It can be seen from the speeches that the gestational process is unique, involving different contexts and emotions. Some mothers planned it and wanted it, while others didn't plan it but wanted it. Regardless of the planning, the mother-child bond begins from the moment pregnancy occurs, whether planned or not, and is influenced by various factors, including intimacy, reciprocity, complicity and involvement between mother and child.

It was also seen that when a woman confirms that she is pregnant, she begins to imagine the moment of birth, what the first bath will be like, the process of breastfeeding, being held in her arms and all the expectations of motherhood. However, when the unexpected happens, and premature birth occurs, expectations are abruptly interrupted, feelings arise that perforate the process of gestation and transform this moment into a period of stress, tension and frustration. As Azevedo and Vivian (2022) state, the creation of the "imaginary baby" begins before pregnancy and continues to develop throughout gestation.

TRAJECTORY OF HOSPITALIZATION DUE TO PREMATURITY

In the second axis, when interpreting the participants' statements, we looked at how they coped with separation at birth, the first visit to the NB, and the impact of living in the neonatal unit environment. When asked what it was like to be separated from their child at birth and how many hours/days before their first visit, they commented:

***So tiny**: "I was very desperate at the time, I cried a lot, I couldn't believe it was happening, so much so that the doctor came and talked to me, the Social Worker, the Psychologist, and to this day they talk to me a lot. They're great professionals, excellent professionals, to this day I also thank God for all of them and they talk to me a lot, especially when I'm most distressed".*

***So immense**:"It was very impactful, because every mother idealizes that even at the time of delivery you take that photo with your child, right? On your lap, right? That they put him on top of you, and he quickly passed by me and went into the incubator".*

***Intense journey**:"It was very painful, it still is to this day (voice broken), I come to see him every day. I wanted to take him home soon.*

***Fingertip caress**: "It's a bit painful, isn't it? Sad, right? Because we think we're going to have the child and it's going to stay with us, right? Then when it's born, it comes here, a lot of time goes by, we practically don't have any time off, right? And our children are far away, right? We have to go home, we have to leave them here... It's a bit sad, isn't it? But...".*

***It's a big struggle**: "It was...on Tuesday. I had him on Saturday, but I was still here, right? until Monday, I was still here, so my visit was on Monday, right? My first visit was on the Monday I was here, still in hospital, right? It*

was on Monday that they allowed me to come and see the baby, right? They brought me to see the baby".

***Love that fits in a hug**:"It was horrible!" (crying)...It's because it was very difficult having him prematurely, and we always heard that from the doctors, that he had no chance of surviving, and that if I did, if I went for a cesarean delivery, I was also at risk of death, right? So remembering all that is very painful, even more so because I'm still living, right?".*

The speeches of the participating mothers clearly show the emotional impact of being separated from their children. This is a very painful time, if we consider that, as well as "breaking the lockdown" (a popular term), the woman will have to return home without her child and also face trips to the hospital, breaking the routine of the postpartum or puerperium period, which involves a series of physical and emotional changes, becoming especially delicate in the circumstances of an early birth. As Campos and Féres-Carneiro (2021) point out, this is a period idealized by women, but experienced with suffering and emotional instability.

Also on this axis, questions were asked about how mothers describe the NICU environment and how the hospitalization of their NB has changed their routine. They described their perceptions of the hospital environment and how they reorganized their activities to adapt to the new reality.

***So tiny**:"When I arrived there to see my little girl, the first time, they all welcomed me very well, to this day, thank God, they all welcome me well, I have nothing to complain about any of them or the environment. I see a lot of affection and care that they have, not only for my little warrior, but for all the little children in the units and outside the units, they are very loving people, love not only for their profession, but especially for the children who are there." "My little girl... when I had her, she went straight to nursery two, she didn't stay in the ICU. My routine is like this, right, every day I come in very happy, I don't complain if I'm tired or not, I'm grateful to God, I thank God every day that my little girl is alive, and I see that she's well, I'm happy.*

***So immense**:"It was scary, right?! I saw my son inside the incubator in the ICU, and I took all the precautions, right, of hygiene, so I could get to him and see, right? But the saying: you can hold your child, you can't, right? You have to be there in his corner, it's... to this day I still avoid contact because he's still underweight, and if he gets stressed, he won't gain weight, so it's quite complicated!".*

***Intense journey**: "Oh, they're all incredible, the doctors, the nurses, the speech therapists, the physiotherapists, they're all incredible, they give us a lot of attention, they're very careful with us, psychologists, everything... very good I think, their attention, I don't have to complain about anything."*

"I didn't come every day... I came every other day, practically, because of the other one, right? But... it was normal for me, right? It was a process, as they say, everything here is a process, right? Everything has its own time in here". "In the ICU, I came, I saw him every day, then I was discharged after six days, but I still kept coming, and again I was re-admitted for another ten days, because I got sick, there were some, yeah... collections in my abdomen, right? The doctor didn't tell me if it was pus or blood. But he said that it was in the operating room that this happened and these collections occurred. But he stayed in the ICU, I think for about ten days in total. I came to see him every day, to look after him.

***It's not a wait**: "It was good, nice, everything was great". "It passed, I think it was only five days, or it was six, then I came twice a week, then I saw him, then I went home, and I was discharged the next day."*

***It's a big struggle**: "He's still here, right, and he's expected to come out in six days, right? He's taking his medication. Pulled. I go home every day, I come back, I've had an operation, right? I had a caesarean section, right? I go every day, I go every day and I come back, but it's worth it, everything is worth it, for my son. I live after Maranguape".*

> ***Love that fits in a hug**:"How do I describe it? Wow, distant. Strange, distant people. Distant, cold scenery, out of my reality, something I'd never dreamed of living, that's the experience I had at that moment".*

It is clear that mothers face a challenging experience when they remain away from their babies, living with the anguish of uncertainty about their child's clinical evolution and, above all, survival. As Cegano *et al.*(2020) describe, premature birth requires specialized medical care and the use of various equipment available only in the NICU. However, this routine, which involves frequent examinations and procedures, the constant presence of connected devices and the sound of monitors, can have a major emotional impact on parents and family, creating a frightening or threatening environment.

It was also observed that the mothers of premature babies usually go to great lengths to look after their children, and even with all the difficulties they face during this journey, the love and faith that prevails among each of them is perceptible. It was also seen that there is a break in social ties, both with family and friends, since they spend a lot of time seeing their babies and end up forgetting to exercise self-care, go for walks, things they liked to do before.

The situation found above is in line with what is mentioned by the authors Santos *et al* (2021), Montanhaur; Rodrigues; Arenales (2020) who describe that the experience of prematurity imposes impacting changes on family functioning, intensifying the need for support from the team involved in caring for the NB, but also being a source of support when relieving family tensions and anxiety, generating feelings of hope, comfort and confidence

MATERNAL ANXIETIES AND PERSPECTIVES ON PREMATURITY

The third and final axis sought to understand the mothers' anxieties and perspectives on the hospitalization process and their expectations. The questions on this axis were guided by the definition of the word "Anxiety", previously defined by the moderator as "*A feeling or state of worry or suffering; affliction, anguish, yearning*".

The questions that followed dealt with the mothers' feelings at the time of the survey, the family's participation in the hospitalization, the most important person/subject/present during the hospitalization and their future prospects

> ***So little:** "Longing? No. It's... so, everything's normal, it's... just that I'm up every day, I'm here to see my little girl, alive and healthy, and I always, first of all, put God before everything, and I believe that everything is fine. Just seeing that my little warrior is well, that's all right with me. The moment my little girl is here? So, my family, I'm grateful to God for all of them, they're helping me a lot, especially at times like this, when I'm passing through, I don't have to complain because I know there are always those times when we're in a tight spot, my family is always there with me, my daughter's father... and he comes, he's already come to visit, he comes to visit his little girl. His children".*

> ***So immense**?:"Yeah... you get really distressed at not being able to look after your child, right? Having good news, in relation to the doctors' conduct, sometimes what we want to hear isn't expected, right? so there were several situations that I was really affected by and you want to cry, you want to blossom, you have to have a lot of faith in God because it's not an easy process, it's a slow process, when your child is born extremely premature, it's a slow process, it's a long process...it's...giving up having to come here every day when you have the ICU and your child is hospitalized, it's not easy, right? Because you're on maternity leave and in reality you can't have a peaceful*

maternity leave, can you? You can't. You come home, you don't see your child, you see everything ready and you can't...it's...that motherly care for your child".

***Intense journey**: "My whole family cares, worries, watches over me, every day they ask how it's going, how it's going, my husband is the most present. The most important thing for me is God first and then my husband. He's being incredible, caring, zealous, concerned about me, about our son, accompanying me every day so that I can come and see him, that's the most important thing for me".*

***Caressing my fingertips**:"Oh, usually nobody comes, right? just me. Because, I think it's... oh I want to see the baby and everything, but I think it's a moment more for the mother than for the father, than for grandma and all... we're the ones who have to breastfeed, we're the ones who have to do everything! Ah, my husband (laughs), my mother also helped, but in general it was more him, he was the one who stayed with me".*

***It's a big struggle**: "There are so many!... (laughs), oh my God, to enjoy my son a lot, together with my husband, right? to enjoy a lot..., it's...to do everything that, to try to do everything that I couldn't now at the beginning of his birth, right? I know there are going to be several things, several changes, right? but I'm going to try, right?! in the name of Jesus, it's...to do everything that I couldn't do at the beginning").*

***Love that fits in a hug**:"At the hospital? To be honest... there are the girls at reception who don't even need to say anything, they already know me, they already say my name, they just give me the paper, there are the nurses who are always talking to me, and that's it, they make the atmosphere less heavy, right? than it already is". "My plans! When I go home, I'm going to enjoy my son, who until today, he's four months old and until today I haven't been able to give him a bath, I haven't been able to put clothes on, give him milk, I haven't been able to give him a bottle, nothing! So I think, when my son leaves here, it's about enjoying him. Enjoy this moment that was so planned, but which has taken other paths, but in the end everything will work out").*

In this area, the participants highlighted and suggested the need to optimize some aspects, such as the physical structure - including expanding the space and providing a suitable place for meals and access to water - and issues related to the team. Among the improvements mentioned were the adoption of more welcoming and empathetic communication, as well as the creation of a space reserved for breaking bad news, ensuring comfort and privacy at these times.

It is important to strengthen the bond of trust between the team and the family, which can be achieved through continuous and effective communication. The way in which information is transmitted has a direct impact on the family's emotions, generating hope or discouragement regarding the NB's recovery.

Couto (2022) points out that changes in the child's clinical condition cause marked moments of apprehension and anguish, accompanied by feelings of helplessness and uncertainty about the future. In this context, Santos *et al* (2021) highlight the importance of initiatives such as organizing support groups coordinated by the NICU's multi-professional team, so that families can share their experiences. This would be a strategy for mothers/fathers and family members to realize that this is not their experience alone and to identify coping strategies

CONCLUSION

Through the viewpoint of the researcher, who has lived through the experience of prematurity, this study has made it possible to understand the path taken by these mothers who have had their pregnancies interrupted. Thus, highlighting the difficulties faced throughout this journey, including feelings in the face of a new and unknown reality.

Including the mother in the care process contributes significantly to a good prognosis, and it is essential that the multidisciplinary

team accompanies the baby, the mother and the family. This accompaniment should not be technical, but rather humanized and effective, promoting the renewal of hope for the recovery of the premature neonate, relieving maternal anguish and providing comfort to family members.

In view of this, it is extremely important for the team to promote moments of reflection that encourage mothers to take an active role, involving them and contributing to the development of their autonomy in caring for their child. We believe that this study can help sensitize professionals from the multidisciplinary team who care for premature neonates and their families to understand mothers' anxieties and perspectives, with the aim of welcoming those who live through such a challenging experience

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