

# Beliefs and practices of caring for pregnant women with diagnosis of fetal malformation

Luz Ángela Argote-Oviedo<sup>1</sup>  
 Alcira Escobar-Marín<sup>2</sup>  
 Luzmila Hernández-Sampayo<sup>3</sup>  
 Liliana Cristina Morales-Viana<sup>4</sup>  
 Martha Lucía Vásquez-Truissi<sup>5</sup>

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### Abstract

**Objective.** To describe the beliefs, experiences, and practices of caring for pregnant women with diagnosis of fetal malformation. **Methodology.** Focused ethnography with the participation of eight women older than 18 years of age with diagnosis of fetal malformation and whose parturition occurred in a tier III hospital. The sample size was defined per data saturation. The information was obtained through in-depth interviews and analysis with the Spradley methodology. **Results.** The women endured the experience as a painful process, from which they manifested fear, uncertainty, and culpability regarding the diagnosis. This situation led them to using coping strategies like faith in God, adhering to recommendations from healthcare personnel, and carrying out cultural practices. Because the diagnosis was made during the advanced stage of the pregnancy, the participants had to continue with the gestation and adapt the self-care practices during this period. **Conclusion.** Self-care practices and relationships were evidenced among the women and the social support networks and the healthcare system, which favored confronting this situation by the pregnant women and their families, which permitted their carrying the gestation until the end.

**Key words:** Caregivers; congenital abnormalities; anthropology, cultural; pregnancy.

## Creencias y prácticas de cuidado de mujeres gestantes con diagnóstico de malformación fetal

### Resumen

**Objetivo.** Describir las creencias, experiencias y prácticas de cuidado de mujeres gestantes con diagnóstico de malformación fetal. **Metodología.** Etnografía focalizada en la que participaron ocho mujeres mayores de 18 años con diagnóstico de malformación fetal y cuyo parto ocurrió en un hospital de nivel III. El tamaño de muestra se definió por saturación de datos. La información se obtuvo a través de entrevistas en profundidad y el análisis con

1 RN, Master. Professor, Universidad del Valle, Colombia.  
 email: luargote@gmail.com

2 RN, Master. Professor, Universidad del Valle, Colombia.  
 email: alesma19@yahoo.es

3 RN, Master. Professor, Universidad del Valle, Colombia.  
 email: luzmy1721@yahoo.es

4 RN, Master. Professor, Universidad del Valle, Colombia.  
 email: liliana.morales@correounivalle.edu.co

5 RN, Ph.D. Professor, Universidad del Valle, Colombia.  
 email: maluvasq@gmail.com

**Article linked to research:** Creencias, experiencias y prácticas de cuidado de mujeres gestantes con diagnóstico de malformaciones fetales.

**Subventions:** Universidad del Valle.

**Conflicts of interest:** none.

**Receipt date:** October 14, 2012.

**Approval date:** May 8, 2013.

**How to cite this article:** Argote-Oviedo LA, Escobar-Marín A, Hernández-Sampayo L, Morales-Viana LC, Vásquez-Truissi ML. Beliefs and practices of caring for pregnant women with diagnosis of fetal malformation. *Invest Educ Enferm.* 2013;31(2): 234-242.

la metodología de Spradley. **Resultados.** Las mujeres vivieron la experiencia como un proceso doloroso, a partir del cual manifestaron temor, incertidumbre y culpabilidad ante el diagnóstico. Esta situación las llevó a utilizar estrategias de afrontamiento como la fe en Dios, la adherencia a las recomendaciones del personal de salud y la realización de prácticas culturales. Como el diagnóstico se hizo en etapa avanzada del embarazo las participantes debieron continuar con la gestación y adaptar las prácticas de autocuidado durante este período. **Conclusión.** Se evidenciaron prácticas de autocuidado y relaciones entre las mujeres y las redes de apoyo social y el sistema de salud, lo cual favoreció afrontar esta situación por parte de las gestantes y su familia, lo que les permitió llevar la gestación hasta el final.

**Palabras clave:** cuidadores; anomalías congénitas; antropología cultural; embarazo.

### **Crenças e práticas de cuidado de mulheres gestantes com diagnóstico de malformação fetal**

#### ■ Resumen ■

**Objetivo.** Descrever as crenças, experiências e práticas de cuidado de mulheres gestantes com diagnóstico de malformação fetal. **Metodologia.** Etnografia focalizada na que participaram oito mulheres maiores de 18 anos com diagnóstico de malformação fetal e cujo parto ocorreu num hospital de nível III. O tamanho de mostra se definiu por saturação de dados. A informação se obteve através de entrevistas em profundidade e a análise com a metodologia de Spradley. **Resultados.** As mulheres viveram a experiência como um processo doloroso, manifestando temor, incerteza e culpabilidade ante o diagnóstico. Esta situação as levou a utilizar estratégias de afrontamento como a fé em Deus, a aderência às recomendações do pessoal de saúde e a realização de práticas culturais. Como o diagnóstico se fez em etapa avançada da gravidez as participantes deveram continuar com a gestação e adaptar as práticas de auto cuidado durante este período. **Conclusão.** Se evidenciaram práticas de auto cuidado e relações entre as mulheres e as redes de apoio social e o sistema de saúde o que favoreceu o afrontamento da gestante e sua família ante esta situação que lhes permitiu levar até o final a gestação.

**Palavras chave:** cuidadores; anormalidades congênitas; antropologia cultural; gravidez.

## Introduction

Congenital anomalies represent a social and health problem due to the morphological or intellectual defects during the development of a new being, as well as from an economic point of view.<sup>1</sup> These anomalies affect approximately 3% of newborns at birth, a percentage that does not include cases in which early fetal death and reabsorption has occurred, which is why the true incidence of the problem is underestimated.<sup>2</sup> The global incidence of congenital malformations (CM) at birth ranges between 25 and 62 cases per every 1000 newborns and the incidence of severe congenital disorders that can cause premature death or chronic diseases along life

is of 43 per every 1000 newborns.<sup>3</sup> According to statistics on neonatal mortality, in developed nations like Canada and the United States, this problem bears important weight (29%), while Latin America and the Caribbean these correspond to 13%.<sup>4</sup> In the United States, mortality due to CM is at 21%, and it is the first cause of infant mortality.<sup>5</sup> These indicators are related to the causes of infant morbidity and mortality, which, in developing countries, due to their origin, can be modified through specific protection interventions like vaccination, promotion of breastfeeding, and environmental sanitation among others, while in developed countries the causes become

irreducible, increasing, in this case, the number of congenital malformations.

In Colombia, since 1994, CMs have occupied the second place as the second cause of infant mortality (11%).<sup>1</sup> The research conducted in 2001 by the Institute of Human Genetics at Pontificia Universidad Javeriana in Bogotá, in partnership with the Latin American Collaborative Study on CM, revealed that at *Hospital Universitario San Ignacio* the global prevalence of malformations was 4.3%,<sup>3</sup> a value comparable to the global prevalence of malformations (3-4%).<sup>6</sup> Similar results are reported in the study conducted at *Hospital Universitario del Valle* in Cali, Colombia during the 2004-2005 period: 2.8% of all births had CM.<sup>7</sup>

Detection of CMs continues on the rise inasmuch as imaging techniques are perfected and new diagnostic technologies emerge. However, positive diagnosis generates in parents a very painful coping psychological reaction, similar to that produced upon any other type of bigger conflict. The main options available for pregnant women or their partners who have been informed that their child has a congenital anomaly incompatible with life or is highly disabling are: fundamentally, interruption of gestation or assuming the risk of having a child with no real possibility of treatment effective surgical correction. Upon a diagnosis of gestation with CM, a series of factors exist dependent on the pregnant woman, partner, and other family members who intervene in decision making, like the perception of the problem, educational level, religious beliefs, family history, and cultural environment among others. Other factors can also influence and these are mainly related to the very congenital anomaly: whether it is isolated or if it may be part of a syndrome, whether it modifies or not the child's external aspect, or if it affects the child's IQ.<sup>5</sup>

Most research has had a clinical focus aimed at describing the prevalence of the problem and variables associated to it. This research seeks to delve into the experiences of women who must face this problem, given that for nursing

professionals who offer healthcare it is of great importance because it permits practicing said care congruently with the culture and can contribute to overcoming the crisis implied by the situation of encountering a CM.

## Methodology

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This study proposed a qualitative-type design and the approach method selected the particularistic or focused ethnography<sup>8</sup>, which – rather than applying the ethnographic methods to a whole culture, applies them to a social unit or a given human group. As every ethnography, the study centered on the systematic classification of the beliefs, experiences, and practices through emic manifestations (meanings founded and based on the individuals and not from the researcher's convictions and practices).<sup>9</sup> The women who participated in the study attended consultation of high obstetric risk at a tier III hospital.

Data gathering was carried out with the endorsement of the Ethics Committee of the Faculty of Health at Universidad del Valle and the researchers conducted the in-depth interviews,<sup>10</sup> which permitted obtaining information on the phenomenon under study and accessing the meanings the women had of their experience. Two to three interviews were conducted per participant, all carried out within the natural environment of the mothers, that is, in the place of residence or where they considered it pertinent. Each interview lasted an average of one hour, and interviews were recorded and transcribed with the participant's consent.

Selection criteria considered the following: women 18 years of age or older, residing in Cali, whose pregnancy had been diagnosed with fetal CM. The sample comprised eight women and data saturation was the criterion used to make it up.<sup>11</sup> Analysis of the information was performed simultaneously with the data collection, following the Spradley method.<sup>11</sup> Domains were identified from the emic perspective advancing in the construction of taxonomies, recurrent patterns,

and – finally – the themes emerged. We, then, proceeded – according to what was mentioned – to seek in each record the literally transcribed interview the domains through semantic relationships as starting point. Each of the domains included the three basic elements: The term covered or cultural domain, terms included, and the semantic relationship, which is in charge of establishing a connection among these and the domain name. To consolidate each one, structural questions were formulated to the key informants to test if the terms included were or were not part of the element. Thus, structural matters were repeatedly inquired on structural matters to verify terms included, semantic relationships and the native language, and adjustments needed in each domain were carried out, per the criterion of the key informants. Thereafter, came the taxonomic construction or set of categories organized on the basis of a sole corresponding semantic relationship. Finally, from the recurrent patterns, the themes were identified, which enabled the researchers to pose the conclusions and recommendations.

## Results

The women participating in the study, initially experienced sadness, distress, anxiety, fear, and culpability among others feelings, given the diagnosis of fetal malformation as described by the following:

### **Theme 1. The illusion of a healthy child vanishes with the news that it will be born with a disease**

The participants made explicit significant events occurring from the moment they received the news on their offspring's state of health. Their expectation and illusion regarding gestation was, like every other mother's, that of giving birth to a child in healthy conditions. This theme emerges when the physician, after practicing an ultrasound on the woman, lets her know, as well as her family, of the baby's morphological state, which brings about in them feelings of sadness, helplessness, and frustration. Expressions like:

*wanting to go mad when I learned that my child was sick, wanting to die after knowing of the baby's problem*, are evidence of the commotion endured by pregnant women when receiving the impact of the news of a CM in the child; in turn, they realize the shock and how incomprehensible it turns out for a pregnant woman to learn that her unborn baby is already sick.

Also, the partners manifest feelings of guilt, as well as having questions regarding their responsibility with respect to the malformation; they rebuke themselves for not having taken care as they should have before and during the gestation, with the aggravating condition that, given that it is a *fait accompli*, no possibilities exist of amending or correcting said faults.

After the initial shock of the news of a malformation, the mother begins to try to neutralize the feelings of sadness and culpability that are generated; expressions like: *I didn't think of aborting...*, *...I gain nothing with becoming desperate...*, *...I must accept it as it coming...*, *...I need to take it with ease...* reflect how these individuals balance that first moment and strive to show that life goes on, which is why painful situations must be confronted so that, somehow, this pain is lessened.

### **Theme 2. Making decisions upon the news of the arrival of the baby with "problems"**

As described in the first theme, learning the news of the arrival of the baby with "problems" provokes, initially, in the pregnant women a diversity of emotions, feelings, and doubts. Once this first stage is over, they feel ambivalence regarding the decision to continue or not with the gestation. This is how some of the pregnant women trust in what destiny holds for them and, although they acknowledge that it is not an easy task, they have faith and hope that the process will not be as complex; besides, *their child will improve with treatment*. This recognition lets them gain balance and enter a period of stability, diminishing the feelings of anxiety and fear

initially experienced. At this time, they begin to adopt decisions on the importance of gestation control in a high-complexity hospital and become aware that the consequences they imagined have not occurred.

However, the situation of acceptance is different for other participants, who commented that *they would have accepted the interruption, if they had been informed early that their child was not arriving well*, which meant for them a feeling of resignation, at that point in which the gestation was well advanced or of conformity for something that had happened to them but which they could not remedy. Upon reflecting on their child's future, they decided to place themselves in the hands of the physicians and nurses from the healthcare institutions they were attending and who could offer them specialized care because they had no other options.

Pregnant women state their resignation in the sense of accepting the *arrival of the baby with problems* and opt for *continuing with the pregnancy, being patient, waiting, and continuing with the pregnancy because now nothing could be done*; they argue that the circumstances they are experiencing fulfill a purpose; meaning that, although the situation is adverse, it can generate positive lessons in their lives and improve some aspects related to how they face problems. It is within this context that women, influenced in good part by the information offered by healthcare professionals on their child's malformation, make the decision to continue or not with the pregnancy. The fact of explaining to them the situation they are confronting, possibilities for survival, future complications they would have, and the actions that could be taken to improve the quality of life of the soon-to-be-born child, permits pregnant women to have faith and confidence in that their child will get ahead. In any case, the decision to continue or not with the pregnancy is quite difficult and committed; the fact of having to make a decision in said regard is very painful and it is related to the personal processes each has experienced, in addition to the social, cultural, and technological transformations of the context.

In making decisions on the future of the gestation there is influence from the woman's feelings and desires, as well as from the family support received – as reflected by the following report that shows how integration and family support contribute to mitigating the pain generated by the news of expecting a child with CM: *... at the moment of the pregnancy when I was given the news, everyone was on the alert with me and would call me all the time: wanting to know about the ultrasound, what had been said about the baby ... Everybody came closer; we have always been very close in my family, whatever happens to any of the others is like it's happening to oneself. With my husband's family, where we are living with my in-laws, everyone was on his own. Now, with what's happened with the baby, there is more closeness.*

### **Theme 3. Healthcare as a strategy to face the situation when “the baby is arriving with problems”**

Healthcare, as an activity aimed at the search for equilibrium, wellbeing, and the health of the mother-child duo, emerges within the discourse of these pregnant women. For them, care is seen as a series of activities guided towards the result for a healthy baby or of adjusting their life routines and new attitudes toward gestation, seeking to diminish the risks of damaging their health or avoid greater complication in their current state of vulnerability. Because of this, they rely on different sources of care: care of themselves, care they receive from their partners, the family, and that offered by the healthcare institution.

This research found that cultural values upon care itself gain importance upon the news women have received on the diagnosis of their child's malformation. Changes on daily living routines and nutrition are influenced by the perceptions and myths that from culture have been assimilated by these women, be it that they have learnt that during the gestation stage it is healthy or not, or because the family's “expert” women or from the community have recommended it so. Pregnant women state that if they did not

follow these recommendations there could be further deterioration of the already altered health situation of the child still in their womb. It was thus manifested by one of those surveyed: *"...I stopped eating acidic foods because I use to say that maybe it would be bad for the baby given that its intestines were on the outside... I'd say I wouldn't drink acids because maybe I would harm him; I stopped drinking acidic drinks...not even lemonade, or orange juice, or lemons... none of that... I'd eat salads without lemon because I felt and still say that I was very concerned with the baby given that I knew his intestines were on the outside... then, I'd say lemon and acidic foods are bad for him."*

Regarding caretaking by the partner, it was found that for some this aspect gained special relevance, given that they relate the malformation as a result of deficient care that a woman and her partner had toward a gestation. Deficient care revolves around poor nutrition due to nausea and vomit that accompany the start of pregnancy, due to physical stress associated to work or unmodified daily routines that can lead to suffering physical trauma, and to the partner's scarce participation in the gestation when not offering affect and companionship, as well as the lack of motivation for the partner to carry out self-care activities like eating, sleeping well, and avoiding intense physical activities. One of the participants expressed it, thus: *... somehow, I felt it was my fault because I wouldn't eat, I would faint a lot and one of those days 'I struck' my head and my back and also struck my belly, and from then on I would not be left alone, I wouldn't eat well and I'd get nauseous, so I wouldn't eat...*

With respect to the care offered by the family in the constant search to protect the health and wellbeing of the mother and unborn child, the women stated that the family, and specially the mother, would strive to care for them during the gestation, through nutrition, protection, and companionship. Also, the healthcare institution emerges upon these women as the link in the chain of possibilities to restore normality or avoid worsening the situation of the malformation

in their children. It is why, upon receiving the diagnosis of the malformation, they adhere more to the controls, recommendations, and monitoring by the healthcare personnel.

An important finding in this research is that in all the women interviewed, the spiritual dimension gains special importance during a moment of crisis and commotion due to the news of the malformation. For them, it is a situation that overwhelms them in terms of explanations and generates feelings of helplessness; hence, because there is no explanation or solution within the human plane, it is sought in the divine plane. It is how all these women told their experiences in the search for the transcendence, self-reflection, and help from a Supreme Being to heal their babies or bring them back to normality. For most of the participants their faith in God gave them hope and strength to face the distress of knowing that the baby in their wombs was not normal. In this regard, one of the participants manifested: *... my mother was told of a church, not closet o us; that if one went for nine Mondays and asked God for a miracle a God that He would grant it. My mother and would go to that church every Monday, which after the nine Mondays, the wish one would ask for would be for an operation, for the baby to be born well, and that was also a basis to leave everything to God; on Thursdays we would go to a healing mass in our neighborhood, where the priest said a healing mass and on Mondays we heard the mass for miracles, so every Monday and Thursday during the pregnancy my mother accompanies me...*

#### **Theme 4. Knowing the beliefs of the women on having a child with malformations**

This study raised some questions like: *Why is this happening to me, if I have done nobody wrong? Have I behaved?* These questions permanently accompanied the participating expectant women. Some of them, attributed the origin of the baby's malformation to the fact that they did not pay attention to some events occurring at the beginning of the gestation like: *I suspected that, but did*

*not pay attention to things that were happening; that was my fault because I lose control, I was struck and paid no attention; a low pain and I did nothing; once I bled with pain and I did nothing, I completely ignored everything; it is all my fault that the baby has that problem.*

In other participating women a religious mythical thought prevails around the origin of the malformations; they consider the congenital defects as a punishment from God; they believe that if any of the parents has committed some sinful action, God will condemn him or her by giving them a defective child; they believe it is a “test of God”. One of the participants stated it in the following manner: *An uncle told me everything was my fault because I had left the church and God punished that and that He had punished me by sending my daughter this way, God punished me by taking her away from me.*

Some participants think pregnant women run the risk of having children with defects when being exposed to a solar eclipse; they consider that when the sun meets the moon it makes the universe form a type of shadow; that shadow, in mole shape, may then appear in the child’s face; they consider that depending on the time the woman receives the shadow, thus, will be the size of the mole. It is, therefore, recommended that pregnant women remain in their homes on that day, or carry with them something metallic, thus, they will avoid having a child with that malformation as told by one of the women: *because they say that when there is a solar eclipse one should not go out to the street; in other words, one must be protected because that can harm the baby, like half the face covered by a shadow, with hair or a mole.*

## Discussion

Madeleine Leininger suggests in her theory of cultural care<sup>10</sup> that nurses should go beyond a mere state of awareness of the different cultures. Culture is for her a set of values, beliefs, norms, and life styles characteristic of a human group,

and which are learnt, shared, transmitted from generation to generation; she also considers that the beliefs guide individuals in their tasks, that is, the practices or activities they perform within the different aspects of their lives.

News of a pregnancy is only a small sample of the large amount of emotions a woman can experience when she learns of the life she is carrying in her womb. Although it is true that each person experiences pregnancy in a distinct manner, usually women and their partners, when they have so desired, feel a big sensation of accomplishment, a feeling of hope, and profound joy for the future birth.

Other times, as in unplanned but accepted pregnancies, when women learn of the news they may feel fear and distress, but, little by little, accept the role of future mother.<sup>12,13</sup> In both cases, women feel great illusion for the birth of the child manifested by the preparations for its arrival. Nevertheless, they also experience anxiety because, among other things, of the fear for the baby having malformations. These feelings of fear, which are frequently present in pregnant women, are compensated because the very women feel that such possibility is remote.

For these women, suddenly knowing that they are carrying a baby with malformations in their wombs represents for them the sensation of a leap into the dark because their illusion was centered on having a healthy baby. Consequently, they experience a multitude of emotions to which they react with consternation, denial, and even anger. The feelings evoked by the women in the study coincide with the sudden blurring of an illusion they created from the moment they got the news, given that they had time to fantasize with a healthy child whom they would care for and love. The presence of a defective baby, independent of the type of malformation and the severity it has, suddenly destroys that fantasy.

In spite of the pain, confusion, and denial they have at the beginning upon the news that their unborn child is already sick, makes them

re-assess the situation, start to look for the bridge toward the way out, and try to reconstruct a path, which starts by accepting reality; that life goes on and evaluating how they can raise that creature that, still in their womb, moves their expectations deeply. This theme has some similarities with the stages occurring during the mourning period when a loved one is lost in the sense that, when learning of the news, people have much difficulty in accepting such a painful reality, but little by little, they begin to accept it. Likewise, women pregnant with a child with a CM accept their reality as something that cannot be avoided and determine that it is precise to continue to heal, somehow, the complications and the stigma that can be generated from having a child under those conditions.

Nonetheless, feelings of sadness, bleakness, helplessness, and guilt helped them to make adjustments in their life routines and, at the same time, permitted them to assume new care attitudes aimed at protecting their unborn children seeking to diminish the risks of damage to their health or avoid greater complication in the state of vulnerability due to the very malformation. It was important to learn how the women in this study managed to harmonize care guided by the healthcare personnel and by culture. It would seem that the group studied did not have the “cultural shock” seen in other similar situations, given that the women expressed that they had followed all the orientations and indications from the healthcare institution and additionally carried out some cultural practices aimed at seeking normality and improvement of their babies, such as: adjustments in nutrition, in physical activity routines, and in the practice of spiritual activities. The prenatal diagnosis of a child with malformation creates different emotions in the family; these are linked to distress and culpability, to the loss and religious belief of being punished by God.<sup>13</sup>

Regarding the family, the participating women stated that it became the main emotional support for them and their partners because the family marked the direction to follow. For the

participants, the family movement generated by the diagnosis of fetal malformation constituted the principal strategy to confront the difficult situation, followed by spiritual authorities, and the healthcare team. In that sense, as expressed by some of the participants, the crisis does not imply experiencing negative circumstances or the maximum expression of a problem, but also the opportunity to grow, overcome the contradiction with the consequent positive valence. Crises are not signs of deterioration, they suppose risks and conquests; they are the driving motors of change.

To conclude, for the participants the fact of enduring the experience of a pregnancy with diagnosis of fetal malformation was quite painful and produced in them and their families uncertainty on the baby’s future and their future gestations; nevertheless, self-care practices and relations among the women and social support networks and the healthcare system were evidenced, which favored coping of pregnant women and their families in light of the situation, which permitted them to carry out gestation to full term. From the service stance, it is necessary to implement a healthcare model in which the future mother participates actively and within which not only their expectations, but also their beliefs and skills are kept in mind.

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