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OF PRETERM INFANTS IN A NEONATAL INTENSIVE CARE UNIT

TEXTO & CONTEXTO enfermagem

TEXT & CONTEXT NURSING TEXTO & CONTEXTO ENFERMERÍA

INFORMATION NEEDS OF FAMILIES ON THE HEALTH/DISEASE OF PRETERM INFANTS IN A NEONATAL INTENSIVE CARE UNIT

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ABSTRACT

Objective: to identify the information needs of the families of preterm infants hospitalized to the Neonatal Intensive Care Unit on health/disease.

Method: exploratory study, with a qualitative approach, performed with 33 relatives of preterm infants admitted to the Neonatal Intensive Care Unit, through a semi-structured interview, recorded in audio, transcribed and analyzed with the aid of the Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires software.

Results: two categories were identified, which are called: Reality versus expectation of obtaining information about the preterm infant; and Information on health/disease on-line: useful, positive and unattractive aspects.

Conclusion: it has been found that the information needs of family members are wide, and different means are employed to satisfy them, ranging from the traditional and every day to the use of technological means to find data and used for different purposes.

DESCRIPTORS: Family. Infant, premature. Intensive care units, neonatal. Consumer health information. Internet.

NECESSIDADES DE INFORMAÇÕES DAS FAMÍLIAS SOBRE SAÚDE/ DOENÇA DOS PREMATUROS EM UNIDADE DE TERAPIA INTENSIVA NEONATAL

RESUMO

Objetivo: identificar as necessidades de informações das famílias dos prematuros internados em Unidade de Terapia Intensiva Neonatal sobre saúde/doença.

Método: estudo exploratório, com abordagem qualitativa, realizado com 33 familiares de prematuros internados em Unidade de Terapia Intensiva Neonatal, por meio de entrevista semiestruturada, gravadas em áudio, transcritas e analisadas com auxílio do *software Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*.

Resultados: foram encontradas duas categorias denominadas: Realidade *versus* expectativa frente à obtenção de informações do prematuro; e Informações sobre saúde/doença *on-line*: utilidade, aspectos positivos e pouco atrativos.

Conclusão: verificou-se que as necessidades informativas dos familiares são amplas e que diversos meios são empregados a fim de satisfazê-las, compreendendo desde os tradicionais e corriqueiros até o uso de meios tecnológicos para encontrar dados, utilizados para finalidades distintas.

DESCRITORES: Família. Recém-nascido prematuro. Unidades de Terapia Intensiva Neonatal. Informação de saúde ao consumidor. Internet.

NECESIDADES DE INFORMACIÓN DE LAS FAMILIAS SOBRE SALUD/ENFERMEDAD DE LOS PREMATUROS EN UNIDAD DE TERAPIA INTENSIVA NEONATAL

RESUMEN

Objetivo: identificar las necesidades de información de las familias de los prematuros internados en Unidad de Terapia Intensiva Neonatal sobre salud/enfermedad.

Método: estudio exploratorio, con abordaje cualitativo, realizado con 33 familiares de prematuros internados en Unidad de Terapia Intensiva Neonatal, por medio de entrevista semiestructurada, grabadas en audio, transcritas y analizadas con ayuda del software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*.

Resultados: se encontraron dos categorías denominadas: Realidad versus expectativa frente a la obtención de informaciones del prematuro; e Información sobre salud/enfermedad en línea: utilidad, aspectos positivos y poco atractivos.

Conclusión: se verificó que las necesidades informativas de los familiares son amplias y en que, diversos medios se emplean para satisfacerlas, comprendiendo desde los tradicionales y corrientes hasta el uso de medios tecnológicos para encontrar datos, utilizados para fines distintos.

DESCRIPTORES: Familia. Recien nacido prematuro. Unidades de Cuidado Intensivo Neonatal. Información de salud al consumidor. Internet.

INTRODUCTION

It is estimated that, worldwide, 15 million preterm infants are born per year, being called this way as a result of birth before 37 weeks of gestation.[1] These infants are admitted to the Neonatal Intensive Care Unit (NICU) to receive specialized care pertinent to their peculiarities and health needs.[2]

In the NICU, it is necessary not only to take care of the preterm infant, but also to take care of their family, since their well-being is intertwined. Thus, it is essential to consider it in the neonatal recovery process, embracing it and establishing a trust relationship between the trinomial: family, newborn (NB) and health team.[3]

This family insertion in the intensive unit reinforces what is advocated by the Family Centered Care (FCC) model, in which the family cooperates with health professionals and participates actively in the life of the newborn, as they will be their main caretaker at home,[4] being necessary to approach the preterm infant to consolidate its familiar role.[5]

For the care provided to the family, it is essential that there is an effective communication with the family, which is part of the quality care, since in addition to support, it needs information related to the environment, the clinical condition of the preterm infant and the care. When communication is developed, the knowledge gaps of the family members are reduced and the professional learns to have greater sensitivity to the feelings and difficulties experienced by them.[6]

For the family, communication and information are essential in the period of hospitalization in the NICU,[7] and the dialogue is the result of trust, reciprocity and empathy established with the professionals.[8] Thus, obtaining detailed and accurate information about the preterm condition culminates in empowerment, respect and involvement in care.[9]

In the intensivist context, the communication cannot be only informative, only of passing on information without commitment and concern about the understanding of it by the relatives. They experience unique experiences and therefore require reliable and detailed data about the health status of the NB.[10]

Families seek to satisfy their needs for understanding the information offered superficially, incomplete or in the event of its non-existence.[10] The data provided by the professionals can be complemented, understood and confirmed by the family,[11] which uses knowledge from different types of media, such as: books, health professionals, other family members and the virtual network to meet these information needs.[12]

In having information, patients and families believe they are better prepared to discuss health/disease issues with the specialized professional. In this case, it is possible to question the professional with a greater theoretical contribution on the subject and to participate in the counseling regarding the most appropriate treatment for the clinical condition presented by the individual or their relative.[13]

It should be emphasized that the term health/disease was used in this study to designate the conditions that involve the well-being of individuals and those that are pertinent to the disease, since the information needs are linked to the period in which one is healthy and also to the moment in which there are diseases.

Knowing the information needs of the families of preterm infants in the NICU can help in the reorganization of the professional practice, improving the care provided and inserting the family as an effective part of the care in the neonatal units, so that the bond with it is strengthened and the hospitalization experienced less traumatic as possible. In addition, based on the identification of the information needs of the family members, it is possible to stimulate their dialogue with the professionals, minimizing the occurrence of doubts and guiding on what means reliable and good quality data can be found when they aim to acquire knowledge beyond the one that is offered by the specialists.

Based on the above, it was questioned: what are the information needs of the families on the health/disease of preterm infants hospitalized in a NICU? And to answer this question, this study aimed to identify the information needs of the families of preterm infants hospitalized in a NICU on health/disease.

METHOD

This is an exploratory study with a qualitative approach. Carried out with 33 relatives of preterm infants hospitalized at the NICU of a teaching hospital in the city of Curitiba-Paraná, from April to July 2016, recruited through a personal invitation and through a flyer prepared by the researchers, which was made available in the unit ten days before the beginning of the data collection period and remaining in the NICU until the end of this period. It should be emphasized that there were no refusals to participate in the study, all the family members who met the inclusion criteria were invited and accepted to be part of it, nor were there any withdrawals from those enrolled.

It was established as inclusion criteria for participation in the study: being a family member of a preterm patient hospitalized for ten days or more in the NICU and having access to the Internet. And as exclusion criteria: to have difficulty of communication and being unable to answer the questions, and to be under 18 years old.

The data collection was performed through a semi-structured interview, which included the characterization of the family and the preterm infant, and guiding questions related to the interviewees' experience regarding the use of health/disease information on-line. Previously, 13 pilot interviews were performed to adjust the data collection instrument. After this stage, some questions were re-adapted with the intention of presenting them more intelligible and appropriate for the purposes of the research.

All the interviews were carried out in a private place in the NICU, by a team composed of three researchers. Of the total of interviews (n=30), three were performed with parents and mothers together, of which 33 were participants in the study. The average duration of the interlocutions was 20 minutes, which were recorded in audio, transcribed and later returned to the participants for reading and approval of the described content. However, 17 participants did not perform it due to the preterm infant's death and/or hospital discharge. There was an attempt to contact the family members for the return, comments and approval of the content, however, without success.

The texts from the interviews were revised in relation to the spelling, without the essence being altered. Afterwards, the data were then analyzed using the six steps[14] which consisted of: organization and preparation of the data, with the transcription of the interviews in full, codification and the layout of the data in a textual corpus format; reading of all the data to obtain the general perception of the ideas expressed by the interviewees; coding of the data through the organization of the information in segments of text (ST), with groupings of these into categories established based on the similarity between the sentences, in this step, the *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRAMUTEQ®) software was used to aid in coding, organizing and separating information into classes;[15] descriptions of the data and with the codification previously assigned, the categories were established to reflect the main results of the study; representation of the analysis by means of categories, which emerged from the themes indicated in the classes from the IRAMUTEQ®; interpretation of the data, with details of the interviews and comparison of these with other findings found in the literature.[14]

In the presentation of the results, the excerpts of the reports were edited, subtracting or adding terms between brackets in order to make them more intelligible, without altering their content. In order to maintain the anonymity of the participants, at the end of the excerpts the "Ent" coding was used, which represents the interview, followed by an Arabic number that indicates the chronological sequence of the interlocution performed and all the names quoted during the interviews were changed by pseudonyms.

The development of the study respected the ethical precepts of voluntary participation, clarified and consented according to Resolution No. 466/2012, of the National Commission of Ethics in Research of the National Council of Health, being submitted to the analysis and issue of favorable Opinion No. 1.170.956 of the Committee of Ethics in Research of the Health Sciences Sector of the Federal University of Paraná and of the partner Institution No. 1.359.923.

The elaboration of the study sought to follow the steps recommended by COREQ (Consolidated Criteria for Reporting a Qualitative Research), which is a research guide composed of 32 items considered necessary for the development of qualitative studies.[16]

RESULTS

The age of the participants ranged from 18 to 47 years old, the prevalent marital status was married (15 participants), the family income of most families (20 of these) consisted of between one and three minimum wages. The length of stay of the preterm infants in the NICU ranged from 10 to 86 days. The most used resource to access the Internet cited by the interviewees was the cell phone (31 of these).

In addition, from the processing of the data into the IRAMUTEQ® software, the ST were classified according to the vocabulary which allowed the presentation with more emphasis of the following words: information, doctor, obtain, doubt, get, nurse, ask, team, Internet, people, receive, question, talk, nursing, these were the analyzed class that gave rise to the categories called: Reality versus expectation of obtaining information about the preterm infant and health/disease information on-line: utility, positive and unattractive aspects, both addressed below.

Reality versus expectation of obtaining information about the preterm infant

The family members emphasized the main sources used to obtain information during the hospitalization of the preterm infant at the NICU, with the medical staff being the main information provider, followed by nursing, consultations to the chart available at the bedside, and use of the Internet, as can be seen in the following excerpts:

[...] *I always talk to the doctors or to the nurses, we read the chart, do not understand much, but what we do not understand, what is not clear, we ask and everything is okay then.* (Ent 13).

[...] *we did not even understand, so at the beginning we used the Internet a lot to find out what the doctors were saying to us, after a while we got used to it. Nowadays I am even thinking about studying Nursing.* (Ent 06).

The information acquired through the Internet is shared with health professionals, whether they are from the NICU or outside the hospital environment, with relatives, and also, some of the interviewees do not dialogue with specialists about the findings from the on-line network, as expressed in the reports below:

I talked to a health professional about the information I found on the Internet, whenever I look for something I talk to doctor X, who is the doctor of the NICU... I spoke with a psychiatrist at the NICU, I spoke at the milk bank with the pharmacists, I do not know if they are doctors, I think they are pharmacists who stay on duty, I think they were the professionals... (Ent 23).

I did not talk to a health professional about the information I found on the Internet, I did not discussed it with anyone because I did not think it was necessary because it was my thing, that I wanted the answer and I found it. (Ent 08).

As a counterpart to the reality experienced by the families when obtaining data from the NICU, the interviewees reported how they would like to receive information, explaining the need to obtain them with clarity, specificity, in a reserved place, in a comforting and welcoming way, with time to explain and resolve existing doubts, clarifying the technical terms, such as the following reports:

I would like to get information from my son in a way that is as direct as possible, get there and talk to the person responsible for him... (Ent 24).

I think it is important that this information should always be passed in a more comforting way, that there were more informational sites, that the information were passed on by doctors in a more humane way, because sometimes it is one or the other that gives it the way you would like to hear, let's say. I think it is very important to explain the technical terms. (Ent 23).

We are lost, wanting to know and it costs nothing, it is five, ten minutes they [doctors] are going to spend with us, so that is how I would like to get information from my daughter. (Ent 13).

I would like to get information from my son, I think the way it is, it is fine, but I think this schedule thing does not work and another, I also think it should be a bit more reserved, I think it would be better not talk in front of others... (Ent 27).

Regarding the expectations of the families, the interviewees mentioned topics of interest to be addressed during the dialogue with professionals, such as: the development of the NBs, neonatal prognosis and survival after the hospital discharge, more details about the events that led to the hospitalization, doubts about care, such as the administration of the milk supplementation, and, finally, some relatives did not know how they would like to receive information about the premature infant, as can be seen below:

I would like to get information from my son as his development goes on... seeing his development, if he really will not have any, I do not know, sequel, anything... (Ent 07).

We believe that at the hospital discharge the staff will let us know this, what is the supplement? Nan? Right? Which Nan is? Should I give this much? Give 30 ml? 40 ml? To reduce? Do not reduce? This information that I think we will receive yet, I believe, I do not know, I think that would be our doubt, I think there is nothing else that we want to know. (Ent 21).

I would not know how to answer to what information I would like to receive because my children are well, I think it is because their condition is really good... (Ent 03).

Finally, the desire to receive the data through the medical, nursing, telephone and on-line network teams was emphasized, with the data standard currently used by families for information; however, with some technological suggestions to extend the communication between the professionals and the family, as can be seen in the following reports:

I could get this information from the doctors, from the nurses, it is several things, some things that we do not understand... (Ent 05).

I think I would like to get information from my daughter over the phone, since the NICU does not pass information by telephone, but I also think it is a way to have parents more present because despite the difficulty, everything, we have to take care of them. (Ent 22).

Well, as I stay a lot on the computer, because I am still working, by e-mail it would be very interesting to receive this information, whatsapp is also a tool nowadays... (Ent 23).

In this category, the disparity between the reality experienced in receiving information and the one sought by the families was highlighted, being emphasized the way in which they would like the reports to be made and the topics to be approached with greater emphasis and depth. However, regarding the professionals and resources employed to obtain data, in the majority of cases, the one desired by family members kept the current pattern of specialists involved and sources consulted, suggesting that the current model in these aspects can satisfy the informational needs of the subjects.

Information on health/disease on-line: utility, positive and unattractive aspects

The families used different means to obtain information about the preterm infant, among them the on-line network. The data from this source were used to acquire knowledge, understanding, clarification, to reduce the curiosity, to ease the anxiety and worries, to provide calmness, to establish communication with the professionals and to position oneself in face of the applied measures and, if necessary, to analyze and question he conduct adopted by the team in the treatment of the NB, to be informed about the lack or insufficient amount of data offered by the professionals, solve existing doubts, assist the premature or other families that are in the intensive care unit, and due to the practicality with which the data are available on the Internet, as expressed in the statements to follow:

[...] *but also, there is another moment that comes a doubt that you also forget to ask, that is why I really want to know what my son's clinical condition is, I look for information on the Internet because I am very anxious, I cannot stand...* (Ent 02).

I look for information on the Internet out of curiosity, to know more about other people, statements from mothers who also had this problem of babies being born before. (Ent 11).

[...] *but what are you* [*team*] *doing? Observing? To be observing, I stay observing, you do not have to be a doctor to observe. So to be able to even demand certain attitudes. No, look, but I saw there is a study that may be this...* (Ent 27).

I look for information on the Internet because I believe it is not very clear, I do not blame the doctors for this, but I think it is not very clear to say that your baby, for example, is hydropic, you look for nomenclature, hydropic: water, water where? (Ent 01).

[...] *what motivates you* [*to look for information on the Internet*] *is the friendship, you see the person suffering and you like the person and have things like I said, you do not ask about it and sometimes you help in some way...* (Ent 03).

I search information on the Internet because it is the most accessible, the medical consultation is not always... sometimes, you will do something, you say: to whom will I ask? It is the most accessible I have! We have all the information at the NICU, but sometimes we stay at home also thinking about the baby, keep watching, trying to get more knowledge about the subject. (Ent 22).

In this sense, the family members mentioned the aspects related to the use of the Internet that they consider relevant, such as: interaction websites for common questions that are answered, results of researches performed with preterm infants, experiences of other families that have undergone hospitalization in NICUs, portals with explanations and information considered of good quality, and those with data related to the gestational growth.

I liked an article by an academic from the Pontifical Catholic University of São Paulo, in which he said everything I had seen and put it in a more humanized way for us... (Ent 21).

The information I liked, positive, was the testimonies of the mothers, more than the medical information, because the medical information always presents the possibilities, and the testimony, when you read a testimony that works, and you identify with the moment you are going through, you also feel you have a chance and a chance for your baby to be well. (Ent 23).

The information I liked was that of the breath that the site explained to me, it is better than the doctor told me, the site explained me more correctly, more explained and such. (Ent 30).

However, unattractive aspects related to the use of the virtual network were emphasized by the family members, such as incomplete, low quality information, few elements about prematurity and information contrary to what was made available by the medical team, as can be observed in the following reports:

[...] *some information on the Internet was incomplete, I was looking for others to complement, and they told me what cyanosis was, so I was discouraged because it did not explain what it was, and in that case I would look for another one...* (Ent 12).

[...] *even the Internet is not a 100% trustworthy thing, we know, but anything you read and do not like will make you feel a bit more scared, and I think, at this moment that our mind is very fragile, it is not something we need, to listen to the doctors in here, after all it is them who are 24 hours caring, it is enough.* (Ent 24).

[...] *in my case it is only premature, but there are other mothers with other problems, I do not know if they find information on the Internet and even here inside, other mothers who had the same problems or a site that speaks specifically about this and that also clarifies, which is difficult...* (Ent 17).

In the present category, the information from the on-line network was emphasized, with the usefulness of these for the families, as well as the positive and negative aspects of the data offered in this medium. Thus, it can be stated that the interviewees exert a certain criticality in relation to the content available on the web, since they point out fragilities and potentialities of health/disease information that is pertinent to the subject matter in question.

DISCUSSION

Doctors and nurses are sources of information for the families and encourage them when they demonstrate availability, attention, respond to questions and minimize the occurrence of doubts; and these practices reinforce the one advocated by the FCC model.[17]

The relatives wish to receive daily medical information as well as know what they can do when they are next to the preterm infant. For them, it is essential to understand the prognosis of the NB, who are the professionals who are watching the baby, the treatment, and how it is being instituted, and have some professional available during the visit to talk and answer their questions.[18] Data that are similar to those found in this study, in which families reported feeling the need to obtain information about the preterm infant on a daily basis, reporting to the medical and nursing teams to be aware of the clinical conditions of the newborn.

Due to the complexity of the NICU, the nursing team is constantly by the side of the newborn, so it creates a bond with the family and has the possibility to offer information. However, sometimes, it transfers and makes the doctor the solely responsible for the dissemination of data.[6]

A study carried out in Rio de Janeiro (Brazil) with mothers of NB undergoing phototherapy in joint housing identified that most physicians provide information, explain the treatment to be performed,

act as a source of support for the mother and provides attention. Meanwhile, the mothers refer to nursing as support during all the hours of the day, responding to all their questions.[19]

Concerning the consultation carried out in the medical records, it was verified that the participants of this study did it so in order to approach the context experienced by the NB through the content described by the professionals. It is known that the patient and/or their caregiver have the right to detailed and complete information about theirr health status, access to it, during the treatment and after the discharge, as well as the confidentiality of their records. In a study conducted in Poland with individuals admitted to a hospital, where patients' rights awareness was assessed, it was identified that the majority of the respondents were aware of their rights, including access to their medical records after the hospital discharge.[20] In this respect, regarding the Brazilian reality, no similar studies were found that could confirm or challenge the previous findings.

Commonly, the motives that drive individuals to check their medical records are for an examination of what is being described by health professionals, especially physicians, in an attempt to become more involved in their care and to thoroughly understand their health condition.[21]

Patients believe that being close to the chart increases their perception of control of the situation experienced, encouraging the communication with health professionals and promoting the approximation and trust between them. However, the professionals emphasize caution as a key element in consulting the medical record, because little understanding can lead to anxiety.[21]

With the objective of obtaining more information about the preterm infant, in this study, the interviewees made use of the Internet. This fact is consistent with another Brazilian study carried out with patients with cystic fibrosis and their families, which identified the Internet as a means used to search for information about the health condition, referred to by the respondents as a fast and current resource for obtaining elements.[22]

In some cases, the virtual network is the first resource used to search for pathology data; however, subjects do not always access content that is reliable or that meet their needs, and some information that is occasionally searched for is not found.[22] Some patients have a direct influence from the information found on the Internet, and are therefore directed to attend medical consultations after the research, confirming the real positioning influenced by the virtual world.[23]

Sometimes, after surfing the web, individuals adopt some attitudes such as conversations with family and friends, followed by the beginning of behavioral changes, dialogues with doctors and appointment scheduling,[24] a fact similar to the one found in this study, in which part of the people reported having discussed the information found with health professionals, family members and friends.

Eventually, patients arrive at the doctor's office with prior information from Internet research, however, doctor and patient appear to change their behavior and put themselves differently in the relationship. In these episodes, many professionals feel uncomfortable and worried about the origin of the information, since the subjects can confront the adopted behavior, while others provide more information and guidelines when they know about the on-line searches carried out. On the other hand, in a considerable number of cases, the access to health/disease information on-line results in informed, empowered patients with the ability to question and discuss with the doctor the established therapy, allowing beneficial results for both individuals.[25]

In a study carried out in Toronto, Canada, with parents, to investigate their use and perception of reliable health information sites for children, it was observed that a little more than half of the parents consulted a health professional about the information they found on-line, such as their pediatrician, family, friends or family members who are health professionals and friends, in that order, in order to confirm the reliability of the data or to obtain further clarification.[26]

In contrast, another study carried out in Scotland with patients residing in a rural area of this country to describe the prevalence of on-line health information was found that two-thirds of the

patients reported not having discussed the information found with health professionals and have claimed new content learning from the virtual consultation. Thus, it is believed that the data surveyed were found satisfactorily and, therefore, there was no need to request professional advice.[23] Most of the individuals in this study assumed the same posture, keeping the findings on the web only for themselves, without sharing them with others, reiterating unnecessary to do so, once the informational need has been remedied.

Individuals can access the on-line network and not discuss information with the health team responsible for their follow-up, unless the team initiates a relevant dialogue. This fact can lead to poorly informed and sometimes unnecessarily worried subjects.[27] In view of this, it is important to highlight the need of health professionals to be aware of the patients 'and/or their caregivers' use of the Internet, so that they can provide guidance on reliable sources and the conscious use of information by families.[28]

In this regard, understanding the information needs of families through dialogue is paramount to promoting quality care, as they need to receive daily, detailed, comprehensive information and understandable explanations. Having information reassures the family and makes it possible to think of a favorable prognosis, however, some professionals do not always have enough preparation to report or feel distressed mainly by giving negative news.[18]

Another aspect affirmed in this study, imbued in the practice of professionals, is the use of technical terms during the reports, in this case, it is essential to use a language appropriate to the subjects' understanding,[17,29] because its use refers to the imaginary of worsening of the preterm infant's condition and potentializes the frailties experienced by the family[17] in this case, it is essential to elucidate them using language that is appropriate to the subject's understanding.[17,29]

In addition to how they would like to receive information, the families of this study mentioned the topics of interest to be debated during the reports, which include the period of hospitalization and the clinical condition of the NB, the reasons that led to a premature birth and consequent hospitalization, and also those pertinent to the care to be performed with the neonate, which comprise preparation for discharge. In this case, it is necessary to prepare the families for the discharge during the hospitalization, providing guidelines according to the ability of assimilation of the individuals, clearing the existing doubts, as well as inserting them in the care of the child as soon as possible, since they will be responsible for this care at home.[30]

The family members need to be advised when changes occur in the clinical condition of the NB, regardless of whether they are at home, they want to receive information via telephone contact, as well as identify who are the professionals who can offer this data.[18]

Providing information comfortably to families is part of the humanized practice. By providing embracing, individualized, responsible and ethical care, individuals are valued, respect is shown and the dignity of the family and the newborn are preserved, who are fragile within the NICU.[31]

With the time spent in the intensive care unit, families find ways to receive support and train themselves to care for the newborn. From this perspective, the technology can be beneficial, helping in the empowerment, during the hospital stay, as well as in the transition from the neonate to the domicile.[32]

In this way, the use of the Internet is evidenced, since it provides a range of sources offered quickly and immediately through search tools. Added to this is the fact that users enjoy detailed information because they optimize time, and the possibility of creating special pages with detailed data, such as communities in social networks intended for specific content.[33] Thus, individuals routinely rely on known data, describe their usefulness, and employ them to improve their health status.[23]

The Internet is considered beneficial because it provides anonymity during research.[23] In some cases, individuals use pseudonyms to facilitate discussions of sensitive issues, however, they may impel statements that are often offensive and inappropriate.[34]

On-line information is of instant use, so they are favorable if compared to the consultation of health professionals. Individuals believe that common subjects can be searched on the web, without the need to go to professionals and disturb them for this reason. The information provided at any time is beneficial, because at certain times, relatives, friends and health professionals cannot be consulted, such as at dawn, for example.[33]

The findings of this study are confirmed by the literature, as in the study carried out in Santos, state of São Paulo (Brazil), with patients and physicians to evaluate the impact of the health information available on the Internet on the doctor/patient relationship, as well as on the efficacy of the proposed therapeutic measures and the use of health resources, which confirmed that patients search the Internet to know about the disease, to acquire knowledge, to evaluate the conduct adopted by the professional, including verifying that the treatment and the diagnosis are suitable. In some cases, patients switched doctors because of information found on-line, believing only those.[25]

On-line health information is used to provide confidence, tranquility, understanding and support. Many family members compare gestational exams and growth, check their child's behaviors, whether they are appropriate, or whether there are problems. It is understood that there is a counterpoint between on-line information, which can support individuals who have no one to turn to for help and, on the other hand, may cause negative feelings such as anxiety in cases of exacerbated information or reports of failure in the stories exposed in this medium, so that access to such information can be avoided, especially by women.[33]

In a study conducted with parents in the Netherlands to assess their perception of the Internet in providing care for common symptoms in infants and their effects on health care use, it was found that parents reported the symptoms the child has and refer to the on-line network as an additional opinion to other consultations, such as family, friends and their own acquired knowledge, because doubts and insecurities have been commonly softened from conversations with specialized professionals.[35]

Through the on-line searches, the subjects can acquire technical and scientific knowledge, understand more about the topic, find reports and associations of patients that have the same pathology, and through social networks exchange information, point out doubts, express solidarity and help, to express intimate feelings related to the experience of the illness and to feel embraced, understood and comforted with the support received.[22] In the case of the participants of this study, they reported the purpose of the data coming from the Internet, emphasizing the use of the network in order to acquire knowledge both to understand the situation of their child and to inform about pathologies and clinical conditions presented by others NB in order to help other families that are in the intensive care unit.

The family members need to acquire knowledge to help the child and minimize the risks and suffering of the child, especially in the face of unknown symptoms or intercurrences. From the instruction, they broaden their understanding and look for ways to resolve their insecurity, to act responsibly. When they find the data, they feel useful, satisfied and feel like they can do something for their child.[35]

In addition to informing themselves through the web browsing, the subjects share their experiences in the virtual network, using the tools available in it, such as support groups, which have been used to help families at the beginning of parenthood, because they provide the exchange of information with other individuals who experience similar situations culminating in mutual support.[36]

The on-line support groups convey the sense that the shared information meets the needs of families, sometimes more than those offered by professionals, given the similarity of shared conditions.[34]

Regarding the searches performed during the gestational period, consistent with this study, a systematic review investigating the ways in which the pregnant women used the Internet to obtain information related to pregnancy found that the most sought topic in this period is the fetal development, followed by others such as nutrition, medications, complications, prenatal care and childbirth.[27] In

addition, the use of on-line information directed to gestation provides new means of establishing connection and improving the bond with the children.[33]

Allusive to concerns about the quality of health information on-line, a study[23] identified that the patients showed concern about the sources consulted, more than half with the reliability of these and with the security of the information researched, however, only a small part adhered to the privacy policy of the sites.

The security of the personal data entered in some portals and the content of their searches is another reason for apprehension, since individuals fear how their data could be used by others and prefer to maintain privacy when it comes to health issues.[23]

In a study conducted in Florida with parents of children with special needs to describe their access and use of the Internet, it has been found that parents who have access to the on-line network use it daily, however, many are unable to differentiate information from high and low quality, leading to a concern due to this difficulty.[37] Conversely, some of the interviewees of this research demonstrated criticality of the data found in the on-line network, since they emphasized positive and negative aspects that involve the content available in that medium.

The quality of information in the on-line medium is questionable. Many sites, applications, and platforms have outdated, incomplete data, not to mention source of origin and language inappropriate to the target audience. Others provide highly technical information, without distinguishing content intended for society and the one proposed to professionals.[38]

Regarding this matter, health professionals could help in the interpretation of data found on the Internet, especially when individuals obtain vague and inaccurate answers, however, they need sufficient time and ability to perform such role, which is not always a reality in health services.[39]

In contrast, high-quality on-line health information can broaden parents' knowledge and be useful for child development counseling; however, it does not replace information offered in person by professionals, especially in cases of indication of specific treatment.[40]

CONCLUSION

This study verified that the information needs of family members of hospitalized preterm infants in NICUs are broad and, due to this, several means are employed to satisfy these needs, ranging from traditional and everyday means to the use of technological means to find data, which are used for different purposes.

Regarding the information obtained from the technological means found in the on-line network, the minority of the family members discussed them with health professionals, especially those responsible for the direct care to the family-preterm binomial in the NICU, a fact that deserves attention and reflection on the part of the experts, since from the dialogue focusing on the data resulting from the searches in the virtual environment it is possible to guide individuals in searching for credible and good quality content, improving the care provided for the families of preterm infants in NICU .

Likewise, reflecting on the expectations that families have about how they would like to receive information and the reality instituted in most NICUs, may direct health professionals to rethink their practice, to be present and close to the family, and to develop an effective communication with them, so that appropriate strategies are used to the understanding of each individual, satisfying their information needs, resulting in humanized care to families who are fragile.

The use of technological resources to provide information, suggested by family members, reinforces the current scenario in which technology is present daily in the lives of individuals, especially in health, which should direct professionals to know the available means and improve their use, using them in a satisfactory way in the care process, since some family members criticize information on the web, considering the benefits and weaknesses that they present.

As limitations of the study, it is considered that the participants are in a single scenario, not allowing national representation and generalizations. However, this may be a point of reflection about the use of information by the families, with the possibility for further research, especially regarding the discussion about the use of on-line information in care. Another limitation is to conduct interviews exclusively with parents and mothers of preterm infants, due to the law's right to remain with the child during hospitalization. Facts that do not compromise the quality and authenticity of this study. It is believed that the dialogue with the other relatives who visit neonates sporadically could enrich the findings.

It should be highlighted that the topic addressed contributed to the understanding of the main informational needs presented by the families of preterm infants hospitalized in NICUs, mainly regarding the means used to satisfy them, especially the use of technology. In addition, when it comes to the use of the on-line network to search for data on preterm infants, it is evident that this is an innovative reality, since there is a shortage of studies in the Brazilian reality and those that portray the Internet focus on other populations and other health/disease contexts.

It is suggested studies that analyze the impact of the use of the on-line information for the families and the care provided to the preterm infants hospitalized in the NICU; and how health professionals deal with these data in their professional practice, in the perspective of care or even in the evaluation of the quality of the information coming from the virtual environment used by the relatives of the patients.

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NOTES

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