

NEONATAL OUTCOME IMPACT IN PUERPERAL MOTHERS OF NEWBORNS WITH CONGENITAL ANOMALY*

Julyane Vasconcelos Oliveira¹, Flavia Westphal², Anelise Riedel Abrahão³

¹Undergraduate student in nursing at the Escola Paulista de Enfermagem, Federal University of São Paulo. São Paulo-SP-Brazil.

²Master's degree student in nursing. Administrative Technician in Education, Federal University of São Paulo. São Paulo-SP-Brazil.

³Nurse. PhD in Nursing. Professor of the Federal University of São Paulo. São Paulo-SP-Brazil.

ABSTRACT: The aim of this study was to identify signs of stress in puerperal women arising from the coping process of gestation of a fetus with a congenital anomaly. This was a cross-sectional study developed at the fetal medicine outpatient clinic of the Federal University of São Paulo between January and April 2014. Two data collection instruments were used for this study: a questionnaire on sociodemographic identification and reproductive history, and the Revised Impact of Event Scale, which were applied to 24 puerperal women. Signs of stress were identified in 62.5% of the study subjects; of these, 41.7% gestated a non-viable fetus. In regard to the gestational period of diagnosis of the fetus, 75% of the women received diagnosis in the second trimester of pregnancy, and of the total number of subjects, 37.5% presented high likelihood of having post-traumatic stress disorder. Thus, early diagnosis enables higher quality care to pregnant women/couples/families, thereby encouraging postpartum development with less stress.

DESCRIPTORS: Congenital abnormalities; Postpartum period; Traumatic stress disorders; Maternal-child nursing.

IMPACTO DO DESFECHO NEONATAL EM PUÉRPERAS DE RECÉM-NASCIDOS PORTADORES DE ANOMALIA CONGÊNITA

RESUMO: Este estudo teve por finalidade identificar em puérperas, sinais de estresse decorrentes do processo de enfrentamento da gestação de um feto portador de anomalia congênita. Trata-se de um estudo transversal, realizado no ambulatório de medicina fetal da Universidade Federal de São Paulo, entre janeiro e abril de 2014. Para este estudo foram utilizados dois instrumentos de coleta de dados: um formulário de identificação sociodemográfica e de antecedentes reprodutivos e a Escala do Impacto do Evento- Revisada, aplicados a 24 puérperas. Foram identificados sinais de estresse em 62,5% das puérperas estudadas, sendo que destas, 41,7% gestaram fetos inviáveis. Quanto ao período gestacional do diagnóstico fetal, verificou-se que 75% das mulheres o receberam no 2º trimestre de gestação e do total, 37,5% apresentaram alta probabilidade de ter transtorno de estresse pós-traumático. Assim, podemos supor que o diagnóstico precoce permite assistência de maior qualidade a gestante/casal/família, favorecendo evolução pós-parto com menor estresse.

DESCRIPTORIOS: Anormalidades congênicas; Período pós-parto; Transtornos de estresse traumático; Enfermagem materno-infantil.

IMPACTO DEL DESHACER NEONATAL EN PUÉRPERAS DE RECIÉN NACIDOS PORTADORES DE ANOMALÍA CONGÉNITA

RESUMEN: Este estudio tuvo por finalidad identificar en puérperas señales de estrés decurrientes del proceso de afrontamiento de la gestación de un feto portador de anomalía congénita. Es un estudio transversal, realizado en el ambulatorio de medicina fetal de Universidad Federal de São Paulo, entre enero y abril de 2014. Para el estudio fueron utilizados dos instrumentos para recoger datos: un formulario de identificación sociodemográfica y de antecedentes reproductivos y la Escala del Impacto de Evento- Revisada, aplicados a 24 puérperas. Fueron identificados señales de estrés en 62,5% de las puérperas estudiadas, siendo que de estas, 41,7% gestaron fetos inviables. Acerca del periodo gestacional del diagnóstico fetal, se verificó que 75% de las mujeres lo tuvieron en el segundo trimestre de gestación y del total, 37,5% presentaron alta probabilidad de tener trastorno de estrés postraumático. Así, es posible suponer que el diagnóstico precoz permite asistencia de mayor calidad a gestante/pareja/familia, favoreciendo evolución posparto con menos estrés.

DESCRIPTORIOS: Anormalidades congênicas; Periodo posparto; Trastornos de estrés traumático; Enfermería materno infantil.

*Article extracted from the end-of-course thesis for the undergraduate nursing course, entitled: "Neonatal outcome impact in puerperal mothers of newborns with congenital anomaly". Federal University of São Paulo, 2014.

Corresponding author:

Julyane Vasconcelos Oliveira
Universidade Federal de São Paulo
Rua Bela Flor, 67 - 02148-050 - São Paulo-SP-Brasil
E-mail: july.fmg@gmail.com

Received: 12/02/2015

Finalized: 23/05/2015

INTRODUCTION

The literature has several definitions for congenital anomaly, congenital malformation or birth defect. Considering the origin of the word "congenital" (born with), one possible definition is any structural or functional abnormality present at birth due to a genetic or environmental, or several concurrent factors⁽¹⁾.

Congenital malformations classified by the authors as viable include gastroschisis, spina bifida and hydrocephalus; the most common considered incompatible with life outside the uterus are anencephaly, bilateral renal agenesis and body stalk⁽²⁾.

According to the World Health Organization (WHO), congenital anomalies affect approximately one in every 33 children, and result in approximately 3.2 million disabilities every year. In 2010, congenital anomalies were thought to cause 270,000 neonatal deaths in 193 countries, corresponding to 8.7% of the causes of neonatal deaths worldwide⁽³⁾. In Brazil, congenital anomaly is the second highest cause of infant mortality, 18% of the total, second only to afflictions in the perinatal period⁽⁴⁾. These data show the importance of the issue and how it is approached in healthcare treatment.

Historically, we have moved from a time when the discovery of fetal anomalies was only possible at birth, to a period in which the advancement of science and technology has enabled intrauterine detection of several birth defects, thus enabling actions for maternal and fetal well-being.

Thus, fetal medicine began revolutionizing and reshaping obstetrics. In the early 70s, important innovations such as improvement of techniques, enzyme assays, fetal cell karyotyping, determination of metabolites in amniotic fluid and development of ultrasound devices reshaped prenatal care, coming close to that which we are familiar with today⁽⁵⁾.

Technological development in prenatal assessment led to significant improvement in health care's ability to diagnose a large number of congenital developmental anomalies and pathologies. Working in tandem, ultrasonography and genetics were the pillars of this evolution in therapeutic capacity and advancement in obstetric management.

Fetal medicine was developed in Brazil between the 1980s and 1990s, with the use of techniques for evaluating fetal health and improvement of transvaginal ultrasound probes, fetal echocardiography and three-dimensional ultrasound, which enabled early diagnosis of anomalies⁽⁶⁾.

With the evolution of prenatal diagnosis, detection of anomalies became a reality that often encourages fetal development through deployment of therapeutic resources. With this aim, various techniques for promoting fetal health are still being developed and introduced in care, such as classical intrauterine, palliative and definitive therapy intervention, the latter being recommended for specific situations in which the risk-benefit of the correction should be evaluated⁽⁷⁾.

However, studies show the existence of malformations that do not improve with treatment during the prenatal period, making diagnosis before birth of paramount importance in order to prepare for an immediate neonatal strategy, which often defines the possibility of fetal survival and enables a prognosis of the child.

Cases with complex diagnoses, such as fetal non-viability, should also be focused. In this situation, prenatal diagnosis allows the couple to request voluntary interruption of pregnancy.

In all situations, information provided to the couple and family should be valued, along with the emotional impacts of these diagnoses, which can lead to the development of post-traumatic stress disorder (PTSD). According to the American Psychiatric Association, PTSD can be defined as a set of symptoms associated with a traumatic event⁽⁸⁾. Studies have shown that symptoms of PTSD are often observed after voluntary abortion of non-viable fetuses, especially if performed at an advanced stage of the pregnancy⁽⁹⁻¹⁰⁾.

The event of the desired child being replaced by one with a diagnosis of malformation causes suffering and distress, which can be greatly intensified when the defect is lethal. Coping with the prognosis of malformation depends on several factors such as the emotional structure of the couple and family, as well as the specialized and multidisciplinary health care available to them.

The evolution of medicine and technology to assist the healthcare team makes diagnosis

more reliable, both in terms of anomalies that the fetus has and those it may develop in the future. This makes the role of healthcare professionals, especially nurses, essential in monitoring the entire process with the expectant mother, always seeking to orient, embrace and support.

Thus, interdisciplinary monitoring is fundamental for pregnant women during the process, with emphasis on psychological and educational support so that they understand the diagnosis and are able to move through each phase of "mourning" for the idealized child, learning to cope with the situation without becoming sick⁽¹¹⁾.

It is very important to understand the relationship between the presence of fetal defects and the emotional impact of this condition on puerperal women. In order to better understand this issue, the aim of this study was to identify signs of stress in puerperal mothers of fetuses with congenital anomalies.

METHOD

This was a prospective, cross-sectional study with sampling by consecutive convenience, using a quantitative approach to emotional aspects through the identification of signs of stress in puerperal mothers that gestated fetuses with congenital anomaly. The study was conducted in the fetal medicine outpatient clinic of the Federal University of São Paulo (UNIFESP), a center for high-risk prenatal care with a multidisciplinary team.

Data were collected from January to April 2014. The sample included women who received prenatal care in the fetal medicine outpatient clinic of UNIFESP, who gestated fetuses with anomalies, and that were at least seven days postpartum or, in cases of non-viable fetuses, post-interruption. Illiterate women who could not respond to the questionnaire were excluded from the study sample.

The sample was composed of 24 participants, 12 of which were puerperal mothers of viable fetuses, whereas the other 12 were mothers of non-viable fetuses. Two instruments were used: the first was a questionnaire designed specifically for this study, which included close-ended questions that considered the identification of the women, demographic and socioeconomic data

and gynecological-obstetrical history (number of pregnancies, births and abortions, via of labor, presence of comorbidities, etc.). The information was obtained through the medical records of patients and supplemented in the interview.

The second instrument was the Horowitz' Impact of Event Scale (IES-R), as revised by Weiss and translated into Portuguese by Caiuby⁽¹²⁾. This is a scale used in screening for symptoms of post-traumatic stress disorder and, in this study, it was used to assess the presence of symptoms in puerperal mothers who received diagnosis of fetal abnormality during pregnancy. This is a Likert scale in which the individual responds to the items, reporting their feelings in the seven days prior to the application of the instrument, which has 22 items divided into three subscales: avoidance, intrusion and hyperstimulation, using criteria of the Diagnostic and Statistical Manual of Mental Disorders - 4th Ed (DSM-IV) as to symptoms of PTSD⁽⁸⁾.

Responses were analyzed by calculating the score of each subscale, and the total score being the sum of these scores. For each question, the score ranges from 0 to 4 points, and the score is calculated by using the mean of the items that make up the subscales, disregarding the unanswered questions.

In this instrument, the results that exceed 24 points can be quite significant, because in patients showing at least some symptoms, PTSD is a clinical concern. Results higher than 33 points represent the best cut-off point for screening and probable diagnosis of PTSD, duly complemented by clinical evaluation. A result greater than 37 points is considered high enough for impairment of the immune system⁽¹³⁾.

The IES-R was applied in a quiet location, and the researcher who applied the instrument read the questions. The results obtained, along with those from the questionnaire, were entered into the Microsoft Excel software program. The variables are presented with mean values, standard deviation, median and variation with minimum and maximum values. Results are expressed in absolute figures and percentages.

This study adhered to standards for research involving human subjects as defined in Resolution No. 466 of the National Council of Health, being approved by the Research Ethics Committee of

Table 1- Epidemiological profile of women who gestated children with congenital anomaly. São Paulo-SP-Brazil, 2014

RESULTS

The age of the women who participated in this study ranged between 20 and 42 years, and the results identified the epidemiological and obstetric data presented in Tables 1 and 2.

Some lifestyle habits were analyzed, showing that 41.1% of the women considered themselves Catholic and 33.3% Evangelical, the remainder being non-practitioners and practitioners of other religions. As for smoking and drinking alcoholic beverages, 95.8% claimed to be non-smokers, 25% drank alcohol socially, and the remaining 75% did not consume alcohol at all. Finally, as regards the use of illicit drugs, 8.3% claimed to have used, and 91.7% claimed to be non-users.

Figure 1 presents results on history of malformation.

In relation to the pregnancy analyzed, there were no reports of unwanted pregnancies, with the number of planned and unplanned pregnancies relatively similar (41.7 and 58.3%, respectively). As for the start of prenatal care, 87.5% of women started in the first trimester of pregnancy, 12.5% in the second trimester, and no cases began in the third trimester. It was identified that 75% of the women received diagnosis of the defect in the second trimester of pregnancy, and only 25% in the first. However, as regards gestational age of admittance to the fetal medicine clinic of UNIFESP, all of the women arrived in the second (83.3%) and third (16.7%) trimesters.

Among the pregnancies analyzed, there was an equal number of viable and nonviable fetuses during the period, and only 16% of non-viable pregnancies had the option to interrupt the pregnancy, as shown in Figure 2.

Assessing the presence of signs of stress by means of the score obtained on the IES-R, as we observed in Figure 3 and Table 3, it was identified that 62.5% of the study participants showed some characteristic symptoms of PTSD, i.e., a score greater than 24. It was also identified that 37.5% (n = 9) of the participants had a score higher than 37, high enough to suppress the immune system and indicative of PTSD; of these, 77.7% (n = 7) were mothers of non-viable fetuses, showing that

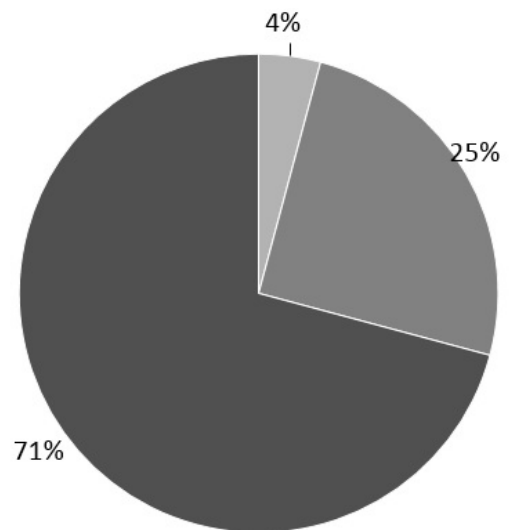
Variáveis	n	%
Marital status:		
Married/stable union	20	83,3
Single	4	16,7
Ethnic group		
White	13	54,1
Non-white	11	45,9
Living situation		
Own property	9	37,5
Rent	13	54,2
Loan	2	8,3
Place of birth		
São Paulo	15	62,5
Other	9	37,5
Level of education		
Primary education	4	16,7
High school	18	75
Higher education	2	8,3
Profession		
Housewife/unemployed	9	37,5
Student	1	4,2
Formal worker	2	8,3
Casual worker	12	50
Family provider		
Study participant	2	8,3
Partner	7	29,2
Both	13	54,2
Other	2	8,3
Family income		
< 1 minimum salary	4	16,7
≥ 1 to 3 minimum salaries	16	66,7
≥ 3 to 5 minimum salaries	3	12,5
< 5 minimum salaries	1	4,1
Age		
19 to 34 years	19	79,1
≥35 years	5	20,9

the occurrence of trauma is greater when fetal non-viability is diagnosed.

There was no significant correlation between the scores on the IES-R and maternal variables such as: age, number of children, level of education, marital status, socio-economic status and obstetric history.

Table 2 - Obstetric profile of women who gestated children with congenital anomaly. São Paulo-SP-Brazil, 2014

Variáveis	n	%
Number of pregnancies		
1 pregnancy	11	45,8
2 pregnancies	8	33,3
3 pregnancies	3	12,5
Four or more	2	8,4
Number of births		
1 birth	11	45,8
2 births	8	33,4
3 or more	5	20,8
Miscarriages		
Yes	6	25
No	18	75
Number of miscarriages		
1	4	66,7
2	2	33,3
Type of miscarriage		
Early	4	66,7
Late	2	33,3



- Prior congenital malformation
- Family member with malformation
- Cases with no prior history

Figure 1 - Characterization of women who gestated children with congenital anomaly, according to the presence of family history. São Paulo-SP-Brazil, 2014

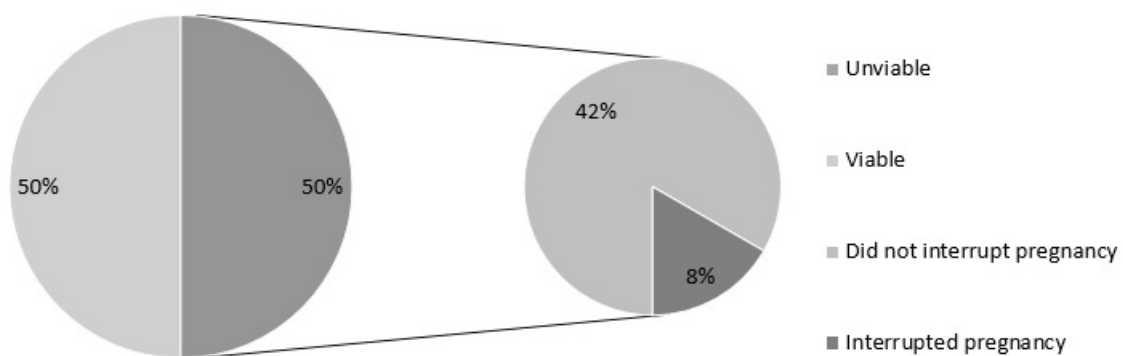


Figure 2 - Characterization of women with fetuses with congenital anomaly, according to fetal viability and option for voluntary interruption of pregnancy. São Paulo-SP-Brazil, 2014

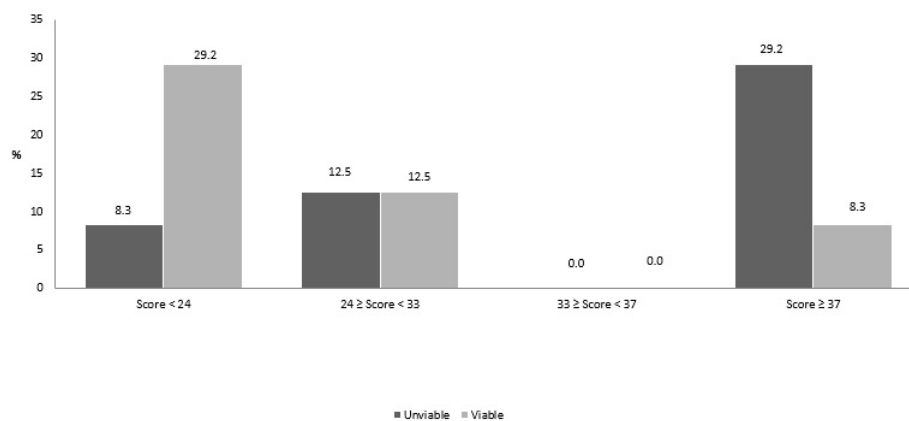


Figure 3 - Characterization of women with fetuses with congenital anomaly according to fetal viability and score of the IES-R. São Paulo, São Paulo, Brazil, 2014

Table 3 - Variation of the IES-R score among women who gestated viable and non-viable fetuses with malformation. UNIFESP, São Paulo-SP-Brazil, 2014

Fetal viability	Mean score of the IES-R	Median	Minimum	Maximum	Standard deviation
Viable	20,2	21	2	44	15,1
Non-viable	37	39	3	62	18,6

DISCUSSION

Some studies report that prevalence of postpartum depression varies from 3.7% to 48.6%, being a fairly common factor among puerperal women as it is a period of great physiological change and maternal demand⁽¹⁵⁻¹⁶⁾.

Other studies report that the risk of developing anxiety and/or depression is greater in women who have undergone stressful experiences in the last 12 months, and this rate is even higher among puerperal women of newborn infants with malformations than in healthy babies⁽¹⁷⁻¹⁸⁾.

The Diagnostic and Statistical Manual of Mental Disorders - 4th Ed (DSM-IV) defines a traumatic event as a catastrophe that may involve death, actual/threatened injury or threat to the physical integrity of oneself, being characterized by intense fear, helplessness or horror⁽⁸⁾. Thus, the experience of a diagnosis of congenital deformity may be considered a traumatic factor to pregnant and puerperal women, because the moment of diagnosis profoundly contradicts the idealization of the unborn child⁽¹⁹⁻²⁰⁾.

Use of the Impact of Event Scale - Revised (IES-R) in this study led to the finding that puerperal mothers of viable and non-viable fetuses

with malformation experience trauma. However, association of PTSD and the postpartum period is very recent. A bibliographical review about postpartum psychiatric disorders found that the prevalence of PTSD caused by peripartum events, such as diagnosis of congenital anomaly, varies from 1.5% to 5.6%⁽²¹⁾.

Another literature review on congenital malformations showed that not only mothers but also fathers need information on resources and aid, to talk about the malformation and, mainly, have time to adjust to the new situation⁽²²⁾. This is particularly serious when dealing with cases of non-viable fetuses, which, when coming late to the healthcare service, are limited to the option of gestating to full term, undermining the possibility of psychological, social and judicial follow-up in a timely manner. This situation was observed in this study, in which women were accepted belatedly into the specialized fetal medicine service. For this group, multidisciplinary and specialized monitoring with individualized care plans is critical to coping when acceptance of the problem is difficult and often traumatic⁽²³⁾.

One limitation of this study was the sample size. Despite having been performed in a well-known state outpatient clinic that serves a large population, composing the sample was difficult

due to the non-return of the puerperal women, which hindered continuous follow-up. Several factors may contribute to this predicament, such as distance between place of residence and the clinic, or lack of meaning to these women as to the importance of continued monitoring after childbirth or interruption of pregnancy.

Whatever the reason, this finding shows the need to establish a greater link between pregnant women and prenatal care services, in order to raise awareness about the importance of continuity of care in the post-partum period. Psychological monitoring is fundamental and should be continued for approximately four months after giving birth, ensuring satisfactory progress and safe re-referral (counter-referral) to the least complex unit of the region where the new mother lives.

CONCLUSION

This study identified that gestation of fetuses with congenital anomalies is an important risk factor for the creation of trauma, being even greater with diagnosis of fetal non-viability.

Given the importance of the subject, and in order to obtain data that provide more consistent statistical analyses, it is suggested that future studies compose multicentric samples similar to other studies of rare syndromes.

REFERENCES

1. Moore KL, Persaud TVN, Torchia, MG, Persaud T. The developing human: clinically oriented embryology. 9ed .Philadelphia: Saunders/Elsevier; 2009.
2. Consonni EB, Petean EBL. Perda e luto: vivências de mulheres que interromperam a gestação por malformação fetal letal. *Cienc. Saude Colet.* [Internet] 2013;18(9) [acesso em 15 jan 2014]. Disponível: <http://dx.doi.org/10.1590/S1413-81232013000900021>
3. Organización mundial de la salud. Anomalías congénitas: nota descriptiva N°370. [Internet]. [atualizada em jan 2014; acesso em 15 jan 2014]. Disponível: <http://www.who.int/mediacentre/factsheets/fs370/es/>
4. Painel de monitoramento da mortalidade Infantil e Fetal [Internet]. Brasília: Sistema de Informações sobre Mortalidade; [acesso em 15 jan 2013]. Disponível: <http://svs.aids.gov.br/dashboard/mortalidade/infantil>
5. Löwy I. Detectando más-formações, detectando riscos: dilemas do diagnóstico pré-natal. *Horiz. antropol.* 2011;17(35):103-28.
6. Gollop TR. Aborto por anomalia fetal. *Bioética.* [Internet] 2010;2(1) [acesso em 10 jan 2014]. Disponível: http://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/94/100
7. Sbragia L. Intrauterine fetal abnormalities therapy. *Rev. Bras. Ginecol. Obstet.* 2010;32(1):47-7.
8. Diagnostic and statistical manual of mental disorders, text revised, DSM-IV TR. 4 th. Washington; 2000.
9. Brunner MAC. Prevalência da depressão pós-parto entre mulheres assistidas no ambulatório de pós-natal do Instituto Fernandes Figueira-Fiocruz [tese]. Rio de Janeiro (RJ): Instituto Fernandes Figueira; 2011.
10. Pereira PK, Lima LA, Legay LF, Santos JFC, Lovisi GM. Malformação congênita do bebê e risco de transtornos mentais maternos durante o período gravídico-puerperal: uma revisão sistemática. *Cad. Saude Colet.* 2011;19 (1):2-10.
11. Santos MM, Böing E, de Oliveira ZAC, Crepaldi MA. Diagnóstico pré-natal de malformação incompatível com a vida: implicações psicológicas e possibilidades de intervenção. *Rev. Psicol. Saude.* 2014;6(1):64-9
12. Caiuby AVS, Lacerda SS, Quintana MI, Torii TS, Andreoli SB. Adaptação transcultural da versão brasileira da Escala do Impacto do Evento - Revisada (IES-R). *Cad. Saude Publica.* [Internet]. 2012;28(3) [acesso em 15 jan 2014]. Disponível: <http://dx.doi.org/10.1590/S0102-311X2012000300019>
13. Reed SB. The remap process: measuring the emotional impact of an event. *Dallas Counseling & Psychotherapy.* [Internet] 2007 [acesso em 23 fev 2013]. Disponível: http://www.psychotherapy-center.com/Measuring_the_Impact_of_an_Event.html
14. Ministério da Saúde (BR). Conselho Nacional de Saúde. Diretrizes e normas regulamentadoras de pesquisa envolvendo seres humanos. Resolução n. 466, de 12 de dezembro de 2012. Brasília; 2012.
15. Perosa GB, Canavez IC, Silveira FCP, Padovani FHP, Peraçoli JC. Sintomas depressivos e ansiosos em mães de recém-nascidos com e sem malformações. *Rev. Bras. Ginecol. Obstet.* 2009;31(9):433-9.
16. Gomes LA, Torquato VS, Feitoza AR, Souza AR, Silva MAM, Pontes RJS. Identificação dos fatores de risco para depressão pós-parto: importância do diagnóstico precoce. *Rev. Rene.* 2010;11(n.esp):117-23.
17. Vieira AP, Almeida ACM, Souza JFD, Piccoli APB.

Prevalência de depressão pós-parto em mulheres de um hospital universitário. Anuário de produção de iniciação científica discente. 2011;14(25):311-22.

18. Tahirkheli NN, Cherry AS, Tackett AP, McCaffree MA, Gillaspay SR. Postpartum depression on the neonatal intensive care unit: current perspectives. *Int J Womens Health*. [Internet] 2014; 6 [acesso em 01 dez 2014]. Disponível: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4247145/>
19. Daandels N, Arboit EL, Sand ICPVD. Produção de enfermagem sobre depressão pós-parto. *Cogitare enferm*. 2013;18(4):782-8.
20. Roecker S, Mai LD, Baggio SC, Mazzola JC, Marcon SS. The experience of mothers babies with malformation. *Esc. Anna Nery*. 2012;16(1):17-9.
21. Cantilino A, Zambaldi CF, Sougey EB, Rennó Jr J. Transtornos psiquiátricos no pós-parto. *Arch. Clin. Psychiatry*. 2010;37(6):278-84.
22. Santos RS, Dias IMV. Refletindo sobre a malformação congênita. *Rev. Bras. Enferm*. 2005;58(5):592-8.
23. Daugirdaite V, Van den Akker O, Purewal S. Posttraumatic Stress and Posttraumatic Stress Disorder after Termination of Pregnancy and Reproductive Loss: A Systematic Review. *J. Pregnancy* [Internet] 2015 [acesso em 23 fev 2015]. Disponível: <http://dx.doi.org/10.1155/2015/646345>