

Parent's support group as a transforming experience for families at a neonatal unit

Grupo de apoio aos pais como uma experiência transformadora para a família em unidade neonatal

Grupo de apoyo a los padres como una experiencia transformadora para la familia en una unidad neonatal

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ABSTRACT

Objective: To understand the meaning of families' participation in the Parent Support Group in the neonatal unit.

Methods: Qualitative descriptive study in the neonatal unit of a university hospital in São Paulo. Data were collected through semistructured interviews with families of hospitalized newborns, and analyzed by Qualitative Content Analysis. **Results:** The results showed that parents support group is a transformative experience for the family, because it promotes the clarification of their doubts, represents support during hospitalization of the newborn, promotes exchange of experience between parents and better interaction between the healthcare team and the family. **Conclusion:** The study reveals the importance of parents support groups by the multidisciplinary healthcare team to strengthen the parent-infant affective bond, to alleviate family's suffering and to promote parents' autonomy in the child's care.

Keywords: Family; Neonatal nursing; Self-help groups.

RESUMO

Objetivo: Compreender o significado da participação da família no Grupo de Apoio aos Pais na unidade neonatal.

Métodos: Estudo qualitativo descritivo na unidade neonatal de um hospital universitário do Município de São Paulo. Os dados foram coletados por meio de entrevista semiestruturada com famílias de recém-nascidos hospitalizados e submetidos à Análise Qualitativa de Conteúdo. **Resultados:** Foi evidenciada que o grupo de pais é uma experiência transformadora para a família, pois promove o esclarecimento de suas dúvidas, representa apoio durante a hospitalização do recém-nascido, favorece a troca de experiência entre os pais e maior interação entre a equipe de saúde e a família. **Conclusão:** Reforça-se a importância do grupo, com o suporte da equipe multiprofissional, para o fortalecimento do vínculo afetivo pais-bebê, alívio do sofrimento e maior autonomia dos pais nos cuidados ao filho.

Palavras-chave: Família; Enfermagem neonatal; Grupos de Autoajuda.

RESUMEN

Objetivo: Comprender el significado de la participación de la familia en el Grupo de Apoyo a los Padres en una unidad neonatal.

Métodos: Estudio cualitativo descriptivo realizado en un Hospital Universitario de São Paulo. Los datos fueron recolectados a través de entrevistas semiestructuradas con las familias de los recién nacidos hospitalizados y después sometidas al análisis de contenido cualitativo. **Resultados:** El grupo de apoyo es una experiencia transformadora para la familia, ya que promueve la aclaración de dudas. Además de representar apoyo durante la hospitalización del recién nacido, promueve el intercambio de experiencias entre los padres y una mayor interacción entre el equipo de salud y amigos. **Conclusión:** Gracias al apoyo de un equipo multidisciplinario, se refuerza la importancia del grupo para fortalecer el vínculo afectivo entre padres e hijos, amenizar el sufrimiento de la familia y ampliar la autonomía de los padres en el cuidado de los niños.

Palabras-clave: Familia; Enfermería neonatal; Grupos de Autoayuda.

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INTRODUCTION

The birth of a child generates intense changes in the family dynamic and its functioning. However, when it comes accompanied by some health complications, such as premature birth, birth defects or the child is diagnosed out of healing possibilities, parents have trouble dealing with these situations. The plans made until that point need to be rethought in order to be adjusted to the new reality¹.

In this circumstance, the parents express feelings of shock, denial, anger, frustration, guilt, depression, hopelessness, helplessness, loss, isolation, confusion and anxiety¹⁻⁴ which contribute to stress. Moreover, other elements linked to the characteristics of the neonatal environment contribute to parental stress as the change in the clinical conditions of the newborn, administrative rules and routines; barriers in the communication with the multidisciplinary team, and difficulty in building parenthood in a collective and unknown environment²⁻⁴.

Receiving the family in this care environment, integrating them and discussing with them the best treatment procedures to be performed is essential so that emotional experiences that may occur during this period are worked and the stress and the suffering of the family can be alleviated^{2,5,6}.

Thus, practices that bring families to participate in the care of the newborn, not only favor the emotional bond between parents and baby, but also are means to reduce stress, anxiety and fear caused by hospitalization. It also prepares the family for the care of the newborn at home⁵⁻⁷.

The care approach in neonatal units has undergone changes over the years, from a traditional model of care focused on the sick baby to a model that allows family participation in the care of their child^{5,6}.

To put into practice this new model, some interventions have been recommended and implemented in neonatal units of some institutions. Some of them are: encouraging the use of the kangaroo method, switching restrictive rules that keep the family away to other routines that include them, encouraging the visit of other family members, the permanent stay of parents with the hospitalized child, encouraging the participation of parents in the care of baby as well as in the decision making about the treatment and the implementation of spaces to listen the family in support groups, among others^{2,5,8}.

In the authors' experience with the use of the support group strategy since 2004, it is observed that in this space, it's possible to meet the emotional and social demands of the families; improve communication between family-staff; provide mechanisms for families to discuss and share their concerns; promote participation and autonomy of the family in care and make the preparation for discharge.

Literature studies^{9,10} show the use of support groups in pediatrics technology as a useful way to encourage interaction between people, provide support, facilitate interpersonal relationships and help in adapting to the situation of having a

hospitalized child in the family. They also recommend the support group as an aid to the family of hospitalized infants and as a tool for the reorganization of the affective and relational world of the individual and the newborn. It provides a space for expression of feelings, needs, expectations and anxieties^{11,12}.

In the support group studied, the experience of parents brought us to the reflection on family participation in this scenario, generating the following question: what meaning families attribute to their participation in this group?

The aim of the study was to understand the meaning given by the family to their participation in a support group for parents in the neonatal unit.

METHOD

This is a descriptive qualitative study, an approach that considers the meaning and intentionality present in acts, in relationships and social structures, taking into account the deepest levels of social relations that can not be measured in numbers and variables¹³.

To guide the analysis of this study, the chosen theoretical framework was the Symbolic Interactionism. It is a theory in which the meaning is the central concept, where individual and collective actions are built from the interaction among people, who by defining situations act in the social context to which they belong. It is an approach that allows nurses to understand the other individuals, considering the meanings those other attribute to their experiences¹³.

The study was conducted in a neonatal unit of a university hospital in the city of São Paulo. It is a unit of quaternary level, reference to premature infants and congenital malformation.

Data were collected after the approval by the Ethics Committee of the institution and in accordance with the Brazilian Council of Health Resolution number 466/12 (protocol number 0755/09).

The members of the research were five families of newborns admitted to the neonatal unit, represented by mothers that take part in the Support Group for Parents. The number of subjects was defined during the collection and analysis of data, the saturation of analytical categories¹⁴. This occurs when there is stabilization and validation between the categories described above and no new data is found by setting the density of the same.

Individual interviews were conducted in the second half of 2009, after the signature of the Informed Consent Term by the participants, in a private room at the institution, scheduled based on the availability of each participant, recorded and transcribed by the researcher. Each interview took around 50 minutes and was conducted with the guiding question: How was it for you and your family to participate of the parents group? The feelings, thoughts, and the actions in family interactions with the experience were explored.

The qualitative content analysis was applied to conduct the process of identification, coding and categorization of primary patterns in the data¹⁴. It is a flexible method of data analysis, which describes a range of analytical impressionist approaches,

inductive or interpretive to strict and systematic analysis. First, all interviews were transcribed in full by one of the authors. Then, the reading and rereading were carried out and extracted the initial codes, highlighting the most enlightening aspects of the findings. After the initial coding, we performed its grouping into categories according to the similarities of the content. After this step, categories were compared for similarities and divergences, forming sub-themes which allowed the identification of the subject of study. The excerpts of the speeches were identified as "I" interviewee, followed by the number of participants in the study.

RESULTS

The analysis performed allowed us to understand the meaning given by family for participating in the Support Group for Parents of the neonatal unit. It is an emotional experience in the family life, whose central theme "The group of parents as a transforming experience for the family" consists of four analytical categories that emerged and sustain the meaning given by the family in the interactions according to the situation.

The four analytical categories that emerged from the analysis are presented below.

Opportunity to have their questions answered

The hospitalization of the baby is a crisis for the whole family. The environment of the neonatal unit is strange and scary, because besides the real baby being different from the imagined, the presence of numerous equipment, necessary to their survival threaten parents who do not know the use of those equipments and enhance their sense of vulnerability.

In this context, when parents do not understand what is going on, they question themselves on the procedures that will be made with their child; about their future and feel insecure and uncomfortable as for the staff. Parents realize that by asking questions, they may disturb the care of other babies, since the dynamics of the unit is rushy and requires full attention and dedication of health care professionals.

Mothers show their satisfaction by participating in the support group, equating this space as an opportunity to clarify their doubts and their families, in relation to clinical baby's conditions and procedures it is being carried out to the treatment. They observe the behavior and the reactions of other families who undergo similar experiences and identify the problems of others. Thus, the family attaches a positive meaning to join the group, identifying their questions on other participants and achieving the necessary clarification without exposing themselves, as early in their participation they prefer to remain more reserved, just watching. The clarification of their doubts by professionals makes the members of the family safe, and feel good for having care and attention.

[...] I felt insecure, because I saw my children in that incubator, full of little tubes, then I was like: My God, what is

the procedure and what will happen from now on... then felt insecure because there was nobody to explain about the problems, what they are, what they are not, what could happen... [...] But now I'm learning and understanding things better, I'm fitting in the group better now (11).

[...] like having my questions answered and listening to the other mothers [...] Oh it's good, you can see that there are some people who are in worse situations than me, or for better, others who are going through the same as me, so it was good... Yeah, and then it made me feel good, you know, also because I did not even ask some questions because they were the same as some other people's questions [...] (15).

The mother reveals that in her individual interactions with the staff not always the shared information sounded clear. She uses the group to clarify her questions, ones that she created at home with her family. There are occasions in which the mother is the spokesperson of a family member who can't join the group, so she brings the questions created by them to be answered at the meetings. Thus, the whole family can join the group through a representative.

[...] Because sometimes we talk with the doctor, the doctor just comes and tells us things and we think we have understood, only when we come home we start thinking about a lot of stuff, so at the meeting we have the opportunity of discussing about these questions (12).

[...] They thought it was good, so that my sister-in-law asked a question, something she didn't understand as well, and passed it to me so I could bring it noted, along with some pen and paper, to write the answers for the questions and take them home, so I can say that my sister-in-law helped me too. I clarified my doubt and so did my sister-in-law [...] (14).

During the meetings with the support group, the participation of the multidisciplinary team facilitates and improves clarification of doubts, since it is possible to have direct access to professionals from other specialties and areas in health. Besides showing preference to elucidate their questions in this space, family members feel more confident to talk to other professionals and not only their physicians.

[...] It is also more comfortable, because at the unit we end up alone, and besides the doctors of the baby, there are also people from other specialties, there is a phonocardiologist, a neurologist, you know, and there (in the group) there are more professionals so I think it is also easier for you to ask your questions, and have your questions answered [...] (12).

[...] They explain things better because for example, to the phonoaudiologist, I once asked what her work was like, how she could stimulate the baby in getting breastfed, and the doctor does not know how answer that because, it's not part of the area of knowledge, he can explain things in general, and as now we have the phonoaudiologist, we have already have our questions answered by her [...] (12).

Support network to the families

The families give the group the meaning of support and support network once it helps them in adapting to their children's hospitalization experience. This meaning is especially given because of the attention provided by the professionals to hear and answer their questions, anxieties and fears. It is also important the support offered by other families, when they bother to know each other's life story, the reason of their children's hospitalization and their clinical evolution, sharing feelings and supporting one another. When exchanging experiences families are sharing their learning.

[...] For me it was very good, at that time it was as a support for me, it was a support of all forms, to answer my questions, to support me emotionally, of all forms [...] the group helped me to adapt, to clarify doubts, to share what you are feeling at the time, to put things out, because in my case I do not have many people to talk to, so for me it was good, very good [...] (14).

There are families who start is the Parent Support Group seeking social support, to receive the benefit of the bus ticket/subway, diapers and aid from government programs. But then they are surprised to identify that the group promotes other forms of social support, as guidance on birth registration, attitudes counseling and guidance from counselors who are available to help them, respecting the limitations of the hospital and the family.

[...] So as for him registering the children, he did not do so record he has a problem in court and can not register, but they guide me if I need any help, they are there to help me, so much that the psychologist says that even if he will come to talk too, which he will not do it, because he does not come to see his children. But we talk about this help, they may be guiding him, talking, but nothing that hinders him to do anything for his children [...] (11).

Space for exchanging experiences with other families

The group becomes an experience sharing space in which families are identified with each other, realizing that they are not

the only ones experiencing those situations. So, They can learn from the experience of other families, becoming calmer and safer when they see families that have gone through the same problems as their and eventually overcame.

But this process is slow, because at first the family reveals reluctance to join the group, having to be encouraged by other members and other families who have participated in the same.

[...] I shared and saw it was not only my case, right? that there are many people who have similar problems to mine, or worse than mine [...] (14).

[...] It makes me feel better. And I'm going to win, the fact of seeing mothers who have experienced this, it makes me see that from now on I can win, you know? I'll go through it, but it's just a phase [...] (15).

When they experience this opportunity, family members evaluate it as very important and they feel very well because they can share their experiences, once it is a learning moment, they can look at their experiences and those of other families, sharing feelings, anxieties, fears and the achievements of their babies. This strengthens them and makes them become more secure.

[...] I found it pretty cool because it is a means of sharing the feelings, right? Sharing anxieties that each one of us has, feels, lives, that's it! Sharing the news, what's happening day by day, right? The progress of our babies [...] They said mine had a problem in the head, column, another one had no moments on his little bent leg, so there were 10 distressing days and this is what I could share [...] (14).

Facilitator scenario of interaction with professionals

In the begging of its participation in the group, the family may feel afraid to expose their questions and concerns, but as time passes they realize that it is a place where they can get closer to the professional. That makes the interaction become closer and facilitates the construction of trust and close relationship between the team and the family.

[...] That is a way I could explain my concerns, all of them. Ask the doctors, we get closer [...] We can know we can trust them [...] (13).

[...] I feel more at ease because there in the group I talk to [...] who is taking care of his case (14).

DISCUSSION

In the early experience with a newborn child in the neonatal unit, the family experiences a very suffering situation, because they feel desperate and insecure in this environment. The search

for support from other family members and the health staff becomes part of the confrontation of this family. By accepting the invitation to join the Parent Support Group, the family finds a place for clarification of doubts, and begin to understand what is happening. Based on this understanding, the family starts to realize the support and security received to better face the moment they are experiencing, so they can feel stronger for sharing their experiences with professionals and with other families. The narrowing of the relationship between the family, and the staff that is present at the meetings of the support group favors closer relations with the building of trust, which makes the family feel safer so that they can give the group the meaning of being a transforming experience.

The data revealed by the study showed that the birth of a child always generates anxiety and changes in the roles in the family context. The disease or clinical complications of the newborn that arises then, cause much suffering^{4,6,7,15}, requiring radical and inevitable changes in the family routine^{6,16,17}.

A goal to be considered by the health team in the treatment of hospitalized infants is to reduce the anxiety of parents by offering support, answering questions, helping them to express their feelings¹⁷.

In this study, families realized the support group as a transformative experience because it offers them the opportunity to clarify their doubt, and helps them feel safer and less anxious. In this sense, the support group establishes itself as a valuable intervention to guide, encourage and enhance the participation of newborns' parents who now have more autonomy to take care of their children. Moreover it allows professionals to know the story of parents and their thoughts and feelings about reactions to the hospitalization of the newborns^{4,5}.

Studies^{12,16,17} show that during the hospitalization of infants, parents have the need to be close to their newborn children; receive timely and adequate information on their health conditions and receive support. The clarification is very important to the patient and family, since it allows the organization of their emotional life and the mobilization of internal resources to cope with the situation¹⁷.

The support of the group provides opportunities for the families to get information. It also improves communication between professionals and family and promotes the involvement of parents in the care of their young kids. But it's necessary to go further than clarifying doubts, it's also necessary to give them support in this moment of vulnerability.

Families seek support when they go through experiences in which they need to rearrange their lives, and seek emotional support, attention, respect, social support, advice in making decisions^{16,18}, as well as the transition from the hospital to their homes².

The Model of Patient and Family Centered Care recognizes the importance of information provision, collaborative practice, family participation in care and decision making. Which assures them dignity and respect. Based on these pillars, parental

responsibility, respect for the values and feelings of the family are reinforced as well as the partnership between staff and family in the neonatal unit⁵⁻⁸.

In this study, families considered as fundamental the group once it is a space for exchanging experience with other families, because they learned to hear the narratives, questions and the answers from the team. The space of group is also favourable for reflexion and sharing experiences, which therefore helps them feel more secure, keeps their hope and encourages their interaction with professionals who care for their child.

Studies have shown that the exchange of experiences between people in a care environment can be a valuable source of information, hope, support, advice. Especially when the child has or has had a similar condition¹⁶⁻¹⁸, which reveals that support groups can influence positively parents and the communication between them and the health team in coping with hospitalization^{10,11}.

CONCLUSION

In the early experience with a newborn child in the neonatal unit, the family experiences a very suffering situation, because they feel desperate and insecure in this environment. The search for support from other family members and the health staff becomes part of the confrontation of this family. By accepting the invitation to join the Parent Support Group, the family finds a place for its doubts clarification, and begin to understand what is happening.

Based on this understanding, the family starts to realize the support and security received to better face the moment they are experiencing, so they can feel stronger for sharing their experiences with professionals and with other families. The narrowing of the relationship between the family, and the staff that is present at the meetings of the support group favors closer relations with the building of trust, which makes the family feel safer so that they can give the group the meaning of being a transforming experience.

The experience of family in the support group, revealed in this study, allowed them to have a transformed reality, going from a solitary experience, fraught with doubt about their lives and uncertainties to another one in which they feel part of a group that offers support and care for their needs. The family perceives the group as a context that enables the sharing of experiences, the formation of support networks, answering questions, the inclusion of the family in care and a learning period for their life, despite the difficult situations they are experiencing. This changes the concept of a support group to a place where the painful experiences of the families can be exchanged.

The findings of this study are aspects to be considered in the guidelines for best practice in the care of the newborn and family in neonatal units. But we must remember that the space of the support group does not eliminate the maintenance of individual meetings between family and staff for discussion and reflection on decision making.

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