






# Experience of mothers after the diagnosis of congenital malformation and the expectations of care

## Experiência de mães após o diagnóstico de malformação congênita e as expectativas de cuidado

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 Ana Cláudia Monzon Zampoli<sup>1</sup>  
 Sebastião Caldeira<sup>1</sup>  
 Karine Brito dos Santos<sup>2</sup>  
 Oscar Kenji Nihei<sup>1</sup>  
 Rosane Meire Munhak da Silva<sup>1</sup>

<sup>1</sup>Universidade Estadual do Oeste do Paraná.  
Foz do Iguaçu, PR, Brazil.

<sup>2</sup>Universidade Federal da Integração Latino-Americana.  
Foz do Iguaçu, PR, Brazil.

### Corresponding author:

Ana Cláudia Monzon Zampoli  
Rua Lontra, 78, Vila A, CEP: 85861-120  
Foz do Iguaçu, PR, Brazil.  
E-mail: [anamonzonzampoli@gmail.com](mailto:anamonzonzampoli@gmail.com)

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### ABSTRACT

**Objective:** to understand the experience of mothers after the diagnosis of congenital malformation and the expectations of care from the health and social network. **Methods:** qualitative research based on Social Phenomenology, with the participation of six mothers living in border towns, by means of semi-structured interviews. **Results:** the reports brought information about the diagnosis of congenital malformation, the experience of pregnancy, becoming a mother of a child with malformation and the expectations of health and social care. **Conclusion:** the social group studied experienced the diagnosis of malformation with suffering, emotional repercussions and changes in their daily lives. **Contributions to practice:** communication by the health team contributes to understanding and facing the malformation. The importance of the family and social network support was highlighted. It is necessary to develop professional skills related to communication and to make more investments in training and working conditions that allow more time for the care of this public.

**Descriptors:** Maternal and Child Health; Fetal Diseases; Perinatal Care; Qualitative Research.

### RESUMO

**Objetivo:** compreender a experiência de mães após o diagnóstico de malformação congênita e as expectativas de cuidado da rede de saúde e social. **Métodos:** pesquisa qualitativa com embasamento na Fenomenologia Social, com a participação de seis mães residentes em municípios de fronteira, por meio de entrevista semiestruturada. **Resultados:** os relatos trouxeram informações sobre o diagnóstico de malformação congênita, a experiência da gravidez, o tornar-se mãe de criança com malformação e as expectativas de cuidado de saúde e social. **Conclusão:** o grupo social estudado experienciou o diagnóstico de malformação com sofrimento, repercussões emocionais e com mudanças no cotidiano vivido. **Contribuições para a prática:** a comunicação por parte da equipe de saúde contribui para a compreensão e enfrentamento da malformação. Destacou-se a importância do apoio da rede familiar e social. É preciso desenvolver competências profissionais relacionadas à comunicação e a maiores investimentos para a formação e condições de trabalho que possibilitem maior tempo destinado ao atendimento deste público.

**Descritores:** Saúde Materno-Infantil; Doenças Fetais; Assistência Perinatal; Pesquisa Qualitativa.

## Introduction

The pregnancy-puerperal cycle is recognized as a period of intense biopsychosocial changes for women and their support network. These changes are directly related to the baby's health, and may become more intense when there is a diagnosis of congenital malformation<sup>(1)</sup>.

Congenital malformations, also referred to as structural and or functional anomalies, are characterized as developmental disorders that occur during the formation of a particular organ or region of the body during the gestational period. They are present at the time of birth and can be detected prenatally or in the moments following birth. These malformations can lead to death or complex health conditions for thousands of newborns<sup>(2-4)</sup>.

In Brazil and Latin America, deaths from congenital malformations have been increasing. These congenital malformations are considered one of the main causes of infant mortality, particularly in the first year of life<sup>(1-3)</sup>. Worldwide, approximately 295,000 newborns die each year due to fetal malformations<sup>(1-3)</sup>. Other babies with malformations start to carry chronic health conditions, which result in high demand in public health services and require specialized multi-professional and interdisciplinary care<sup>(1-4)</sup>.

However, we warn about the under-enumeration and unavailability of recent data regarding the capture of anomalies in municipalities of the state of Paraná, particularly in the border municipalities and the international border strip, with their peculiar characteristics referring to barriers of access to services, which often leads mothers to move from their cities to the reference cities. In this sense, it is important to take a more careful look at the published indexes, because they may not accurately represent the total number of occurrences. In this scenario, the importance of maternal and child care is highlighted, since malformations can be avoided through vaccination, intake of folic acid and iodine through food consumption or supplementation, as well as adequate care during prenatal care<sup>(5-6)</sup>.

In order to seek qualified care to this population, in 2011 the federal government created the Stork Network, and in 2012 the State of Paraná initiated the Paranaense Mother Network Program with the purpose of organizing maternal and child care in all regions of the state<sup>(7)</sup>. This organization includes early and specialized care throughout the gravidic-puerperal cycle, since the network in many municipalities has difficulty in regular monitoring of the child during the neonatal period, with greater exposure to the risk of diseases due to the restricted actions of prevention and health promotion<sup>(7-8)</sup>.

Despite the significant number of cases in the country, added to the constant investment in hard technology for screening, diagnosis, and new assistance protocols<sup>(9-10)</sup>, the number of women who receive little information or have difficulties in understanding the diagnosis of their children and their health condition remains high. Many times, this happens because of the poor face-to-face relationship, the difficulties of communication between the team and the pregnant women, in addition to the focus on the control of such issues only under the physical and obstetric aspects, which causes little attention to be directed to the biopsychosocial and relational aspects<sup>(10)</sup>.

In a research with nine pregnant women from the high-risk prenatal program at a university hospital in Rio de Janeiro, the importance of this relationship between the pregnant woman, her family, and the health team was observed. The communication of the diagnosis of malformation precedes the whole process of mourning the child and the idealized motherhood, as well as the difficulties experienced during pregnancy, which will bring up a series of feelings such as denial, guilt, anger, shock, emotional withdrawal from the baby and from social interactions, until it can give way to acceptance<sup>(10-11)</sup>.

Another important factor in the process of care to overcome and adapt to this new situation is the social support network of these women, which often consists of their nuclear family<sup>(11)</sup>. In this sense, it raised the need to answer the following question: How do mothers living in a border region and borderland

experience the diagnosis of congenital malformation of their children? Thus, the objective was to understand the experience of mothers after the diagnosis of congenital malformation and the expectations of care from the health and social network.

## Methods

Research of qualitative approach, with Social Phenomenology as theoretical and methodological reference. The choice of this referential was due to the possibility of understanding the subjective and intersubjective experience of mothers in their social relations based on the “reasons why”, the experiences already lived, materialized and the “reasons for”<sup>(12)</sup>, which correspond to the expectations of care and support from the social network and health team. This experience includes the subjectivity established in the care relationship, the face-to-face relationship between health professionals and mothers who experience having a child with malformation, the baggage of knowledge on the part of professionals and mothers, in which it is possible to establish the social relationship between the professionals who care and the mother who requires care, resulting in the social action of care. In this way, the social group studied is typified, a process in which not individual experience, but common aspects are valued.

Interviews were carried out with six mothers, selected through records made available at the respective institutions where the mothers whose children had been diagnosed with malformations such as the syndrome of “cap” tegmental dysplasia, cleft lip and transforaminal cleft palate, cleft lip and bilateral cleft palate, gastroschisis, hydrocephalus, and esophageal atresia. The first communication with the participants took place by telephone contact, and all were included in the study because they were residents of municipalities in the ninth and tenth Health Regions of the State of Paraná, border region and strip.

The interviews were conducted between the months of July and October 2021, one of which occur-

red in person, and the others occurred via video calls due to the COVID-19 pandemic and the distance between the cities of residence of the researcher and the participants. A reserved place was prioritized, and the use of headphones was recommended to protect confidentiality. In addition, the Informed Consent Form was read, and after verbal acceptance, the interviews were started. The researcher, the interviewer for this study, has a degree in Psychology and has knowledge and experience in interview techniques and an affinity with Social Phenomenology.

A script with semi-structured questions was used to answer the following questions: “Reasons why”, that is, the concrete experiences: Tell me about how it was for you to receive the malformation of your child? Tell me about how the health care team (Obstetricians, Nurses, Obstetric Nurses, Psychologists and others) provided care during your pregnancy? How do you experience having a child with congenital malformation? Tell me about how your support network (family and others) has been helping you in the care of your child? What changes do you notice in your routine and in your life after the birth of your child?

The “Reasons for”, that is, the expectations: What are your expectations from your support network in the care of your child? What are your expectations from the health team in the care of pregnant women diagnosed with congenital malformation?

The average duration of the interviews was 30 minutes. The content was recorded and transcribed in full for later analysis. Data collection was closed when the convergence of the “Reasons why” and the “Reasons for” occurred, allowing the constitution of the lived type of mothers after the diagnosis of congenital malformation and the expectations with the health and social care network.

The organization of the data was based on the guidelines and steps of Social Phenomenology<sup>(13)</sup>: careful listening of the reports for manual transcription of the recorded interviews, careful reading of each report to understand the global meaning of the experience of actions lived, grouping of significant aspects

to form categories of the concrete lived for further analysis and understanding of the “reasons why” and “reasons for”, typification of the mothers’ social group and discussion in the light of Social Phenomenology and other references related to the theme. No software was used for the organization and analysis of the data. To maintain the confidentiality of the research participants, they were identified as MOTHER 1 to MOTHER 6.

Authorizations were requested from the Health Secretariats of the aforementioned municipalities for the research to be carried out. After obtaining the authorizations, this project was submitted for consideration by the Ethics Committee on Human Research of the State University of Western Paraná, which issued a favorable opinion number: 4,722,500/2021 and Certificate of Submission for Ethics Consideration: 46873721.0.0000.0107.

## Results

Six mothers between 20 and 35 years old were interviewed, of which two lived in the cities of Cascavel, one lived in Guaíra and was attended in Cascavel, and three lived in Foz do Iguaçu. Of these, two were single and four were married; three mothers had one child and three had two children. Regarding the diagnosis of malformation, four received it during prenatal care, one received it two days after birth, and another participant received the diagnosis two months after the baby’s birth. As for education, one mother had elementary school education, two had high school education, one had incomplete higher education, and two had complete higher education. Regarding the professions of these women at the time, one was unemployed, one was a security guard, one was a seamstress, one was a trader, one worked as a social media, and one mother was a nutritionist.

The referential of Social Phenomenology allowed us to understand the experience of mothers who had a diagnosis of congenital malformation in their children during pregnancy, or after birth, as well as

the care actions taken by health professionals and the social support network. This experience did not happen in an individual way, but within the scope of social relationships.

Some concepts or assumptions of Social Phenomenology were evidenced in this study, such as: social world, social relationship, face to face social relationship, intersubjectivity, baggage of knowledge, motivation encompassing the “reasons why” and the “reasons for”, the reciprocity of intentions between the professionals who provide care and the mothers who require care. Thus, the experiences that were similar or typical of this social group, represented in the present study by mothers who received the diagnosis and lived with the congenital malformation of their children, were evidenced.

In this way, relevant themes were selected based on the auditions and transcriptions of the participants’ reports, and five concrete categories of what was lived were identified, of which three were related to the “Reasons why”: Receiving the diagnosis of congenital malformation; Experiencing pregnancy in the context of the support network and therapeutic itinerary and Becoming the mother of a child with malformation. Two categories referred to the “Reasons for”: Expectations of care with the social support network and Expectations of care with the health network.

The Category - Receiving the diagnosis of congenital malformation, translates the knowledge of the care actions required and experienced by mothers regarding the professional care, especially when communicating about the diagnosis during pregnancy or after birth, as well as the emotions and feelings aroused when communicating about the health condition of their baby: *At the beginning it was very hard, it seems that our world ends at that moment... You get shocked, then comes the support of the husband, the family, my mother, my friends, my sisters. The obstetrician helped me a lot, very humanized (MOTHER1). It was a shock in truth because she was born so tiny, so delicate, and to be born with this malformation was very sad, wasn't it? (MOTHER2). Ah, for me it was a little complicated because I was expecting and I was already afraid since the beginning of pregnancy because I already had an*

abortion (MOTHER 3). So I felt very guilty at the time, but then I kept trying to comfort the people around me, but now I understand that I shouldn't have done it. The doctor tried, she said "look, mother, your daughter has a little problem here" and I thought "oh my God, what problem? What is going to happen?" I was like, you know, after that I didn't pay much attention. By the time I got out of there I grabbed my cell phone and started to look and read. I was very overwhelmed and everyone was like, "no, a miracle is going to happen, Jesus is going to free her" and I was like, he is going to free her from what he is not (MOTHER4). I was lost, because they portrayed to me saying that it was a rare syndrome, so the first question I asked was, will my child be normal? Will my son walk? Will my child talk? Will my child eat? So all this, they did not know how to answer me (MOTHER5). I had no reaction at all in truth at the first moment, because I did not know what it was, I did not know. Then I went, after I left the doctor's office I went on the internet, didn't I, on Professor Google, then I went there and read all the interviews they had, then I looked for CEAPAC [Center for Attention and Research in Craniofacial Anomalies] here in Cascavel (MOTHER6).

The Category - Experiencing pregnancy in the context of the support network and therapeutic itinerary, brings all the experience of gestating a baby with malformation with fears and difficulties faced; it also reflects the path taken by mothers after the birth of the baby and other care that is routinely required: I discovered the toxoplasmosis, but when I found out that he had hydrocephalus, the lady at the ultrasound scared me a lot, one of the worst days I have ever lived. He didn't have any malformation in his head, because this follow-up was to see if there was no pressure, the hydrocephalus didn't make pressure and if it started to grow too much I would have to remove it to do the surgery soon, but thank God he reduced the liquid and now he only has the calcifications due to the toxoplasmosis. According to the ophthalmologist, it will not hinder his vision at all (MOTHER1). It was always one more consultation, one more ultrasound, always so one more care during pregnancy (MOTHER3). I started to look for a group on Instagram, I contacted some mothers, they were explaining their experiences and that's how I found out, that's how I accepted. I wanted to know what I was going to go through, the experience I was going to have, and they didn't tell me that, so I felt that they were not prepared for that situation, you know. The obstetrician did not tell the pediatrician that a girl was coming with cleft lip and palate, she was very frightened at the time, my

baby bronchospired, she almost died in hospital, there was no assistance for her, they had to discharge me ahead of time to see if I could be admitted to Costa Cavalcanti [Hospital] (MOTHER4). I had a lot of difficulty at the beginning because of a lot of prejudice, people are still very prejudiced. So every day that passes I am learning to deal better with people (MOTHER6).

The Category - Becoming the mother of a child with malformation shows the changes that mothers felt and feel in their lives during the transition from pregnancy to having their children amidst insecurity, the adaptations that were necessary, but mostly finding support in the family and health support network: I didn't have so much change, of course not before, now I am still in the diet phase, but before I used to take care of the house all by myself, and now I have more help, but the routine hasn't changed, not yet (MOTHER1). Gee, it was much more tiring, much more tiring because it is from six in the morning that my husband leaves here to work, isn't it, from six in the morning until five o'clock in the afternoon, there at the hospital isn't it, then I stay at the hospital, I have breakfast at the hospital, lunch at the hospital, at home there is not much time except to get home and sleep so that the next day the same routine, at six o'clock in the morning I am there at the hospital (MOTHER2). Ah, it changed a lot, in view of my work because I work on the farm, it has been two weeks that I went back to work, I didn't go back before because he was only at the breast, feeding at the breast, and now that I am getting him used to the bottle I went back to work, that's all that makes it difficult (MOTHER3). I work at home office so my dedication in the morning is to take care of the baby, I do one thing or another at work, and in the afternoon my husband comes home and stays with her and I do the things I need to do for my clients... But the routine totally changed, so did my husband, he used to work at the ramp, now he has gone to the administrative area to be able to help me and stay with the baby, you know, she demands a lot of attention (MOTHER4). Since he was born and since he had this problem that already hospitalized him, I stopped working to dedicate 24 hours a day to him and he has activities every day. And I am the only one who accompanies him. I gave up my whole life, I gave up a lot of things to be able to take care of him (MOTHER5). Like it or not we end up worrying, don't we, I always stay on top of the exams that he has the different care, don't we. Everything is through CEAPAC if he gets sick I already contact them and they give care. Everything is directed there (MOTHER6).

The Category - Expectations of care with the social support network - refers to the “reasons for” and reveals how important the support of family and friends becomes during the confrontation experienced in being the mother of a baby with malformation: *The oldest son I intend to put him in school, then I don't know how this pandemic is, but I don't have much to think about the help, only my husband will help me, daily help. This emotional support is very important in this, even more so, it gives us a relief, it takes a load off our shoulders, it is not only me that is, let's say, suffering, it is not, there are people helping me to go through this, isn't it (MOTHER1). My expectations are high and for sure they will love her, in fact they are already loving her more than I do (MOTHER2). My mother has always supported me, has always been close to me and my brothers, so this will be wonderful for me, that she will always be there taking care of me (MOTHER3). Ah so I thought that, in fact everyone works close to me, so I have no one to count on to tell you the truth, so it is me and my husband and we manage (MOTHER4). Whenever I need something I ask my mother, I ask his other grandmother, his father's voice like this and more daily it is me, me, me, I prefer myself, I don't like to ask for help, it is me. I like, I pulled the responsibility to the chest and I take care. But they help, they help a lot (MOTHER5). I say my husband is an essential part... he helps me, he helps me to take care of him, he helps at the consultations when I can't, because sometimes I have my own things, he takes me to the consultations... (MOTHER6).*

The Category - Expectations of care with the health support network - pregnant women and mothers brought in their reports in the “reasons for” the importance of clear and sincere guidance, humanized care, empathy and respect: *Talking isn't it, nicely, I think that helps a lot, isn't it. Also explaining to us, I think that information, sometimes, like if I didn't have all this information that I have today, it can be reversed, it gives us a certain security that makes us calmer, you can think more, reason more, this humanized communication (MOTHER1). They should talk openly with the mothers, shouldn't they (MOTHER2). There is no support network, there is no real medical assistance, I didn't have either. I think that it would make all the difference, but I think that there was a lack of preparation from the team, in terms of knowledge, you know (MOTHER4). That they have empathy when they are going to talk isn't it. I just think that the professionals should have more empathy, know how to use words, be respectful (MOTHER5).*

## Discussion

Based on Social Phenomenology, it was possible to understand the subjectivity of mothers of children with congenital malformation and the social world they are part of through the “Reasons why”, where they report their experiences since the moment their children were diagnosed, thus bringing their concrete experiences and the deconstruction of an idealized maternity<sup>(11,14)</sup>.

The main emotional reactions reported by the mothers participating in this study upon receiving the diagnosis of malformation were fear, shock, sadness, guilt, devaluation, and even a suspicion that something was not right with the health of their children due to the history of miscarriage in previous pregnancies. Thus, coping with the prognosis of malformation is involved in several factors, such as the knowledge acquired about the situation experienced, the contexts such as the emotional state of the mother and her family, as well as the health care provided by the multiprofessional team<sup>(15-16)</sup>.

With regard to the “Reasons why”, it is observed that the use of hard and soft technologies permeate the moment of diagnosis that usually starts from the ultrasound. However, what stands out as an emotional protection factor during pregnancy and as a facilitator in the acceptance process are the care actions by means of soft technologies, that is, the face-to-face relationships performed by the health team professionals, such as the communication of the malformation itself in a clearer and more explanatory way, the attention given during the prenatal, delivery and postpartum periods, the more frequent consultations, as well as the orientations that were performed on a daily basis and that made it possible to increase the knowledge of these mothers about the health status of their children<sup>(9,15-16)</sup>.

Based on these considerations, the participating mothers reported the difficulties experienced during the process of accepting the malformation of their child, which was often dreamed as healthy; in

addition, they reported the importance of faith and family as a support network and as a coping resource<sup>(11,16)</sup>.

The search for support is permeated by a multitude of paths, but it is in the family that the mother finds the first point of listening and attention in this trajectory and, consequently, they are the first to offer help and support to face this difficult moment. Considering the relevance of family support, in the absence of the child's father, the difficulties to solve the adversities resulting from congenital malformation become greater<sup>(11)</sup>, an aspect not evidenced by the participants, since the father figure was present to care for the child.

All participants reported that, in some way, there were changes in their daily lives after the diagnosis of their children, whether major or more discrete, and that both the health team and their social support network were presented as motivators for emotional security and adaptation, and that this support and attention given by the support network and the need to receive this care by the mother are seen as reciprocity of intentions<sup>(12,16)</sup>.

It is still strong in our culture the fact that the mother is considered and taken to be the main caregiver of her children, centralizing in her not only the attention to her offspring, but also the domestic chores, being the first ones to leave work to take care of these other chores. This is amplified when a child with malformation is born and needs more intense, constant care, bringing, many times, a social and professional separation, marital conflicts, as well as financial difficulties, increasing even more the fragility of this woman and her family<sup>(17)</sup>.

Based on these experiences, these women reported the "Reasons to"<sup>(12)</sup>, that is, their expectations before the health team and the social support network and how they could contribute in a positive way to benefit pregnant and postpartum women and mothers, from the communication of the malformation to the subsequent care.

This care was provided through the social relationship between the professionals who provide care and the mother who requires care, the social action of care, and the reciprocity of intentions between the pregnant woman, mother, family, and health team, where the face-to-face relationship happens<sup>(12)</sup>, which permeates all the care received by these women during the pregnancy-puerperal cycle, including prenatal care, labor, delivery, birth, and the postpartum period, as well as the infancy of their children, which significantly marks their experiences in this period.

The communication among health professionals is also highlighted in the "Reasons to", being one of the mothers' expectations, who envision a humanized, empathic, and clear communication, adding knowledge and evidencing the importance of the use of soft technologies<sup>(9,11)</sup>.

In this sense, the importance of constant training of health professionals who work in the maternal and child area is observed, in search of knowledge baggage not only in relation to the question of acquiring technical skills, but also to develop skills related to emotional and relational abilities. It also includes the possibility of actions in the area of public health regarding the prevention of malformation that can begin before the conception period, as well as early diagnosis and greater investments in outreach care, seeking to strengthen the community and the local health network, especially for these women who live in the border strip and need to constantly move from their cities to the reference cities<sup>(6,9)</sup>.

## Study limitations

The main limitations found in this study are related to the fact that the collection was restricted to mothers residing in only some of the cities in the ninth and tenth Health Regional of the State of Paraná, since the methodological framework adopted allows for the analysis of the participants' reports when these become repetitive.

## Contributions to practice

This research shows the importance of the presence of the health support network during the prenatal, diagnostic and postpartum care of mothers of babies with malformation who live in a border region and strip. The use of light and light-hard technologies of care presents itself as essential from the communication of the diagnosis of malformation, during the prenatal consultations, when the concern about the baby's health and the possible pregnancy outcomes increases, to the hospitalization period of the mother and the baby. In this sense, the development of professional competences related to communication stands out, as well as the need for more investment in training for the development of these abilities such as the ability to listen, welcome and guide these pregnant women, as well as to have working conditions that allow more time for the care of this public.

## Conclusion

Mothers experienced their children's malformation, surrounded by changes in their daily lives soon after the diagnosis, since these changes will be permeated throughout their lives, whether they are major transformations or something more subtle, and that both the health team and their social support network were presented as motivators for emotional security and adaptation.

The studied group points out as their main expectation the care actions by the health team, that have technical, scientific, ethical and humanistic knowledge, showing the importance of the use of soft technologies in the care of this public. While their expectations from the social support network are the reception, emotional support and help in caring for the baby.

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## Authors' contribution

Conception and design, article writing and relevant critical review of the intellectual content: Zampoli ACMZ.

Analysis and interpretation of the data, critical review of the content and approval of the final version to be published: Caldeira S.

Relevant critical review of the intellectual content and approval of the final version to be published: Nihei OK, Silva RMM, Santos KB.

Responsible that all aspects of the manuscript related to the accuracy or completeness of any part of the work are properly investigated and resolved: Zampoli ACMZ, Caldeira S, Santos KB, Nihei OK, Silva RMM.

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