

Maternal care of the premature child: a study of the social representations*

O CUIDAR MATERNO DIANTE DO FILHO PREMATURO:
UM ESTUDO DAS REPRESENTAÇÕES SOCIAIS

LOS CUIDADOS MATERNALES AL HIJO PREMATURO:
UN ESTUDIO DE LAS REPRESENTACIONES SOCIALES

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ABSTRACT

The objective of this study was to identify the social representations of mothers regarding the maternal care provided to a premature child. The participants were 30 mothers of premature infants, who attended three early stimulation classes in Jequié-BA. The Free Words Association Test was used for data collection. Participants were asked to say five words about provision of maternal care to the premature child and to rank the words according to importance. The data were processed using EVOC 2003, generating a four-place chart. In the upper left corner, the words love and affection appeared; in the upper right, anguish, attention, affection, and patience; in the lower left, fear and prevention; and in the lower right, joy, devotion, dependence, difficulty, experience, protection, responsibility, and overcoming. Love and care appear to be the center of the representations. Love refers to the exercise of the mother role. Care may represent the wish to find improvements for their child.

DESCRIPTORS

Infant, premature
Mothers
Home nursing
Mother-child relations
Neonatal nursing

RESUMO

Este estudo teve como objetivo apreender as representações sociais de mães sobre o cuidar materno diante do filho prematuro. Participaram da pesquisa 30 mães de bebês prematuros que estiveram em três serviços de estimulação precoce em Jequié-BA. O instrumento de coleta de dados foi o Teste de Associação Livre de Palavras, que solicitou às participantes que evocassem cinco palavras sobre o cuidar materno diante do filho prematuro e que atribuissem ordem de importância para as palavras. Os dados foram processados pelo EVOC 2003, gerando um quadro de quatro casas. No quadrante superior esquerdo apareceram as palavras amor e cuidado; no superior direito, angústia, atenção, carinho, paciência; no inferior esquerdo, medo, prevenção; no inferior direito, alegria, dedicação, dependência, dificuldade, experiência, proteção, responsabilidade, superação. O amor e o cuidado aparecem como núcleo central das representações. O amor diz respeito ao papel de mãe a ser exercido. O cuidado pode representar o anseio de encontrar melhorias para seu filho.

DESCRIPTORIOS

Prematuro
Mães
Assistência domiciliar
Relações mãe-filho
Enfermagem neonatal

RESUMEN

Se interpretaron las representaciones sociales de madres sobre cuidados maternos al hijo prematuro. Participaron 30 madres de bebés prematuros que estuvieron en tres servicios de estimulación precoz en Jequié-BA. El instrumento de recolección de datos fue el Test de Asociación Libre de Palabras, solicitándose a las participantes que evocaran cinco palabras sobre el cuidado materno ante el hijo prematuro, atribuyéndoles orden de importancia. Se procesaron los datos con EVOC 2003, generando un cuadro de cuatro casas. En el cuadrante superior izquierdo aparecieron las palabras amor y cuidado; en el superior derecho, angustia, atención, cariño, paciencia; en el inferior izquierdo, miedo, prevención; en el inferior derecho, alegría, dedicación, dependencia, dificultad, experiencia, protección, responsabilidad, superación. El amor y el cuidado aparecen como núcleo central de las representaciones. El amor habla del respeto al papel materno a ejercerse. El cuidado puede representar el ansia de encontrarse con mejoras para sus hijos.

DESCRIPTORIOS

Prematuro
Madres
Atención domiciliar de salud
Relaciones madre-hijo
Enfermería neonatal

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INTRODUCTION

Premature babies are considered high-risk children, who, after being discharged from the hospital, require special care from their mothers for a long period of time in order to improve their neuropsychomotor development and particular health conditions. Therefore, their development depends on the care they receive from healthcare professionals and parents, particularly from their mothers in order to be satisfactory.

It is observed that premature babies have a higher risk of not developing appropriately, due to the immaturity of their organs and systems, as they are born with less than 37 weeks' gestation. Full-term infants are those born between 37 and 42 weeks' gestation⁽¹⁾.

According to the gestational age, preterm babies can be classified as near-term (between 35 and 36 weeks), moderately preterm (between 31 and 34 weeks) and extremely preterm (less than 30 weeks)⁽²⁾. Regarding the birth weight, infants are classified as low birth weight if below 2,500g; very low birth weight if below 1,500g; and extremely low birth weight if below 1,000g⁽¹⁾.

A 2009 study reported a rise in the number of newborns hospitalized in nurseries and Neonatal Intensive Care Units (NICU). The study authors analyzed the data from the Live Births Information System (Sistema de Informações sobre Nascidos Vivos - SINASC), which showed that the premature birth rates in Brazil increased from 5% in 1994 to 5.4% in 1998, 5.6% in 2000, and reached 6.6% in 2005⁽³⁾.

Together with the increase in the prematurity rate, technological advancements have taken place in neonatology, because there has also been a progressive increase in the survival rates of premature infants. The modern NICUs have been equipped with a good technological apparatus, which improves the healthcare provided to high-risk infants. However, the baby's family, particularly the mother, also needs special attention because they are experiencing unexpected and/or undesired feelings. Therefore, there have been more discussions on this topic in the academic environment, with the purpose to change this reality, aiming not only at the healthcare of infants, but also that of the mother/child/family triad⁽⁴⁾.

This follow-up is necessary, because, in the gestational period, women experience a number of different feelings, which are often contradictory, such as the joy and happiness of becoming a mother *versus* the anguish, anxiety and fear towards a preterm baby, with some type of congenital pathology or complications due to a difficult childbirth. In this period, she dreams with the moment of becoming a mother, of touching her perfect and healthy

child, and going home with the fruit of her gestation – her baby, a desire that is postponed when a premature child is born. The idealizations once built are undone and the birth of a preterm infant, most often, is something difficult for mothers to accept⁽⁵⁻⁶⁾.

Preterm births usually occur as emergencies, which means the mother is not psychologically prepared, and, thus, feels premature as a mother, and, often, not ready to take care of her child, showing different reactions to this tense situation⁽⁷⁾. Therefore, several feelings and reactions may emerge; and, in many cases, it is common that the mother will try to escape from the situation so she is not made responsible for taking care of a preterm child, while others try to be with their child every second they are allowed by the health team, aiming at learning how to take care of the baby and increase the affective interaction between them.

Hence, actions developed during the preterm infants' hospitalization period should include the mothers, aiming at their participation of the care to the baby, thus reducing their fears and anxiety⁽⁸⁾. The communication of the health team with the parents, the welcoming and interaction between them, are essential to reduce the parents' suffering during the hospitalization of their children, and to help them (parents) learn the homecare procedures.

However, the hospital discharge of these preterm babies does not always mean their complete recovery, which may imply several concerns for the family, the healthcare professionals, and also for the government authorities involved in the management of public healthcare⁽⁹⁾.

Therefore, within the context of maternal care of the premature baby after hospital discharge, some particularities in the home are necessary, which namely include: the availability and skills of one or more caregivers; some changes in the family to welcome the child at home; financial resources to continue the treatment; and help from public services in case there are any changes in the baby's health condition⁽⁹⁾.

However, when the preterm baby undergoes hospitalization, in the future, that child can develop some type of complication. It is for this reason that, after discharge, the medical team refers preterm infants to an early stimulation service with the purpose to achieve satisfactory development and autonomy.

Therefore, it was from dealing with these infants and their mothers that the interest in this topic emerged, because different forms of mother-child relationships were observed, showing that there is a connection between some of them, with more care, affection and attention, while others appear to be more distant in this affective

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relationship, showing fear, anguish, and anxiety when taking care of a premature child.

The theoretical framework used was the Central Nucleus Theory of Social Representations, which seeks the structural elements of a representation⁽¹⁰⁾. The objective of this study was to identify the social representations of the mothers of preterm babies about maternal care at home.

Hence, the relevance of this study consists of the contribution to promoting/strengthening the educational policies and humanization interventions aimed at training the professionals involved, considering that the orientations provided to the mothers of preterm children are essential to assure that the care to that child, after discharge, is efficient and satisfactory.

METHOD

The design of this study was supported by Jean-Claude Abric's Central Nucleus Theory of Social Representations, which is a complementary approach that presents detailed descriptions of the supposed structures, explaining how they function, and thus, is compatible with the general theory⁽¹⁰⁾.

The participants were 30 mothers who took their preterm infants, after being discharged from hospital, for treatment at three early stimulation services in Jequié-BA, between March of 2010 and March of 2011. The inclusion criterion was that they should be mothers of children three years of age or younger undergoing treatment in the referred stimulation services. After identifying the mothers, all of them agreed to participate, so none were excluded from the study.

Considering the 30 mothers who participated in the study, 25 took their children for treatment at the Teaching Physiotherapy Clinic at Universidade Estadual do Sudoeste da Bahia (CEF-UESB); four mothers took their children for treatment at the Jequiá Municipal Center for Physical Prevention and Rehabilitation (Núcleo Municipal de Prevenção e Reabilitação Física de Jequié - NUPREJ); and one to the Association for the Parents and Friends of the Mentally Disabled (*Associação de Pais e Amigos dos Excepcionais* - APAE).

After identifying these mothers, a visit was scheduled for the data collection at their homes, considering it would be more comfortable for them. The data collection was performed in the period between February and March of 2011 in Jequié, in Southeast Bahia, 365 km from Salvador, the state capital. Jequié is a city with a total area of 3,227 km², and 151,921 inhabitants⁽¹¹⁾.

This quantitative study used the free word association test for data collection, which quickly reveals the content of the social representations, and allows participants to freely express themselves⁽¹²⁾. This technique identifies implicit or latent elements that could be lost or masked in other methods⁽¹³⁾.

Therefore, the mothers were asked to evoke five words that came to their minds after the triggering question: *associate five words to taking care of a premature child*, and then they were asked to rank the words according to their order of importance.

It should be highlighted that, before the free words association test was applied, a random stimulus was used with the participants with the objective to clarify the procedure that would be applied. When it was realized that the participants had understood how the test worked, the actual research test was applied.

The data were statistically processed using EVOC 2003 software, with the purpose to perform the statistical analysis of the textual data of a specific associative network, in which it is permitted to combine the frequency in which the evoked words appeared, assigning their order of importance⁽¹⁴⁾. The data were analyzed using the four-place chart, which specified the central nucleus, the intermediate elements (or 1st periphery system and contrast elements) and the peripheral representation elements (or 2nd periphery system)⁽¹²⁾, using the appearance correlation of the structural approach of the Central Nucleus Theory⁽¹⁰⁾.

The structural approach establishes that a social representation is adequately described or identified only when its content and structure, of the central and peripheral nuclei, are learned. Hence, the representations are organized into two connected systems, the central system responsible for the materialization of the representation in the mental structure, and the peripheral system containing the elements that support the central nuclei, with transformations mediated by the changes in the peripheral nuclei⁽¹⁰⁾.

This study resulted from a dissertation research and complied with the norms of Resolution 196/1996, which regulates human research⁽¹⁵⁾. Therefore, the study was submitted to and approved by the Research Ethics Committee at Universidade Estadual do Sudoeste da Bahia, under protocol 203/2010, and the participants only initiated the test after signing the free and informed consent form; if the participant was a minor, the term was signed by a parent or legal guardian.

RESULTS

The present study results showed that the 30 participants were able to contemplate the requested orientation, as each of them evoked five words, totaling 150 words, and then ranked the words according to their order of importance, from the most important to the least important.

Considering the 150 words, there were 22 different words, but some were very close in meaning, and were, therefore, standardized under the same designation (semantic approximation), assuring that they would be processed by the software as synonymous⁽¹²⁾. Based on this approximation, 16 specific words were generated.

However, considering the 150 evoked words, six were evoked only once, accounting for only 4%, which is considered insignificant. These words were, therefore, disregarded. Hence, 96% of the evoked words were used (144 words), which made the analysis more consistent and representative.

The analysis generated the necessary data to create the four-place chart. Based on this chart, it was observed that the words' mean frequency (upper cut-off point) of occurrence was 9; and the average order (RANG) was 3; and the minimum frequency (lower cut-off point) was 2, as shown in Chart 1.

Chart 1 – Four-place chart regarding the triggering question Taking care of a premature child

CENTRAL NUCLEUS ELEMENTS			ELEMENTS OF THE 1st PERIPHERAL SYSTEM		
Frequency >= 9 / Rang < 3			Frequency >= 9 / Rang >= 3		
	FREQ	RANG		FREQ	RANG
Love	25	1.680	Anguish	14	3.071
Care	20	2.950	Attention	17	3.941
			Affection	15	3.333
			Patience	10	3.100
ELEMENTS OF CONTRAST			ELEMENTS OF 2nd PERIPHERAL		
Frequency < 9 / Rang < 3			Frequency < 9 / Rang >= 3		
	FREQ	RANG		FREQ	RANG
Fear	8	2.375	Joy	3	4.000
Prevention	2	1.500	Devotion	8	3.000
			Dependence	2	3.500
			Difficulty	6	3.667
			Experience	4	3.750
			Protection	2	4.000
			Responsibility	6	3.500
			Overcoming	2	4.000

RANG: 3 Minimum frequency: 2 Mean frequency: 9

The evoked terms, distributed in the four-place chart, permit to identify not only the content of the representation, but also its organization or structure⁽¹⁰⁾. This way, the upper left quadrant of the chart groups the evocations that represent the elements of the central nucleus, considered the most frequent and most important ones; the upper right quadrant gathers the most important peripheral elements; the lower left quadrant contains the elements with low frequency, but considered important by the subject; and the lower right quadrant is comprised of the least frequent and least important elements⁽¹²⁾.

In this study, it was observed that the words love and care were the most frequent and of greater importance, which shows they are part of the central nucleus. The words anguish, attention, affection, and patience, on the other hand, were considered the most important peripheral elements. The words fear and prevention appear less frequently, but at a higher level of importance. Finally, the words joy, devotion, dependence, difficulty, experience, protection, responsibility, and overcoming appeared less frequently and at a lower level of importance.

The present study results showed that taking care of a premature child involves a number of feelings, both positive and negative. It is also emphasized that because they are so small and fragile, their mothers often feel somewhat afraid of taking care of a baby in these conditions, and, thus, become anxious and insecure for some time.

Considering the results presented herein, it was observed that the social representations of the mothers of a preterm child showed that taking care of these children at home is directly associated with love and care, and these are the two elements that comprised the nucleus center of their social representations of maternal care of a premature child. Therefore, we found that love is a feeling related to the mother's role towards her child; and care is an attitude regarding the desire to see her child improve every day.

After the elements found in the central nucleus, those comprising the 1st peripheral system were identified (which reinforce the central elements), considered to be the peripheral elements of greatest importance: anguish, attention, affection, and patience. Thus, it was found that to take care of a preterm child, the mother deals with the anguish of having a fragile child that depends on her care; she needs attention to be able to make the adequate improvements for her child; affection is indispensable so the mother is devoted to her child; and, finally, patience is a crucial element for mothers to accept taking care of a child with special needs.

The words fear and prevention appeared as contrast elements. Fear appears as the apprehension of taking care of a child with special needs, and prevention emerges as the precaution that mothers take to avoid their preterm child from developing any complication.

Hence, the elements of the 2nd peripheral system were understood by the words joy, devotion, difficulty, experience, responsibility, and overcoming. They can be considered the true peripheral elements because they appear in lower frequency and importance to the participants. It is noted that the word overcoming may be related to the word joy, because it is considered that overcoming the difficulties involved in taking care of a preterm child is a reason of joy to these mothers. It is understood that they need devotion to reach their goals, they undergo difficulties during the most critical period of care, gain experience in this context, and eventually protect their children more and more, and, therefore, gain more responsibility.

DISCUSSION

It is understood that the expectation of having a full-term healthy child is completely different from the reality of having a child born preterm and needing special care. When the baby is discharged from the hospital and goes home, it means that from that moment on the hospital is no longer responsible for the care, which is now responsibility of the family, particularly of the mother.

Not all mothers are prepared to take care of a premature child at home, and this fact can be revealed as something somewhat frightening. The condition of being a mother of a premature baby unfolds into several meanings in view of the specific situations that the mothers assign to the days that went by⁽⁴⁾.

The results found in the central nucleus of the present study reinforce those of a prior study⁽¹⁶⁾ that demonstrated that the mothers see to the basic physiological needs of their child, such as feeding, hygiene, sleep and rest, among others, and also give them emotional support through affection, playfulness and love. It also confirms that their way of caring may reveal feelings of affection, attachment, and pleasure, but also reinforces feeling of demanding and a surveillance for the promotion and maintenance of a healthy growth and development.

However, the family context and the home environment have a strong influence on the recovery of the premature baby and in his/her development process. Usually, children who were in a NICU, cared by specialist professionals, and that now need special care, suffer a strong impact after being discharged and going home, because it usually lacks the adequate infrastructure to receive that child, besides the fact that the situation, in most cases, is completely new to the main caregiver – the mother⁽¹⁷⁾.

The anxiety, insecurity and doubt were evidenced for most women who participated in a 2011 study. Those mothers reflected about the importance of being trained during their child's hospitalization and how these lessons about homecare were important. They revealed that day after day they became more and more adapted to the routine of giving the baby the necessary care, overcoming

their lack of preparation and fear, and that this daily experience of care developed a relationship of love⁽¹⁸⁾.

In view of the representational elements found in the present study, it is also concluded that the mothers of premature babies need to be instructed by healthcare professionals still while their children are hospitalized. It is considered that through health education and by giving pertinent orientations about the homecare that they will provide, it is possible to reduce the mothers' concerns and anxiety.

The results found in recent studies also demonstrate the importance of a more frequent follow-up by healthcare professionals with the purpose of preparing the mothers for homecare, in order to prepare them to deal with possible complications and tranquilize them regarding the development of their child, understating that the parents will be responsible for the continuity of the homecare⁽¹⁶⁻¹⁷⁾.

This way, it should be understood that, during hospitalization, healthcare professionals should not focus the care exclusively on the child, but also gather their universe of relationships, considering that the family and child become one single client. Based on this conduct, care is humanized and will make the family feel welcomed and valued⁽¹⁹⁾.

Therefore, the parents' restlessness after the birth of a premature child and during his/her hospitalization is concentrated on the child's survival, and, after the child is discharged, that restlessness is replaced by the maintenance of health and the search to improve his/her development⁽¹⁶⁾.

This study shows that the mothers undergo difficulties to take care of their premature child, particularly related to their feelings and limitations; however, they manage to overcome those difficulties, as they demonstrate, above all, their will to win the obstacles they find.

CONCLUSION

This study identified the social representations that mothers of premature children have regarding the maternal care at home, and achieved its objective, as it identified several feelings and meanings related to the theme, categorizing them into the central nucleus, intermediary and peripheral elements of these social representations.

It was evidenced that in order to perform this care, the mothers deal with several difficulties, both negative and positive feelings, but in the end they are capable of achieving their goals, because of their courage and determination to always improve their child's development.

Therefore, this study contributes with the strengthening of humanization policies in view of actions that can change neonatal care so as to provide premature children with care not only during their hospitalization, but also after they are discharged, by providing the parents with orientations about homecare, and preparing them for a new reality.

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