

On the way to interrupting the gestation or not: experiences of pregnant women with anencephalic fetuses

Iulia Bicu Fernandes (<https://orcid.org/0000-0002-2857-2938>)¹

Rozania Bicego Xavier (<https://orcid.org/0000-0003-3435-8038>)²

Paulo Alexandre de Souza São Bento (<https://orcid.org/0000-0002-1598-3340>)³

Andreza Rodrigues (<https://orcid.org/0000-0002-1873-5828>)⁴

Abstract *Anencephaly is a malformation characterized by the total or partial absence of the brain, and Brazil records the fourth largest number of births of anencephalic fetuses in the world. Fetal anencephaly is associated with a more significant number of maternal complications. As of 2012, women with anencephalic gestation were empowered with the right to carry the pregnancy to term or terminate it, if they so desired, without any judicial authorization. Objectives: to understand the experiences of women with fetal anencephaly and to identify the determinant factors for interrupting the gestation or not. This is a qualitative study using the Life Narratives method with 12 women over 18 years old diagnosed with an anencephalic fetus, who interrupted gestation or delivery in a public maternity hospital in Rio de Janeiro. Data were collected between June and November 2016, and the process was finalized when the narrative patterns reached progressive saturation from the recurrences. The statements that emerged following floating and in-depth reading were articulated in Narrative Nuclei, and data comparative and comprehensive analysis was performed. The reports brought to light the intense experiences of these women, as well as the weaknesses existing concerning care and the pregnancy termination issue.*

Key words *Anencephaly, Legal abortion, Abortion candidates, Women's health, Public health*

¹ Hospital Municipal de Petrópolis Alcides Carneiro. R. Vigário Correias 1345, Correias. 25720-320 Petrópolis RJ Brasil. iulia.bicu.86@gmail.com

² Departamento de Ginecologia e Obstetrícia. IFF, Fiocruz. Rio de Janeiro RJ Brasil.

³ Núcleo Interno de Regulação, IFF, Fiocruz. Rio de Janeiro RJ Brasil.

⁴ Escola de Enfermagem Anna Nery, Universidade Federal do Rio de Janeiro. Rio de Janeiro RJ Brasil.

Introduction

Anencephaly is a malformation characterized by the total or partial absence of the encephalon, the latter being the most common form; it is incompatible with extrauterine life, and the fetus survives only for hours or days after delivery¹⁻³. According to the World Health Organization, Brazil ranks fourth in the number of anencephalic fetuses (1/1,600 live births), behind only Mexico, Chile and Paraguay^{2,4}. Of the pregnancies that are carried to term, approximately 75% of the anencephalic ones are stillborn, and the rest dies in the neonatal period^{4,5}. Confronting the diagnosis of a child incompatible with extrauterine life leads parents to experience great suffering and intense emotional experiences⁶, as well as health complications in pregnant women, such as hypertension, prolonged pregnancy, polyhydramnios, among others^{4,5}.

Despite the risk of physical and emotional complications, in April 2012, the Federal Supreme Court decided to decriminalize the interruption of gestation of anencephalic fetuses. The right to the therapeutic cessation of gestation was established without the need for prior judicial authorization, or for carrying the pregnancy to term if the woman so desired.^{5,7} The practice of interrupting gestation in cases of anencephaly cannot be configured as abortion because it is a therapeutic interruption of gestation or therapeutic anticipation of delivery, due to the increased risks to the health of pregnant women and fetuses with no possibility of life after birth^{3,5}.

Studies on *anencephaly* and *legal abortion* referring to the Brazilian reality in the last 15 years pointed only to three studies^{4,6,8} that specifically discussed the emotional aspects of anencephalic fetal gestation. Thus, this paper aimed to understand the experiences of fetal women with fetal anencephaly and to identify the determining factors for choosing to interrupt gestation or not.

Methods

The study method was Life Narratives as proposed by Bertaux⁹, with the participation of 12 women over 18 years of age diagnosed with anencephalic fetuses, who performed the interruption of gestation or delivery in a public maternity hospital in the city of Rio de Janeiro. Data was collected after the assessment and approval by the Maternity Research Ethics Committee, observing the norms of Resolution 466/12¹⁰. The

interview took place between June and November 2016, at the time and place of the participants' availability and after signing the Informed Consent Form. A single triggering question was asked: "can you tell me about your pregnancies?". Other inferences were made respecting what was said by the participant. The interviews were carried out at least one year after the birth of the anencephalic baby, allowing the respondent to reflect on their experience, seeking through this strategy to minimize discomforts due to the process of re-signification of the lived history. The narrative patterns reached progressive saturation in the fifth interview, from the recurrences, and data collection was finalized in the twelfth interview, allowing the negative case study^{9,11}. After the transcriptions and readings of the interviews, the statements that emerged were articulated in two Narrative Nuclei to allow a comprehensive and comparative analysis in the light of Bertaux⁹. Anonymity was respected, and each interview was identified using the letter E (interview) followed by an alphanumeric system from 1 to 12.

Results and discussion

The twelve women interviewed were of reproductive age, between the ages of 23 and 42 years. Most reported having a live child, ranging from zero to three children per participant. Nine identified themselves as married or in a common-law marriage status and the others self-declared as being single. Ten had secondary and higher education and nine reported being formally employed. The household's income ranged from zero to 11 minimum wages.

Regarding the gestation of the anencephalic baby, half of the cases involved the first pregnancy, and 75% of the women reported having undergone a planned pregnancy. Concerning resorting to the Judiciary to obtain authorization for the cessation of pregnancy, four of the women appealed, although in eight cases, there was jurisdiction for the procedure.

Some women had to bury their children because they were fetuses with a gestational age over six months. If the interruption occurs with a gestational age of fewer than 20 weeks' gestation, the fetus weighs less than 500 grams and is less than 25 centimeters tall, the death certificate is optional, according to current legislation, and is issued when there is a family wish to bury. Otherwise, the fetus will remain in the hospital, and then is incinerated or given to adequate hospital collection¹².

From a plentiful womb to an empty cervix: shifting from expectation to reality

A first line to be considered in this analysis is that the realization of biological maternity remains, for some women, a strong desire and is confused with socially constructed gender roles. It is well known that in contemporary times – considering the drawbacks evoked by this classification – women have conquered several spaces of the public scope, seeking professional fulfillment, insertion in the labor market, political voicing and economic autonomy.

While being a numerical majority in Brazil (51% of the population), women still receive 30% less than men to perform the same jobs, have fewer leadership positions and not only contribute to their household's income but of many others as well¹³. For a part of these women, one of their projects is the desire for motherhood. More than this, society still strongly requires it as a social role of women⁴.

The notions of vocation and compulsion in gestating and giving birth to a biological child have a historicity that confers identity aspects linked to women, which gathers representations capable of establishing links between “being a woman” and “being a mother”. Fulfilling this social role, which has patriarchal and utilitarian sociocultural roots, is like meeting a broad cultural tradition that is directly or indirectly imposed on women⁴.

Thus, a question is structuring for this narrative nucleus, that is to say: what are the expectations on gestation shared by women? The emphatic response of E2 when she learned of the diagnosis of pregnancy – “*we were delighted*” – represents the expectations of the participants of this study and their partners, since the couples desired a large number of pregnancies and, in these cases, the pregnancy was lived with joy and personal fulfillment. Only the statement of E3, a mother of three children, evidenced some signs of insecurity due to a difficult financial situation, while at the same time it was an unplanned pregnancy. Even so, the participant shared the same feeling of joy at the diagnosis of her gestation.

The millenary valuation of maternity leads many women to assign a personal and significant meaning to bearing a child. Pregnancy may represent the confirmation of her femininity and position of apparent social prestige¹⁴. There is also a set of dreams, hopes, and expectations that women place in the future gestation, idealizing and imagining the “being” that is in their womb,

where women, and often spouses are involved by feelings of personal fulfillment and the idealization of a perfect child^{15,16}. In situations of vulnerability, as in the case mentioned above of E3, the literature indicates that single mothers have problems with low income as a result of a poor job offer, lack of support from the father, limited public benefits, and a greater need of support networks¹⁷.

Thus, the idyllic reality of motherhood as an attribute of women, together with the high expectations of the participants of this study with their pregnancies, have imposed other reflections. After all, what does the pregnancy of a fetus with anencephaly show of concrete reality to these women? If on the one hand, the diagnosis of pregnancy brought joy, the diagnosis of anencephaly brought a range of adverse feelings. Expectations were put to the test. Such negative feelings were shared by the wife, spouse and family, bringing about a rupture related to the idealization of the perfect baby¹⁵. Gestation becomes a reality of intense emotional distress and anguish due to the frustration of expectations¹⁶. It is the awkward transition between happiness-related expectations to the harsh reality of facing a malformed fetus – a double that has been experienced sharply in diagnosis, through decisions, birth, the fate of the dead baby and going back home.

The pregnancy of an anencephalic fetus triggered in women and their spouses' reactions that involved words, as reported in the statements: shock; anguish; sadness; suffering; despair; panic and disorientation. A word from the popular vernacular appeared in four statements and carries the notion of these women's feelings, that is, they verbalized that it was “devastating” to discover that the baby was malformed:

I lost my ground; I was alone [...] I fell, I cried [...] those were such terrible days [...] I dragged on almost a week in that situation – E12.

Faced with frustrated expectations and distressing feelings, women narrated about another feeling, which was blame. Self-blame in the face of this occurred by being hard on oneself, as well as in the evident relationship with the man, since she “carries the baby”, raising her more propitious status to consider herself responsible for the outcome of gestation¹⁶. In these meanders, they questioned the unexpected situation in search of explanations and justifications, not always successfully obtained¹⁸:

“Why me? What did I do wrong?” You ask yourself – E6.

Another reality was not knowing what anencephaly was. Of the women interviewed, nine of them had never heard of this problem, and ignorance was a factor that linked the process to feelings of anxiety and stress. It is necessary to consider that, faced with this delicate and poorly addressed subject, the professionals responsible for reporting this diagnosis to a woman should practice what is called hard news communication.

Radiological examination is a technical procedure that provides the diagnosis of anencephaly. It is necessary to point out that the procedure is performed on an individual with subjectivities that cannot be disregarded and, thus, it is imminent that the professionals are aware, because they also have their subjectivities, that when performing the procedure, they are before someone with an intense emotional burden. After all, ultimately, it is precisely this professional who, for the first time, displays the image of the child to his mother, and the information related to the health or not of the baby is at stake in this clinical scene¹⁹.

Of the participants in this study, seven gave birth to fetuses with gestational age greater than six months, and, therefore, babies had to be buried. These are among the acme of the rupture between the imaginary and the reality put to these women – the burial. The diagnosis of a baby with anencephaly imposed, suddenly, the experience of mourning, in the plane of ideas, gradually experienced until the moment of childbirth. Before the baby born and dead, mourning shifts to the concrete, visible and palpable plane. This movement implied a process of emotional readjustment on the part of women, their partners, and family, according to the available subjective resources¹⁸. The other five participants in the survey did not need to live the situation of burying the child, but went through another, which is to authorize the genetic study of their babies.

Considering that the feeling of frustration and loss does not end with the birth and fate of the dead babies, the return home has been characterized as the segment of the lived experience of unexpected reality. The study participants also used words loaded with intensity on the subject: sadness; loss; pain; unacceptance; anger; guilt and emptiness. Shifting from the idealized to the harsh reality of the absence of the baby was present regardless of the time of gestation in which it was interrupted¹⁸. For many parents, the birth of a child is a portal of hope for the future. Standing before a defective child is interrupting this ide-

alization; it is facing an imperfect future, where mourning is a response to the loss of an idealized child but also to failing expectations^{20,21}:

The hardest part for me was coming back home [...] with a cesarean section [...] it hurt to look at the mark and [...] not to have the child – E5.

One of the respondents (E7) reported having suffered from post-traumatic stress after a cesarean section at the end of gestation. Although the decision not to anticipate the delivery was unanimous between the couple, the woman had a diagnosis of post-traumatic stress on her return to work and pointed out that she was able to overcome the situation with the unconditional support of the husband and family. Posttraumatic stress symptoms can be found in women who interrupt gestation, mainly at a later gestational age⁶.

Concerning E2, the loss of an anencephalic baby meant breaking with the desire for a new gestation – “*I did not feel like having another child, I was very traumatized.*” For other participants, the desire to become pregnant spoke louder, as was the case with three of them. In the case of two respondents, the experience of the previous loss led them to a gestation lived with fear and apprehension related to generating a malformed baby. The trauma caused by the previous loss enhances a not so silent memory, one that does not want to return to experience a frustrated gestation, nor later mourning¹⁸:

This gestation now [...] every ultrasound that I take triggers that despair in me – E5.

Faced with this reality, the presence of the partner and other relatives, who show concern and provide support, has a fundamental role toward recovery of the emotional balance of women who suffered the loss. The family can cooperate in the grieving process and the support provided will undoubtedly help the couple to manage the loss from what is established as a support network¹⁸.

Most of the participants in this study had the support of the partner or the mother, a central aspect to the experience of the problem, from diagnosis to returning home. But this reality was not always presented to all women, as were the cases of E3 that had no support network, E4 no husband support, and E8 who sought help in the figure of the husband and mother, not getting it in either. It is worth emphasizing that, in the presence of companions, mothers and other relatives, the professional can receive and guide women, do the same with their family network, explaining that support is fundamental to expe-

riencing this moment in life. Some personal and socioecological resources to cope with the process of developing a baby with malformation, and those that permeate ideological beliefs and marital relationships, as well as social networks²², are available:

My family very close by my side, my mother [...] my husband always there for me – E10.

The relevance of the support network can also be identified by its absence, through the reports of the women who declared having lived a solitary path. Such narratives point to the lack of support from the companion, family and close people, assumed as obstacles to overcome the situation:

I've always been alone, my husband never wanted to accompany me [...] I felt alone, completely alone – E8.

As if the lack of support were not enough, participant E6 revealed that a group of religious people had persecuted her. Once expressing the desire to interrupt the gestation and for appealing to the judiciary, she was accused of being a *murderer*. Not having a support network is a solitary and distressing experience for women before an anencephalic fetus pregnancy. Being accused of being a murderer for deciding to stop gestation, besides harming her legal right, is making her endure a situation of violence perpetrated by people who, in principle, should give support and reception, she is being judged morally/spiritually by people and institutions:

I had church stuff bothering me, they even came home [...] they went to my door and said that I was a murderer because I wanted to take it away – E6.

The judgments in question are rooted in the controversy over abortion in Brazil, which literature frequently raises, even in cases of severely affected fetuses. The opposition to the interruption of pregnancy in cases of anencephaly has a religious background²³, and since most of the Brazilian population declares itself religious, we can witness such behavior directed at women who decide for the interruption of pregnancy, a denial of rights.

Faced with the expectations shared by the women of this research versus the necessary concreteness of the experienced reality of an anencephalic fetus, this narrative nucleus is based on the lack of a support network and various judgments that are violence against women. On the other hand, the pregnant woman must find a safe and welcoming environment, a facilitator to verbalize and reflect her feelings, concerns, meanings, beliefs and personal needs without fear of

reprisals. It must be respected, first of all, avoiding value judgments, regardless of her decision, thus reducing possible feelings of guilt⁸.

In this challenging transition from expectations to reality, with all the vicissitudes, one aspect deserves prominence, that of women's resilience. Most of the participants in this study stated that it was an experience that provided them with great lessons. They succeeded in signifying what had happened, transcending unimaginable limits, verbalizing a maturity that generated strong transformations in their lives, in their companions, and in their families²⁰:

It's a life experience... we begin to mature without knowing it – E11.

The women's journey: decisions and care

Understanding women's journey requires us to point out immediately the "where" and "how" of problem diagnosis and the care provided by the professionals, and then understand choices and decisions. Women received the disturbing news that they were living a pregnancy of an anencephalic baby in the space of prenatal care visits or ultrasound centers. The women in this study reported that the professionals were careful to report the diagnosis and clarify the details that involved information related to the total unawareness of this type of problem, the technical specifications about the disease and the possible choices in this situation, which required thinking, choosing and deciding to interrupt gestation or not, since the outcome was already known.

Thus, it was in this relational space – prenatal care visits or ultrasound center – that, on the one hand, professionals cared for these women following care protocols, providing clarifications that included those related to their rights and current legislation⁶, and on the other, women and their companions facing their subjectivities that would influence their choices. Although it seems at first to be a focal decision – *the choice to terminate gestation or carry the pregnancy to term* – choices have been complex given the plurality of situations traversing this process. It should also be pointed out that, in the case of relational space, the professional relationship/women and companions was built based on the intersubjectivities involved.

The medical team has the responsibility to inform the pregnant woman about the malformation and lethal prognosis since no therapeutic approach can bring improvement. Doctors should also expose the possibility of interrupt-

ing gestation, either by legal means, through an official authorization, or through an ultrasound with the signature of two doctors. They should not impose or express their opinion and should seek impartiality in the information provided, as well as complete clarifications on the diagnostic and therapeutic procedures^{6,8}, a fact that has been revealed in the interviews:

“The decision is yours”; she explained all our legal rights [...] she was very delicate, caring and said all this holding my hand, she was very human indeed – E7.

According to the literature, the availability of information and specialized care of the health network are essential elements for the pregnant woman and her family to reorganize themselves following this diagnosis and to assist in coping with and managing the situation¹⁶.

The quality care provided by the professionals is an expected result since this research was developed in an institution with a history of handling pregnancies of anencephalic fetuses even before the current legislation. That is, in addition to being used to this, professionals are qualified for this care, care that must be present in other spaces for the health care of women because, before the condition of developing a baby with malformation, women need particular attention on the part of health professionals, are welcomed and respected¹⁶. This role must be assumed by health professionals at all times of care, starting with prenatal care¹⁵.

The interruption of gestation itself can be classified as a dilemma in these cases, where different issues emerge, from the *decided choice*, the *decided non-choice* and the scope of *concerns*. The latter revealed several outcomes, from complications with maternal health to legal and religious issues.

In the cases of the participants E1, E3, and E8, we were faced with women decided to stop the pregnancy, with *well-based choices*. Among their reasons are: the desire to end with that gestation, once and for all, shortening the time to try to become pregnant again (E1); and the fact that one of them, once knowing that her current pregnancy would not give her a healthy child, did not want to “get stuck” (E3) and prioritized to return home and care for her three children.

Of the 12 women, *only two did not want to interrupt* and were able to keep their *decided choices* to the end (E5 and E7), their babies were born through a full-term cesarean. Concerning E5, the decision not to interrupt was closely related to what she reported as a lack of courage related

to the meanings assigned to maternal love. In the case of E7, she desired to give a name to the baby so that the child could be buried next to her family after birth.

Many women can find meaning in continuing pregnancy, even in the face of the fetus’ unfeasibility, and must be respected in their desire to remain pregnant⁸. Some need to give a name and bury²⁴.

Four women discontinued their pregnancies for reasons related to their health (E2, E4, E10, and E12). In the case of E2 and E10, these were not slow in the decision to stop because of the complications. In contrast, E12 decided to stop only in the third quarter, when complications began to compromise the quality of life of the couple:

I constantly had arrhythmia and other complications – E10.

Despite health complications, the decision to interrupt, in the case of E4, was complicated, since she did not want to interrupt the pregnancy due to the belief that the mother should not interfere in the fetal life time²⁴:

I could not accept the fact that I had to interrupt, I wanted to let it run naturally – E4.

Gestations of anencephalic fetuses are related to various obstetric complications; this is one of the points raised by the literature in favor of the interruption of gestation. Among the complications are hypertensive diseases, complications at the time of delivery, renal and heart failure, placental abruption, premature rupture of the membranes, and infection are identified in these cases. More than just clinical-obstetric interurrences, the psychological consequences of gestation of an anencephalic fetus must be emphasized^{8,24}. Both physical and emotional complications were factors that influenced the decisions of women in this study.

It is interesting to observe the narratives of E6, E9, and E11, women who, at first, wanted to interrupt, but who had courses that involved legal difficulties, discontinued interruption and interruption in advanced gestational age. Thus, we must establish here points of view that have traversed their initial decisions. As discussed previously, four women had to judicialize their interruption, among them, were E6 and E9. At first, they wanted to interrupt, so much that they resorted to justice, but over time changed their minds for different reasons.

The case of E6 caused a stir due to the pilgrimage in search of the authorization to interrupt the gestation, which later resulted in the dis-

closure of this case in the media. In fact, this was one of the factors that aided in the promulgation of the pregnancy cessation precedent of anencephalic fetuses. This woman faced the embarrassing denial of her request three times, which is frequent in Brazil, before the promulgation of the precedent⁸:

It was tough; I went every day [...] I just took "no" over and over again [...] he (the appellate judge) found it absurd [...] he sent it to the media [...] with the statement of the case of my baby [...] this procedure started to be authorized – E6.

After so many denials, she had already given up on the interruption. Finally, at seven months of gestation, the favorable ruling came, and she decided to stop gestation by cesarean section.

In the case of E9, she went into labor at six months and, of course, the gestation was discontinued. It so happens that, in this course, she was summoned judicially to interrupt, but it was something that she said did not wish to pursue the issue any longer:

I went to have an abortion, but deep down I did not want to take it out – E9.

E11 changed her mind because of religious reasons. In her case, the baby ended up dying, and childbirth was induced. The literature shows that the gestation of an anencephalic fetus is related to preterm labor and intrauterine death^{1,4,24}, and that was the case for these women.

E2 wanted to interrupt, she went to court and, in fact, realized the interruption both because the fetus was anencephalic and of own health complications. However, it is a case that reveals exemplarily the anguish experienced by some women in the situation of interrupting gestation or not, where choices are contradicted. E2's reasons were also related to her religious values. She stated vehemently that she was "against abortion", although she chose to terminate her pregnancy. In the contradiction between interrupting the gestation or not, she chose the former. Her emphatic assertion was a way of taking on a *mea-culpa*:

When I went to get the authorization, I felt awful in court, me, in a criminal place, like a crook – E2.

In this case, the ambiguity of feelings was remarkable and revealed an inner conflict between interrupting gestation or not, leading her to rethink condemnatory concepts of what she called abortion practice. There are intimate issues raised by non-conformities, including self-blame, the feeling of committing a crime, and the decision to "hide what she did" from friends. With feelings of guilt, women may experience

interruption as a mark of character and not being stigmatized by friends and society. There is a need to silence this practice²⁵. Religion is one of the factors mentioned by pregnant women in order not to end gestation⁸.

If the prenatal care relational space was evidenced as a quality care site, the processes that involved hospitalization were different. The humanistic care of the professionals remained present, but the difficulties were found in the subjective aspects of women related to the approximation of delivery and objective aspects related to the maternity infrastructure.

Being hospitalized to give birth to an unviable fetus is facing a painful experience. Diverse feelings involved women during their hospital admissions: nervousness, despair, sadness, pain and intense suffering. E2 was an extreme case because she had a suicidal ideal due to the experience of going through labor and not being able to take the baby home:

I was very depressed; I was very sick [...] I had thoughts I never thought, to throw myself off a window – E2.

As the unwanted outcome neared, the women reported that the time of delivery with the visualization of the baby was one of the worst experienced moments. Not all women wanted to see their children; four of them, because they believed that contacting and seeing the deformities would make it difficult to grieve⁶:

I did not want to see, to know the gender. I did not want to know anything at all – E2.

The rest of the respondents made a point of seeing the baby soon after delivery, both for the curiosity to visualize the deformities and to say goodbye. It should be considered that they were already dealing with still not palpable mourning, of an intrauterine baby, and the farewell is the beginning of the realization of the mourning from the visualized reality:

I wanted to [...] I said goodbye to him. I just wanted to say to say goodbye to him – E4.

Delivery and birth are moments of confrontation between what is still hope of having there been an erroneous diagnosis of malformation and the real conditions of the newborn, besides being the first direct encounter with the baby. This moment is distressing and marked by the expression of mourning reflected in the absence of a healthy baby¹⁵. Some mothers must see the fetus with all the problems so that they can fully believe in the diagnosis of the malformation from a visible reality, establish a psychic meaning for this experience⁶. It is up to the caregiving

team to respect women's choice concerning the moment lived and to provide what is necessary so that this woman can experience this encounter with the baby in the least possible traumatic way.

Once the delivery and the (non) farewell of the dead baby are over, these women moved on to the stage where they were referred to the postpartum hospital in the institution. There is an objective marker that can facilitate or hinder the experience of this moment – the place where this woman went through her puerperal period in the institution.

This is because they are usually referred to an infirmary called Joint Accommodation. The problem is not the place itself but because it is a space shared with women who are accompanied by babies. It is a violent act for women who have lost her child to be in the same room with mothers with usually healthy babies. This is not due to the insensitivity of the professionals, but in general, due to a lack of a restricted space for these women or even due to hypercrowding of maternity wards. Even if they are well treated and cared for, the place will always trigger negative memories for the vast majority of women.

The very concept of 'maternity' as a hospital environment carries the idea that this is a place where mothers and their babies are. Moreover, in fact, this is what happens. Routine and the most diverse situations fill this space of meanings: baths, caring for the umbilical stump, breastfeeding, changing diapers, babies crying, and so forth. That is, they are not spaces for women who have lost their child, not allowing the experience of mourning. On the contrary, it potentiates emotional issues by bringing immeasurable weaknesses. The reports of the participants pointed to the desire to try to place the babies in their lap and, thus, returned to the imaginary of being able to leave with them in their arms at hospital discharge.

Sharing the space with other women and their children puts those who experienced the loss in direct contact with everything that their child represented, evidencing what is being missed, the feeling of not winning¹⁸. Hospitalization provides contact with successful pregnancies, which causes more intense feelings of failure, due to incapacity in gestation and the absence of the imagined and lost son, rather than by the interruption itself^{6,8}.

E6's statement shows the importance of not being hospitalized in the same space, cohabiting with mothers and babies, in that period. She reported that the team was careful to leave her in an infirmary of pregnant women after delivery in an attempt to minimize the pain of the loss:

When I had my child [...] they put me together with the others who were expecting to deliver, so as not to stay with those who already had a baby – E6.

The preparation and sensitization of health professionals working directly with bereaved women, such as the choice of the ward that the woman should be allocated in after childbirth, should be emphasized¹⁸. Of course, the conditions, infrastructure, and size of the wards must be taken into account. However, if possible, one should not place women who suffer a loss in wards shared with mothers and babies.

Given this, humanized care, women's right assured by the guidelines of the Unified Health System (SUS), is fundamental in the elaboration of the mourning experienced by the parents from the moment of diagnosis of malformation, through hospitalization and after discharge¹⁶. Thus, health professionals must provide qualified care and adequate emotional support to promote coping with this situation¹⁸.

Final considerations

Knowing the narratives of women who have experienced gestation of anencephalic fetuses encourages us to think about the unpreparedness of services – as institutions and as individuals – in addressing the decision process experienced by women, their partners, and their families. In each life narrative, we are confronted by the scarcity of literature that deals with the (new) issues analyzed in the statements.

The feelings experienced by women throughout their path (made notorious during the interviews), the problem of interrupting gestation of anencephalic fetuses and the difficulties faced during the whole journey are crucial points that the study identified. However, the weaknesses that must be managed to build a comprehensive SUS, aiming to improve the current (dis)organization of care for these women, and assure their reproductive rights, often disrespected, are necessary reflections to move forward in the field of care to women facing unviable fetus pregnancies.

Collaborations

The authors participated equally in the conception, discussion of results, review and approval of the final version of the study.

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