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RESEARCH

Vivências de mães de bebês prematuros no contexto da espiritualidade

Experiences of mothers of premature infants in the context of spirituality

Experiencias de las madres de niños prematuros en el contexto de la espiritualidad

Juna Maria Fernandes Vieira ¹, Maria de Fátima Farias ², José Lotero dos Santos ³, Rejane Marie Barbosa Davim ⁴, Richardson Augusto Rosendo da Silva ⁵

ABSTRACT

Objective: to understand how mothers of preterm infants perceive the relationship between health and spirituality and its benefits on the severity health picture of their children. **Method:** qualitative research with 32 mothers whose children were admitted to a Neonatal Intensive Care Unit of a maternity hospital in Natal/RN/Brazil. There were semi-structured interviews and focus groups between February and May 2012, after a favorable opinion from the Ethics Committee in Research of UFRN and CAAE 0336.0.051.000.1. Data analysis was thematic analysis. **Results:** the relationship between health and spirituality was unveiled in the study as a positive phenomenon helping mothers avoiding discouragement and keeping hope in restoring the health of the child in the Intensive Care Unit. **Conclusion:** it is suggested after the results, actions and projects that promote soft technologies, aiming at promoting and completeness in health care. **Descriptors:** Nursing, Spirituality, Adaptation psychological, Health, Qualitative research.

RESUMO

Objetivo: compreender como mães de bebês prematuros percebem a relação entre saúde e espiritualidade e seus benefícios diante da gravidade do quadro de saúde de seus filhos. **Método:** pesquisa qualitativa realizada com 32 mães, cujos filhos estavam internados em uma Unidade de Terapia Intensiva Neonatal de uma Maternidade Escola em Natal/RN/Brasil. Realizaram-se entrevistas semiestruturadas em grupos focais no período de fevereiro a maio de 2012. A pesquisa teve parecer favorável do Comitê de Ética em Pesquisa da UFRN com CAAE 0336.0.051.000.1. Para análise dos dados, optou-se pela técnica de análise temática. **Resultados:** a relação entre saúde e espiritualidade desvelou-se no estudo como fenômeno positivo que auxilia as mães a evitar o desânimo e a manter a esperança no restabelecimento da saúde do filho na Unidade de Terapia Intensiva. **Conclusão:** após os resultados, sugere-se ações e projetos que promovam tecnologias leves, visando promoção e integralidade do cuidar em saúde. **Descritores:** Enfermagem, Espiritualidade, Adaptação psicológica, Saúde, Pesquisa qualitativa.

RESUMEN

Objetivo: entender cómo las madres de bebés prematuros perciben la relación entre la salud y la espiritualidad y los beneficios de la gravedad de la salud de sus hijos. **Método:** investigación cualitativa con 32 madres, cuyos niños fueron ingresados en una Unidad de Cuidados Intensivos Neonatal de una Maternidad Escuela en Natal/RN/Brasil. Hubo entrevistas semi-estructuradas y grupos focales entre febrero y mayo de 2012, luego de la aceptación favorable del Comité de Ética en Investigación de UFRN y CAAE 0336.0.051.000.1 Para análisis de datos se eligió técnica de análisis temática. **Resultados:** la relación entre la salud y la espiritualidad dio a conocer en el estudio como un fenómeno positivo ayudando a las madres evitar el desánimo y mantener la esperanza en la restauración de la salud del niño en la Unidad de Cuidados Intensivos. **Conclusión:** se sugiere después de los resultados, las acciones y proyectos que promuevan tecnologías leves, con miras a la promoción y la integridad en la atención de la salud. **Descritores:** Enfermería, Espiritualidad, Adaptación psicológica, Salud, Investigación cualitativa.

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INTRODUCTION

In the capitalist and globalized world of today, the technology is used for economic purposes, overcoming the ethical and technical standards. The techno-science paradigm stimulates the technical component, task valorization and professional manual skills.¹ The concern of the population is directed at rational training of health systems and professionals, as something dehumanizing, scientific and biologist in caring for and treating individuals to find alternatives in the search for a new care practice toward the humanization in integrated hospital environment to the individual as being endowed with reason, emotion, sensitivity and spirituality.

The challenge of health professionals is to take care of the human being, exercising actions to the pain and suffering of the physical, mental, social, spiritual and human dimensions. The World Health Organization (WHO) supports the health on a holistic view as a state of complete physical, mental, social and spiritual well-being and not merely the absence of the disease. Considering the relationship between health and spirituality in the health world allows to contemplate a dimension of human existence, which can provide dignity and allow the sick person seeking strength in faith, respecting their beliefs and receiving spiritual care.²

In Brazil, the Ministry of Health (MOH) has approved the Order number 1,820 of August 13, 2009, which consists of ten articles dealing with the rights and duties of health users who now constitute the Charter of Health Users' Rights. In this charter, there is Article 5 highlighted, which includes the religious aspect of the user stating that every person should have their values, culture and rights respected, and the guarantee of receipt or rejection of religious, psychological and social assistance positively and recognized as human needs that points to the user's care.³

Is there distinction between religion and spirituality? According to the literature, religion is related to belief in the right to salvation by any faith tradition, belief that as one of its principles, there are aspects of metaphysical or supernatural reality. Spirituality is one of the qualities of human spirit, such as love, compassion, patience, tolerance and forgiveness, causing happiness both for oneself and for others.⁴

Spirituality corresponds to the opening of consciousness to the meaning and full of life, enabling qualitative review of the life process. The difference between religion and spirituality helps rescuing the high relevance of this distinction to the present day, which are marked by the secular way of seeing the world and the rediscovery of the mysterious complexity of human subjectivity.⁵

It is understandable that the main function of spirituality is to reconnect people things and the source from the human being is emanated: God. The drama of the current human beings is losing spirituality and their ability to live a sense of connection. Religion encodes an

experience of God and gives doctrinal power, moral and ritual, while spirituality is guided by the experience of the meeting experience with God.⁶

According to WHO, about 20 million children are born with less than 2500g worldwide. One third of these children die before their first year of life, in particular the children with low weight. Depending on the socio-economic reality in developing countries, the occurrence of premature births and newborns (NB) with low weight is higher. Prematurity and/or low birth weight are 61.4% of neonatal deaths in Brazil. These babies are less likely to survive due to complications, infections and injuries that can trigger cerebral palsy, ophthalmic and neurological disorders.⁷⁻⁸

After the birth of a premature NB, conventional care provided its hospitalization to the neonatal intensive care unit (ICU-NEO), remaining in incubators for prolonged periods, days and months apart from the mother and family. From the experience with these women in a maternity school, it was possible observed a religious appeal by mothers to justify and reassure family and in particular the mother, before son's risks. Spirituality is identified as the primary source of hope, playing a key role in supporting people, helping to overcome and understand the disease and death process.⁹

It was started from the assumption that the practice of spirituality can work as a family support in particular to the mother, in the situations by the arrival of a premature baby. In this sense, this study aimed to understand how premature infants of mothers perceive the relationship between health and spirituality and its benefits on the severity of the health status of their children. The relevance of the research is justified based on knowledge of benefits in the relationship between health and spirituality, for discussions, aimed at comprehensive care and strategies to structure care models directed to these mothers.¹

METHOD

Qualitative descriptive research, focus group type, developed in Januário Cicco Maternity School (MEJC), Education Research and Extension Institution of the Federal University of Rio Grande do Norte (UFRN) in Natal/RN, with assistance by the Unified Health System (SUS), reference and counter reference in general and specialized in gynecology and obstetrics area in the state of Rio Grande do Norte.

The choice of the area is related to the experience of researchers since 2007 in the creation of prayer group *Mother of Faith for Life* formed by families and members of the multidisciplinary team of MEJC. The purpose of this group was to provide relief and spiritual comfort to mothers and family of premature babies, sharing faith, hope and belief in a transcendent being (God), promoting inclusion of spiritual/religious care in the hospital.

The sample consisted of 32 mothers who had their premature NB in the ICU-NEO of the institution during the data collection from February to May 2012, being accompanying mothers in the rooming-in. According to the literature, rooming-in is an important place where the

nurse/nursing must continue the actions already initiated in prenatal care, promoting appropriate and well directed guidelines in order to ensure the safety to the postpartum woman and her NB to the development of care in this postpartum phase.¹⁰

To compose the sample, the following inclusion criteria were: mothers older than 18 years old with premature NB hospitalized to the ICU-NEO; participants of the prayer group *Mothers of Faith for Life*; and sign the informed consent form (TCLE). These mothers were invited to participate in the study, explaining the objective at the time of the invitation, guarantee of anonymity and secrecy of information, as well as the right for not participating in any time of the study. To preserve the identity of the subjects, the letter G for each group was used followed by the number 1, 2, 3 and 4, designated to four focus groups, with 8 participants each one.

The data was collected through a semi-structured interview form, with the help of a tape recorder, lasting at most 01h30min after these mothers have participated in the prayer group *Mothers of Faith for Life*. The study was approved by the institution and the Research Ethics Committee of UFRN with CAAE 0336.0.051.000.1.

Therefore, two questions prepared by the researchers guided the meetings of focus groups: what is your opinion about the benefits of spirituality in the health of your babies? Did you notice any changes in your lives after beginning to attend the prayer group *Mothers of for Life*?

Data were analyzed using content analysis, specifically, thematic analysis.¹¹

The categories that emerged from the speeches of the interviewees were: *a) Faith and hope in God, b) Effects of prayer c) Benefits of the health/spirituality relationship*. Socio-demographic data were obtained from the records of these mothers.

RESULTS AND DISCUSSION

Participants characteristics

Participating mothers were SUS patients, most of them (85%) of cities surrounding Natal without ICU-NEO. They were from 19 to 41 years old. The education level was 40% did not complete high school, 30% complete elementary school, 25% with higher education and 5% with incomplete higher education. About monthly income, 75% earned less than a minimum wage and 25% two to three minimum wages.

With regard to religion, 55% were Catholic, 40% Pentecostals and 5% for other religions. Regarding the religion, in a study of 110 adults in the Federal District in 2006, the participants reported that religiosity influenced positively on the health status (78.2%) and a minority (18.2%) said not influencing, corroborating the results of this research.¹²

DISCUSSION OF CATEGORIES

FAITH AND HOPE IN GOD.

A study showed that preterm birth is a period of crisis for the whole family, permeated by imbalance and/or confusion that parents may be temporarily unable to respond adequately. It is known that the sum of these moments determines future problems or possibilities in inadequate development of experiences that occurred in that moment.⁸

From the analysis of the following lines, feelings such as fear, insecurity, guilt and worry invade the lives of the parents at the time of their child hospitalization in the ICU-NEO.

With the hospitalization of my baby in the ICU, fear of death appeared, the guilt of having given birth to a premature child, weak, tiny and the doubt if he would heal and also the concern about his health at all times. (G1)

Faced with these difficulties, the experience of God through the primary sources of hope and faith is presented as a coping strategy. In addition, with this knowledge, they not only find God, but themselves; it becomes more human and deified, considering that it becomes one with God in communion.⁶ It is observed, in the following speech of G3, the path pointed to experience situations of adversity before the son's prematurity.

We realize that mothers are experiencing the same situation with the child in the ICU, it is when we start to experience our spirituality, whatever religion we are, seeking God and mood improves, when we see the experience of the other, we get more faith in God; then, is how I see the benefit of spirituality. (G3)

In prematurity, the severity of the newborn picture and the need of mothers being separate from the child, it became apparent the use of religious strategies by them as mitigation for adverse situations arising with the birth prematurely. Research on the situation of mothers of premature babies highlights the importance of using religiosity/spirituality and emotional and spiritual support in fighting the disease and/or prematurity of children.¹³

Thus, the category represented here expressed perceptions of participants in the study about faith in God in the group *Mothers of Faith for Life* in the hospitalization of their son in ICU-NEO, as the following statement.

Searching faith in God and strengthening it every Friday in the prayer group causes to know us better, then you can feel a harmony, inner peace, also new people arriving with more problems, we will give them strength and seeking strength with faith in God. (G4)

Before this report, it is noticed the evocation of faith for spiritual empowerment. Faith promotes health, creating a personal healthy environment and social conditions for life.³ In this sense, faith promotes inner harmony with themselves, with others and with the Other.

EFFECTS OF PRAYER

Including prayer in health treatment may provide comfort, spiritual well-being, confidence and support, and strengthen the doctor-patient relationship. Prayer should be short, supportive, comforting and its consistent content within individuals' beliefs¹⁴. Corroborating this statement, one of the participants of G3 refers.

I realized that my son's health was bad and I prayed and he improved. It's great because we do not know how to handle this situation and learn to have more faith in God, the person becomes more aware of what we are doing and learn to deal with the situation. (G3)

In this context, it is understood the importance of prayer as a coping strategy on the child's disease. Prayer when held in self-help groups acts as support, strengthening the faith of the participants.¹⁵ In addition, the simple exchange of experiences on the use of prayers, the benefits achieved and sharing difficulties in spirituality make members feel that are not isolated, as experienced in G1.

I like to participate in the prayer group, to pray for my baby, the other mothers and my family. I hear the testimonies of the people who suffer and pray for God reaching a grace and improving life. My life has improved a lot, I felt very sad and when I prayed, I felt quite relief. (G1)

With mother's speeches, healing and comforting aspects are evidenced that prayer raises through different states of psychological, emotional and spiritual stress. Reflecting more deeply in the context of prayer, we ask: when do we really go to God and pray? Faced with this challenge, the literature states: in the Brazilian historical reality, everyone is called to pray always and make their prayer be their work and their work be their prayer. They never have to put in conflict pray and work, they are actions performed by the same person who must be integrated in order to create harmony of the human being, generating deep inner peace.¹⁶

BENEFITS OF HEALTH/SPIRITUALITY RELATIONSHIP

The relationship between health x spirituality is a complex situation involving constitutive dimensions of the human being, a nature complex human being. As result of this understanding, when speaking of health, it is immediately thinking in the context of the hospital, which is correct in view of the concept of health in a broader and more complex view that, according to WHO, includes psychic, social and spiritual aspects.²

Noting the spiritual support groups, there was identified in the literature the experience of people feeling recognized, loved and cared by God being the source of human and spiritual strength, overcoming adversity, enhancing the process of inner healing.¹⁴

These speeches of the participants show the importance of including the spiritual and practical support to mothers in maternity wards in order to improve coping with the prematurity of children.

When we pray we are more strengthened, for me every day we need prayer circles for us to pray and thank God for our children [...] it is good that I was there praying and asking that every day had a prayer

circle that is rewarding, we become stronger and strengthens the confidence that my son will get out of ICU and going home with me. (G1)

Once I got to participate in prayers I had more courage to face life, feeling safe, with more faith in God, the fear that had my baby die was lesser. (G3)

Certainly my life changed and I learned to have more patience and faith in times of difficulty and distress. [...] Today I am stronger knowing how to deal with the hospital, we need to have such a group in all maternity hospitals. (G4)

After the prayer is like if the spirit closed wounds. (G2)

In this study, it was observed that the child's health establishment is due to the exercise of spirituality stimulating to the mothers searching for prayer groups in the hospital as a strategy to not discourage more on the negative feelings caused by the hospitalization of the child, as can prove in this speech.

I was very discouraged and I went find this mood to stay here, because we know it's a long and difficult stay, and I went to get in the prayer group that strength, to continue here with my baby and keep cheerful and not lose heart. (G1)

Therefore, it was identified that mothers need to believe in something beyond medical care and technology. Believing in the power of a transcendent being (God) gives courage to be in an environment surrounded by high level of tension about life and death, believing that Heavenly Father can save their child's life.

The disease is one of the essential events of life, it is the complex experience that goes against the desire to live, as it reveals the fragility of the human condition and introduces who is affected in a world full of questions, different and strange.¹

It was also observed, living with mothers in the prayer group *Mothers of Faith for Life* of MEJC that the spiritual support has proven as encouragement strategy in situations of risk and fear of their son's death in the ICU-NEO. The hope to observe the improvement of the child is strengthened by the prayers. In the life circle, a circle of prayer and faith, these mothers and family commune solidarity in times of loss and pain with mothers suffering and especially those facing the loss process and neonatal mourning. It is something deep that enables finding faith in God even in physical and psychological suffering that is present in the world of health, experienced by the people who constitute it.

In this sense, the involvement in prayer groups are to reduce mechanism in the process of suffering. As a source of interpretation for what is happening in life, religiosity is support for coping with difficulties and attitude change.¹⁷

It is observed that the spiritual dimension has its relevance in the world of health, so it cannot be forgotten by care professionals, since care in other dimensions, such as spiritual, is of fundamental importance in sustaining and coping with health-disease process.¹

Care should not be restricted only to the physical structure. It is noteworthy that although the ICU-NEO work process provides wear and involves factors that are obstacles to the provision of humanized care, the team tries to provide the ideal humanized care, state of the art to meet the needs of newborns and family, keeping a pleasant environment.¹⁸

This is observed in a study conducted with adult patients, in which the perceived benefits to using religious coping was investigated. The participants reported a variety of benefits to their religious beliefs and practices, such as favoring emotions and feelings of comfort, sense of strength, power and control, facilitating the acceptance of the disease, relief from fear, uncertainty towards death, suggesting that these potential mechanisms along with religiosity may affect the psychological adaptation of beliefs or damage to health.¹⁹

For this reason, religious practices and prayer groups in hospitals can work as a health promotion tool. This is a fundamental human right and essential for social and economic development, being a process of enabling people to increase control over their health and improve quality of life. Therefore, faith, beliefs or specific religious rituals such as prayer, rosary practice, mass celebrations and promises are interventions of spiritual and religious support actions that act as support for acceptance of suffering and pain.²⁰

CONCLUSION

Despite the feelings of fear, insecurity, guilt and worry of mothers on prematurity and admission of their child in the ICU-NEO, this study showed that they use spirituality as a strategy to face and live better with this prematurity.

It was observed that the mothers' perception about the relationship between health and spirituality it is unveiled as a positive phenomenon helping them to avoid discouragement and keeping hope in restoring the health of premature child. These benefits acted as welfare factor, comfort, hope and health, in addition to emotional and psychological support to cope with situations experienced by mothers in the ICU-NEO at the time of their son's hospitalization. Among the benefits of this relationship, it is noted that it is an adaptation strategy, providing courage to mothers to live better with prematurity of children.

Recently spiritual practices as a health promotion strategy were simply not considered important, but now they are being taken in health care. This practice, even still very distant in the context of health actions, can significantly contribute to the humanization of care, strengthening the bond between mother/child/family/multidisciplinary team around the human essence.

Thus, this study contributed to discuss the effects of spirituality in the hospital and a new look in the practice of care for mothers and their premature babies. In that reflective way, there is the challenge to consider the importance of ecumenical experience and interreligious meeting marked by dialogue, respect and tolerance of religious pluralism prevailing today in the society.

Finally, it is reaffirmed the possibility to continue the research on the relationship between faith and spirituality, disease, healing/health. The search for answers continues

encouraging to unveil the miracles of faith and spirituality as the great manager of human hope about life.

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