Maternal repercussions of fetal anomaly pre-natal diagnosis

Repercussões maternas do diagnóstico pré-natal de anomalia fetal

Tatiane Santos Nunes[1]
Anelise Riedel Abrahão[1]

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Congenital abnormalities; Pregnant women/psychology; Adaptation, psychological; Prenatal diagnosis

Descritores
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Abstract

Objective: To compare coping strategies for congenital abnormalities pre-natal diagnosis of viable and non-viable fetuses.

Methods: Quantitative cross-sectional study of 120 pregnant women, conducted in a center of excellence of fetal medicine, from January to December, 2014. Data were obtained through the following: semi-structured interviews which included socio-demographic information, personal and obstetrics history, and use of the coping strategies inventory. The tests used to compare categorical variations between viable and non-viable malformations were the chi-squared test, and Fisher's exact test or likelihood ratios. Student's t-test was used for continuous variables, and when necessary, it the Analysis of Variance was used.

Results: There were significant differences in the self-control strategy between pregnant women diagnosed with a non-viable fetus compared to those diagnosed with a viable fetus.

Conclusion: Pregnant women diagnosed with a non-viable fetal anomaly presented a greater tendency to use the self-control strategy than those diagnosed with a viable fetus.

Resumo

Objetivo: Comparar modos de enfrentamento mediante diagnóstico pré-natal de anomalia fetal viável e inviável.

Métodos: Estudo transversal de análise quantitativa em 120 gestantes realizado em centro de referência de medicina fetal, de janeiro a dezembro de 2014. Os dados foram obtidos por meio de entrevista semiestruturada contendo características sociodemográficas; antecedentes pessoais e obstétricos; e aplicação do inventário de estratégias de enfrentamento de *coping*. Teste qui quadrado, teste exato de *Fisher* ou razão de verossimilhança foram utilizados para comparar variáveis categóricas entre malformação viável e inviável. O teste *t* de *Student* foi usado para variáveis contínuas e quando necessária, foi aplicada a Análise de Variância.

Resultados: Houve diferença significativa da estratégia autocontrole entre as gestantes com diagnóstico de inviabilidade fetal e as com fetos viáveis.

Conclusão: As gestantes com diagnóstico de anomalia fetal inviável apresentaram maior tendência à estratégia de autocontrole que as com feto viável.

Corresponding author
Tatiane Santos Nunes
Napoleão de Barros street, 754,
04024-002, São Paulo, SP, Brasil.
ns.tati14@gmail.com

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[1]Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brazil.

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Introduction

According to the World Health Organization (WHO), anomalies or fetal congenital malformations are functional or structural abnormalities identified prenatally and/or at birth. About 10% of the anomalies are attributed to environmental factors while 25% is attributed to genetic factors, and 65% have unknown causes, constituting the second greatest cause of neonatal death.[1]

Currently, with the advances in technological, it is possible to detect these congenital anomalies and, in many cases, use intrauterine therapy to improve fetal prognosis. However, situations may occur where fetal diagnosis reveals fetus unviability.[2]

A non-viable fetus is one which is incapable of surviving on its own outside the uterus as a result of either incomplete formation (immaturity) or deficiency (malformation), in which etiology is multiple, being influenced by genetic or environmental factors, or a combination of both.[3]

The breaking news about fetal malformation has great emotional impact on a pregnant woman's and her family's lives. The breaking news has different repercussions, and it may cause a destructive process in the pregnant woman's life, leading to physical and emotional stress.[4,5]

Coping mechanisms are directly related to stress, and they are used by individuals to adapt to adverse demands, which gives them strength to deal with certain healthcare issues, whether they are acute or chronic.[6]

Studies in the literature corroborates the role of stress in managing life. This concept is derived from the idea that one's body seeks both internal balance and homeostasis as a mechanism of adaptation. However, excessive stress is harmful and dangerous when it is greater than the body's ability to assimilate and adapt as it seeks balance.[7-10]

The fetus death is always a life-changing event in couples' lives. This event results in deep repercussions, leading to a variety of strong emotions and reactions every person involved, from close friends to family members.[11]

It is critical for a pregnant woman whose fetus has been diagnosed with congenital abnormality to have a multi-professional, suppo including Genetic Counselling which is done by a trained professional, who can provide information related to occurrences, or risks of occurrences of a specific disease or genetic condition. It is clear that an experienced professional can assist in choosing strategies to reduce the negative impact of the diagnosis of a severe congenital abnormality.[12,13]

Given this issue, the following question arises: are the professionals involved in assisting this demographic actually prepared to help this woman, the couple and their family?

Studies show that healthcare professionals are unprepared, and at many times unaware of how to approach a pregnant woman and her family after the diagnosis of congenital malformation.[12]

Within this context, this study aims to contribute to the training of healthcare professionals who assist pregnant women whose fetuses have been diagnosed with congenital malformation, helping them to deal with the actual proportions of the impact caused on the pregnant woman and her family members. This understanding is critical and reasonable when seeking to identify if there are any significant differences in the outcome of the diagnosis (viable or non-viable fetuses), as well as enabling professionals to find mechanisms that match their approaches , which will prepare them even more during the prenatal assistance of this highly specific demographic.

Therefore, tour objective was to compare coping strategies used by pregnant women whose fetuses (viable and non-viable fetuses) were diagnosed with congenital abnormalities.

Methods

Quantitative cross-sectional study, developed in a Fetal Medicine Clinics, from January to December of 2014 in São Paulo (SP), comprised of pregnant women who received the diagnosis of fetal congenital malformation.

The clinics where this study was developed was one of the centers of excellence of São Paulo regarding the development of pregnancies with fetuses diagnosed with congenital abnormalities. The service included a multi-professional team, comprised of obstetric doctors, ultra-sonographers, nurses, and psychologists, who were in constant communication with geneticists, neonatologist, pediatric surgeons, neurosurgeons, cardiologists, and other professionals involved based on the type of each fetal anomaly.

The inclusionary criteria for this study population were all pregnant women who received the diagnosis of fetal congenital malformation, within the referred period, who accepted participating in this study, and had the necessary cognitive abilities to answer questions during the interview; regardless of their age and education level. The following group of pregnant women were excluded from this study: those who presented some type of severe or moderate personality disorder, those who had some form of cognitive limitation that could prevent them from answering questions during the interview, and those who refused to participate.

During the study period, 166 (100%) women received the diagnosis of fetus malformation in their current pregnancy, in which 39 (24%) were excluded from this study for not meeting the inclusion. Therefore, our sampling population had 127 pregnant women, who corresponded to 76% of the total population that received the diagnosis of fetal congenital malformation during the referred period. Out of the total sampling population, 7 (4%) dropped out of this study, and thus, we concluded the interview with 120 patients, corresponding to 72% of the initial sampling population.

Data collection was done by one of the researchers in two stages through semi-structured individual interviews with duration of 30 to 40 minutes, which happened in private areas at the clinics to offer comfort and privacy to participants. The first stage occurred soon after the enrollment of pregnant women, when the Informed Consent Form was provided in two copies and the objectives and ethical aspects of the research study were clarified, anonymity was guaranteed, and the free-will to participate or not in the study was assured. After this first contact, the interview using a questionnaire was done to gather socio-economic and demographic data.

In the questionnaire, the following variables were considered: age, color, marital status, living arrangements with partner, education, religion, occupation, income, and the number of persons in the household. Personal background information and obstetrics were also included. The second stage of this study was carried out after the psychoprophylactic assessment, in which pregnant women answered the coping inventory strategies of Folkman and Lauzarus[14] and validated by Savoia in Brazil.[15]

The coping inventory was translated to Brazilian Portuguese and validated afterwards, which showed an association between the original version in English and the translation, and that made it possible to use it the current study. This inventory is composed of 66 items that include thoughts and actions used to deal with internal or external demands under stressful situations.[15]

Each item of the inventory is composed of four options of answers as follows: zero, for I didn't use the strategy; 1, for I used it a little; 2, for I used it somewhat; and 3, for I used it a lot.

When performing data analyses, we considered the eight classificatory factors, initially proposed by Folkman and Lazarus,[14] and the proposed reorganization by Savoia et. al.,[15] which are: Factor 1 - Confrontation, which describes the efforts to changea stressful situation; Factor 2 - Withdrawal, which describes someone's efforts to distance themselves from that stressful situation; Factor 3 - Self-control, which describes someone's efforts to control their own feelings; Factor 4 - Social support, which describes someone's efforts in seeking information and emotional support; Factor 5 - Acceptance of responsibility, which describes the knowledge of someone's contribution to the problem and the attempt to act correctly; Factor 6 - Escape - Avoidance, which describes the desires, thoughts, and behavioral efforts to escape or nulli-

fy the problem; Factor 7 - Resolution of problems, which describes the efforts to change the situation with analytic analysis to resolve the problem; Factor 8 - Positive reappraisal, which describes the efforts to create a positive meaning, focusing on personal growth; with emphasis on beliefs and religion. To analyze the data obtained using this inventory, the sum of all the scores attributed to each item of the same factor was computed and this sum was divided by the total number of items that compose the factors.

Before filling out the coping inventory, pregnant women were instructed to think about the day when they received the breaking news about the congenital abnormality of the child they were expecting. They were then instructed to think about the strategies they used to be able to deal with this situation.

Data were saved and organized in an electronic Excel file (Office 2010), and it was later analyzed electronically usingthe IBM software Statistical Package for Social Science (SPSS v.19).

For continuous variables, the average, standard deviation, the median, and the maximum and minimum values were calculated. For categorical values, frequency and percentage were calculated. To compare categorical variables between viable and non-viable fetuses, the chi-squared test was used, and when necessary, Fisher's exact test or the likelihood ratio was used. To compare continuous variables between viable and non-viable fetuses, the t-test was used and when necessary, the Analysis of Variance (ANOVA) was used. The level of significance was set as 5% (value of $p<0.05$).

Results

According to table 1, the majority (61; 50.8%) of pregnant women considered themselves white, and 70 (58.3%) of them stated their marital status as "single", but 100 (83.3%) lived with a partner. Most of them (71; 59.2%) finished High School, and 49 (40.8%) referred to their occupation as "stay at home".

Table 1. Socio-demographic characteristics of pregnant women assisted at the Fetal Medicine Clinics

Characteristics	n(%)
Race	
White	61(50.8)
Brown	42(35)
Black	17(14.2)
Marital Status	
Without a partner	50(41.7)
With a partner	70(58.3)
Education	
Elementary School	31(25.8)
High School	71(59.2)
Higher Education	18(15)
Religion	
Catholic	54(47.8)
Christian	52(46)
Kardecist	7(6.2)
Agnostic	7(6.2)
Occupation	
Stay at home/Unemployed	67(55,8)
Works outside the home	53(44.2)

The average age of participants was 28.94 years, so the median age was 28, in which the youngest age was 14 and the oldest age was 45, with a standard deviation of 7.02. The average time for living with a partner was 5.8 years. The average income was R$2,499.00. The average number of family members in the household was 3.25.

First-time moms who received the diagnosis of fetal malformation were classified according to the severity of the malformation, either viable or non-viable pregnancies. Our data shows that, out of 120 (100%) pregnancies, 41 (34.2%) were considered non-viable and 79 (65.8%), viable.

Most women (64; 53,3%) received the diagnosis of fetal congenital malformation during the second trimester of their pregnancy.

We did not observe significant differences between the two groups based on the variables described (Table 2).

Significant differences were found between groups on the item 'self-control' (Figure1). Patients with the diagnosis of non-viable fetus presented a greater score for self-control than those with a diagnosis of fetal viability. The confidence index was of 95% (IC95%).

Table 2. Distribution of coping values compared to the diagnosis of viable and non-viable fetal malformation

Variable	CFM Diagnostics		Total	p-value
	Viable	Non-viable		
Confrontation				
Average (SD)	8.47 (3.03)	9.17 (3.81)	8.71 (3.32)	0.2734
Median	9	10	9	
Min-max	0-13	2-15	0-15	
Total number of patients	79	41	120	
Withdrawal				
Average (SD)	5.62 (2.87)	6.02 (2.78)	5.76 (2.83)	0.4612
Median	6	6	6	
Min-max	0-12	0-12	0-12	
Total number of patients	79	41	120	
Self-control				
Average (SD)	7.53 (3.15)	8.88 (3.99)	7.99 (3.5)	0.0454*
Median	7	10	8	
Min-max	0-16	2-17	0-17	
Total number of patients	79	41	120	
Social Support				
Average (SD)	11.89 (4.92)	11 (4.21)	11.58 (4.69)	0.3284
Median	11	12	11	
Min-max	3-39	1-18	1-39	
Total number of patients	79	41	120	
Acceptance of responsibility				
Average (SD)	4.19 (3.21)	4.05 (2.78)	4.14 (3.06)	0.8117
Median	4	5	4	
Min-max	0-12	0-10	0-12	
Total number of patients	79	41	120	
Escape-Avoidance				
Average (SD)	8.78 (4.26)	9.29 (4.47)	8.96 (4.32)	0.5436
Median	9	9	9	
Min-max	0-20	0-19	0-20	
Total number of patients	79	41	120	
Problem of resolution				
Average (SD)	7.78 (3.79)	8.15 (3.68)	7.91 (3.75)	0.6181
Median	8	8	8	
Min-max	0-16	1-16	0-16	
Total number of patients	79	41	120	
Positive reappraisal				
Average (SD)	10.94 (3.5)	11.41 (3.87)	11.1 (3.62)	0.4953
Median	11	11	11	
Min-max	3-18	3-18	3-18	
Total number of patients	79	41	120	

*Significant differences between the groups; SD - Standard deviation; ANOVA - Analysis of Variance; Congenital Fetal Malformation diagnosis; T-test - applied to variables: Confrontation; Self-control; Escape-Avoidance; and Problem resolution; ANOVA - applied to the variable: Withdrawal; Social support; Acceptance of responsibility; and Positive reappraisal.

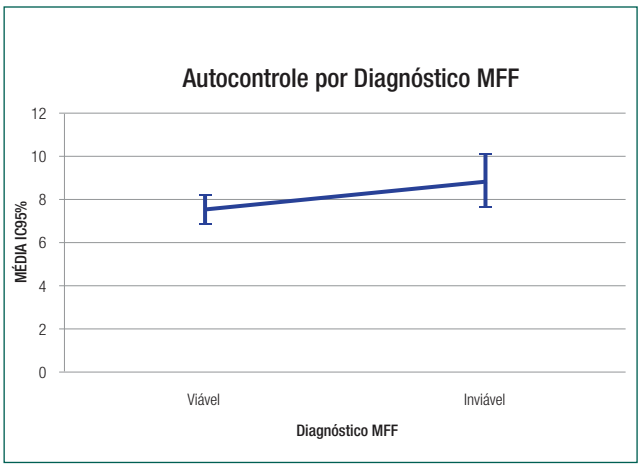

Figure 1. Results for Factor 3 - Self-Control, comparison between diagnoses of viable and non-viable Congenital Fetal Malformation (CFM) - CI95% - Confidence Interval of 95%

Discussion

Regarding the socio-demographic population of this study, there was a prevalence of white women. We also found that most women had and/or lived with an intimate partner, and they were currently stay-at-home/unemployed women.

This data was expected based on the characteristics of the Brazilian population, where the white race is the most prevalent. The "single" marital status exceeds that of 'married' in all regions of the country, but most of the sampling population lived in common-law unions.[16]

In 59.2% of cases, the sampling population stated that they have finished High School. According to the Brazilian Institute of Geography and Statistics (IBGE), our data contrasts the average educational level of the Brazilian population in which more than a half of Brazilians at age 25 and up have not yet finished Elementary School, although access to education has advanced in the past decades in Brazil.[16]

Another result that stood out was the income of the sampling population that reported an average of R$2,449.00 per family, and the average income for the Brazilian population is R$1,052.00. So, the sampling population was above the average income according to the IBGE, which also contradicts few studies that identified low income as a predisposal factor for congenital abnormality.

Prenatal screen is a preventative care that complements the pre-conception care, and they both follow the whole gestational process, which is a plus towards the physiological progress during this stage. Fetal medicine also plays a key role in modern obstetrics, proving early diagnosis of congenital abnormalities. However, the success of this type of support depends on a highly trained t professional who should also be show compassionate care.[17,18]

Studies show that early diagnosis of congenital abnormalities helps to implement therapeutic options proper for fetal development. It also helps to reduce child morbidity and mortality rates during the first year of life as well as the mother's wellbeing.[19]

Currently, although there has been an advance in technological resources in modern medicine, most people still do not have access to fetal medicine. It is not always possible to find specialized professionals who can work on the most complex cases, such as congenital abnormalities. This difficulty fatally affects the time required to process these cases and send them to other specialized services, which negatively impacts their results.[20]

In the analyses of coping strategies used by pregnant women, our data showed that the impact about the diagnosis led to a great adaptive movement to deal with the situation in both groups, which is represented by the high indexes for the use of strategies.

When comparing the coping values of pregnant women who received the diagnosis of viable and non-viable fetuses, there was a significant difference onFactor 3 - Self-control. Patients with the diagnosis of non-viable fetuses presented a greater score for self-control when compared to those with a diagnosis of viable fetuses.

Some concepts about 'self-control' are found in the literature. For example, the effort of persons in controlling their own feelings have been described. Confrontation based on emotions is associated with strategies that inhibit negative feelings, which prevents the actions that favor the resolution of their own cognitive or behavioral problems.[6,14,21]

In our study, women whose fetuses were diagnosed as non-viable apparently presented a better self-control over their emotions compared to other pregnant women. This self-control can be related to the outcome of their pregnancy that has a date already set to end. However, these pregnant women may be keeping her emotions to themselves as an attempt to rationalize the problem, and at many times, it could be related to social pressures. This behavior could greatly impact their future, causing her to be at a seriousrisk of puerperal depression.

On the other hand, pregnant women with viable fetuses must deal with an uncertain future surrounded by concerns and fears. Thus, their vulnerability is easier to notice, which helps to diagnose their needs. There is a mix of feelings, 'feeling of power' mixed with the frustration of having a malformed child. At many times, the desire to take care of the child is incompatible with the demands that these women have while experiencing the problem.[22]

Professionals involved in assisting these women must pay special attention to these behaviors, especially in women with non-viable fetuses who apparently tend to show a better emotional self-control. This behavior can lead to negative repercussions for many years, and if not noticed and treated, it can result in various compromising behaviors, socially, emotionally, and physically. Understanding these behaviors t is critical to the multi-professional team to be able to identify and help these women in a personalized manner.[23]

There are different reasons why stimuli and the response to them is difficult to observe, which it is not because of a physical barrier between observer and the one being observed, but rather because of formal aspects related to the actual responses.[23]

The group of women who had to interrupt their pregnancy due to lethal congenital malformation, and whose results showed that in most cases the breaking news about the diagnosis was received with shock and surprise, said that interrupting their pregnancy as one of the most difficult decisions the couple had to make.[24]

It is clear that when receiving the diagnosis of fetal congenital malformation, pregnant women experienced periods of doubts and questioning, in addition to the feelings of anguish, pain, and deception. Thus, professionals need to be compassionate and clarify all questions that these women have, as well as to provide psychological support, and when possible, refer them to psychoprophylactic assistance. This means that congenital malformation should notust be treated by healthcare professionals only focused on the physical and functional aspects, but rather focused on the psychological aspects impacted by the breaking news. Therefore, psychotherapeutic treatments should be made available to reduce the intense suffering in this scenario.[25,26]

The lack of knowledge and resources to deal with perinatal loss makes the attitudes of involved professionals inadequate during the process. This leads to a sense of abandonment, anxiety, and frustration, which often compromises the professionals' competence to do their work. This way, it's necessary to promote training programs to gain knowledge, aptitudes, and skills, and develop guidelines of clinical practice to care for pregnant women and their families.[27]

Conclusion

The impact on pregnant women due to the diagnosis of fetal anomaly was enourmous. However, when the diagnoses of viable and non-viable fetuses were compared, there was a significant difference regarding Factor 3 - Self-control, which was more evident in the latter group. This group showed higher scores of self-control than pregnant women diagnosed with viable fetuses malformations.

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Collaborations

Nunes TS and Abraão AR declare that they contributed with the execution of this study, the interpretation of data, the critical review of the intellectual content, and the final approval of the version to be published.

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