







Meanings of support group for family members in the neonatal intensive care unit

Significados de grupo de apoio para familiares na Unidade de Terapia Intensiva Neonatal

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ABSTRACT | OBJECTIVE: to analyze the meaning that family members of newborns admitted to the Neonatal ICU attribute to the Support Group. **METHODS:** this is a descriptive-exploratory study with a qualitative approach, developed at the unit of a public hospital. Seven family members of newborns admitted to the unit participated. Data were collected in 2017 through semi-structured interviews and analyzed using Bardin's Content Analysis. **RESULTS:** two categories emerged, namely: Support Group as an emotional support scenario for family members in the unit and Support Group as an information scenario for family members in the unit. The Group meant a scenario of support and care for the family in the unit, in the form of emotional support associated with the formation of bonds and information support, emerging as an excellent support tool for its members. **CONCLUSION:** the Support group was configured as a space of care and support for family members, through the sharing of experiences, established bonds and information offered, obtaining a positive effect on the process of hospitalization of patients and their families, solidifying the humanization among health professionals.

DESCRIPTORS: Self-help groups. Family. Intensive Care Units Neonatal.

RESUMO | OBJETIVO: analisar o significado que familiares de recém-nascidos internados na Unidade de Terapia Intensiva Neonatal atribuem ao Grupo de Apoio. **MÉTODOS:** trata-se de um estudo descritivo-exploratório de abordagem qualitativa, desenvolvido na unidade de um hospital público. Participaram sete familiares de recém-nascido internados. Os dados foram coletados em 2017 por meio de entrevista semiestruturada e analisados através da Análise de Conteúdo de Bardin. **RESULTADOS:** emergiram duas categorias, sendo elas: Grupo de Apoio como cenário de suporte emocional para familiares na unidade e Grupo de Apoio como cenário de informação para familiares na unidade. O Grupo significou um cenário de suporte e cuidado para a família na unidade, sob a forma de suporte emocional associada à formação de vínculos e suporte de informação, surgindo como excelente ferramenta de apoio aos seus membros. **CONCLUSÃO:** o grupo de Apoio se configurou como espaço de cuidado e suporte para os familiares, através do compartilhamento das experiências, vínculos estabelecidos e informações ofertadas, obtendo efeito positivo no processo de hospitalização dos pacientes e seus familiares, solidificando a humanização entre os profissionais de saúde.

DESCRITORES: Grupos de apoio. Família. Unidade de Terapia Intensiva Neonatal.

Introduction

The arrival of a child brings a range of modifications in the family nucleus resulting from both the incorporation new responsibilities by family members, as well as from the insecurity of the birth and care of a premature and/or risk child¹.

When the child is referred to the Neonatal Intensive Care Unit (NICU), which consists of a hospital sector of urgency and immediacy, with assistance focused on babies at imminent risk of life and that, in common sense, brings a strong association with the imminence of death. In this context, the family feels fragile and experience disappointment, guilt and fear of loss, which entails stress and distancing from the baby, impairing attachment and bonding².

Thus, it is important to create spaces that allow family members to feel less psychologically stressed during hospitalization and the formation of a support network with other family members undergoing the same experience and with health professionals³. In the NICU scenario, the Support Group emerges as a proposal to facilitate the approximation between parents and multidisciplinary team, clarifying doubts about the baby's general condition, tests and procedures performed, explanation about the service routine, besides allowing the exchange of experiences between parents⁴.

This research adopted the concept of family as a dynamic unit, composed of individuals united by blood ties, of interest and/or affection, who coexist for a period of time, building a life history⁵.

There is need to approach this theme, in view of the little explanation on the theme in the literature and academic environment, as well as its benefits for the relatives of hospitalized children, and, consequently, the positive effects on the health-disease process of these family nuclei.

Therefore, the following question emerges: What is the meaning that relatives of newborns hospitalized in the NICU attribute to the Family Support Group?

Thus, the aim of this research was to analyze the meaning that relatives of newborns hospitalized in the Neonatal Intensive Care Unit attribute to the Support Group.

Method

This is a descriptive-exploratory qualitative research, developed in the NICU of a hospital in inland Bahia, focusing on the Family Support Group of this unit.

The Support Group of this institution emerged with the aim of promoting orientations with various themes focused on the care of newborns, the norms and routines of the NICU and the Nursery, as well as the return home and emotional aspects and care with the own companion⁶. Currently, it develops playful and support activities for the relatives of newborns hospitalized in the NICU and Nursery, being carried out by the Psychology and Occupational Therapy team once a week. The average participation is 10 to 20 companions of these sectors, lasting one hour and a half.

The research collaborators were seven relatives of NB hospitalized in the NICU of the hospital, namely: four mothers, a father, an aunt and a grandmother. The inclusion criteria were: being relatives of newborns hospitalized in the NICU, who had experienced at least two weeks of hospitalization of the child and who had participated in at least two meetings of the Support Group, considering this period a minimum time to establish meanings regarding participation in the Group. There was no age limit for these family members, since there is a predominance of underage parents in the NICU where the study was conducted. On the other hand, the exclusion criteria were: family members with hearing and speech impairment or psychiatric disorder; as these conditions would hamper data collection, because of the researcher's technical limitations.

The semi-structured interview was used as a data collection technique, from October to November 2017, more precisely on Monday afternoons and Friday mornings, using a voice recorder to store the respective interviews, which lasted around 30 minutes. Prior to the interview, socio-demographic data were collected about the interviewee and the hospitalized newborn, aiming only to know them. Subsequently, the interview was conducted, which contained the following guiding questions: What do you understand about Support Group? How do you feel when you participate in the Support Group? Describe your experience by participating in the Support Group here at the hospital.

All family members contacted during the collection period agreed to participate in the research, and were later referred to the room reserved for the interview, in order to guarantee privacy. To approach the field, we introduced ourselves to the Psychology team that coordinated the Support Group, as well as to the coordinator and assistance team of the NICU, when the research and the whole collection process were explained.

Data analysis was performed through Content Analysis, which consists of a set of communications analysis techniques that aim to survey indicators that enable the interference of knowledge⁷.

The categorization occurred after exhaustive readings of the transcribed texts and the clipping of each record unit of the interviews, which were grouped into themes by similarity or approximation of content, focusing on the relationship between the discourses and the objectives of the study.

Data collection began after approval of the research by the university's ZIP Code, respecting the criteria of Resolution 466/2012⁸. Furthermore, the interviews took place only after the eligible collaborators agreed to participate voluntarily and signed Informed Consent Form or the Informed Assent Form, whose guardians also consented through the Guardian's Authorization. For identification codes, each family member was asked to choose the name of a feeling to preserve anonymity and confidentiality. Thus, our universe was formed by: Love, Miracle, Peace, Victory, Hope, Gratitude and Emotion.

Results and discussion

The participants of this research were mostly: mothers of hospitalized children, aged between 16 and 47 years, being characterized as catholic (57.1%), unmarried (71.4%), black (57.1%), with complete secondary education (42.8%), students (57.1%), earned less than one minimum wage (100%), with only one child (57.1%) and living with their partners (85.7%).

The analysis of the discourses unveiled several aspects about the meanings that relatives of newborns hospitalized in the NICU attribute to the Family Support Group, which were organized through

three categories, called: Support Group as a scenario of emotional support for family members in the NICU; Support Group as a scenario of bonding between family members of the NICU; and Support Group as an (non-)information scenario for family members in the NICU.

The idea of "scenario" in this context is attributed by its meaning as a place where an event or action occurs, that is, the Group is a concrete support space for the NICU sectors, where actions that have support and care as central meaning for the family are unfolded.

Support Group as a scenario of emotional support for family members in the NICU

This category included the statements that translate the different forms of emotional support that the Support Group provides to family members. Here, understanding emotional support as the relationship that individuals establish with each other and that serve as aid to the other, leading the individual to believe that it is possible to find courage to react and overcome possible difficulties in the affective sphere⁹.

Family members understand the Group as a scenario of support and embracement, which helps them face the hospitalization process in the NICU, which seems pertinent, because the embracement in this space can be translated into the form of listening and embracement, recognizing the needs of the family and patient, constituting itself as a care practice in this environment¹⁰.

What I understand about Support Group is... They help comfort us [...] we feel embraced and I like it very much because it also supports people (Love).

I was embraced so well, the girls of the Group helped me a lot... Every time the group happened, they would call me and I felt so embraced (Gratitude).

Thus, support was configured as support and care in the Group scenario, resulting in emotional assistance for the family, given the difficult process of hospitalization of the child in the Neonatal ICU.

One of the difficulties found in the context of hospitalization is to face the closed environment of the hospital, especially in a restricted sector such as the NICU. In addition to carrying the suffering due to the child's condition of hospitalization, family members

come across a place rich in different devices, noises and constant movement of professionals who work under surveillance and continuous care.

The deprivation by family members of the relationship with their external social network triggers feelings of anxiety because they are out of their homes, distant from the frequent support of friends and relatives¹¹. Thus, the Support Group uncovers the space that provides the rescue of small daily details, which make a difference, as moments of distraction; thus minimizing the anguish of being in the hospital, added to the concern about the baby's hospitalization.

It is a distraction for those focused on that issue, seeing all that suffering and having this time, this moment, is very important, so that we return stronger (Victory).

We have fun participating in here. It makes us feel more relaxed, we even get the moments of sadness, the fears we have there in the room (referring to the Neonatal ICU), those machines all beeping ... (Emotion).

Considering that the NICU is a closed sector, the need for interaction with elements of the extra-hospital environment emerges, according to the possibilities.

So, as I cannot leave the hospital, moms feel the need to go outside, see the sun, smell the air... So, I think the group could gather the mothers outside, for example, in the open air, in a cozier place, with trees, flowers, to feel better, because we feel imprisoned inside [...]. Inside the hospital is never like out there... I mean, they do not have to take us out there every time, but sometimes, out there... One outside, one inside the hospital, so we can remember there is still a place out here (Gratitude).

In view of this report, it is interesting to reflect on activities that can be developed in the Support Group and that provide family members with this contact with the environment outside the hospital, within the limits recommended by the hospital institution, or promote a conversation wheel within the Group, guiding the family on the possibility of other family members acting as companions, so that they can leave the hospital environment a little, avoiding the burden and suffering that hospitalization promotes.

The child's hospitalization in the NICU generates a significant impact for family members, triggering an emotional imbalance and the emergence of feelings

such as insecurity, frustration, stress, fear and guilt¹². Therefore, this family begins to seek emotional support, attention, respect, social support and decision-making advice¹³.

These needs of family members were minimized in the Group as emotional support for the family, serving to cope with crisis and teaching new behaviors for acceptance. The excerpts show the meaning of this emotional support:

I arrived in the blue, afraid to face it. Because it a whole new situation, so I got so frustrated... And scared. After the group, I am a person who with an expectation, that anything is possible. That we can do everything (Miracle).

The Group is always with me, supporting me [...]; it was difficult, but they supported me, they said, "Don't be like this, God knows things"... Then they really helped me, they supported me, they embraced me, it is good to have the Group because they strengthen you, help you, it makes you think positive (Love).

We observed a change in some negative feelings experienced, where the Support Group helped the family members face the hospitalization process positively. It was noticeable the Group members promote emotional support by listening to the family members, sensitizing themselves with their pain, respecting their complaints, offering words of comfort and establishing trust with them. It replaces fear, anguish, guilt, depression or even anger, with the resilience that helps them keep winning every day of their baby's hospitalization, coming to believe that being in the NICU may not mean the end of life, but the struggle to keep alive.

Thus, it is essential that professionals who work in Support Groups, ICU or other health sectors understand that emotional support permeates the gestures towards the family and the patient.

Emotional care is the ability to capture the imperceptible and nonverbal communication is an example, expressing itself in posture, facial expressions, gestures, appearance and body contact of one of the subjects, and that touching someone affectively, in this way, is essential to their safety, protection and self-esteem¹⁴.

The family members' reports evidence nonverbal communication and its importance in interpersonal relationships.

Because, I mean, no one has the gift of making anyone feel good all the time. We come here, we feel in the air, you look at their faces (referring to the psychologist and occupational therapist who participate in the Group), you already feel good just with their smile, so I think it not everyone who has the gift of doing it, I think it is the own person... (Hope).

They treat us and our children as if they were theirs. That is all that matters. I keep watching each professional, each one has a way, but the way they do it, they are very loving. Because I could be there just to be... (Love).

In this perspective, family members, within their particularities, consider the Support Group in the NICU as a scenario that allows emotional care, providing a new meaning for coping with the hospitalization of their babies, with more strength, hope and optimism.

The Group comes in the sense of encouraging even, waiting, having more faith in God, hope. And trust we are leaving here, by God's will. There is no denying... (Emotion).

Support Group as a scenario of bonding between family members of the NICU

The importance of the bonds established by the family members in the Support Group, before coping with the hospitalization of their babies in the NICU, shows that the bond translates as a source of emotional support for them.

The bond¹⁵ expresses a union with lasting characteristics, based¹⁶ on the relational aspect, with mutual influences between individuals, which can be based on love, knowledge and recognition, besides an emotional factor that gives meaning to the relationship.

Thus, from the reports of the family members, we analyzed that the interpersonal relationships established in the Support Group culminated in the formation of friendships, which promoted the necessary support to circumvent the difficulties experienced during the routine in the Neonatal ICU.

In the Support Group we make friends... They let us blow off steam, not everything that happens in life, but what we are unable to keep ... (Love).

I had acquaintances in the Neonatal ICU, but after the Group, it was good because we get to know more people... I made friends not only with the people of the Neonatal ICU, but with other "ICU" (Victory).

These reports show that, from the moment the Support Group allows combining different family members with the professionals who are at the head of the Group, interpersonal relationships are established, culminating in the formation of the bond.

The sharing of experiences among family members within the Group allows them to understand that they are not alone, which ends up feeding the hope to cope with difficulties. This aspect was evidenced in the speech of a relative:

I am shy, but I try to be in the Group, we need everyone, we cannot walk away, because sometime we are alone here, but, at a time like this, when we are in despair, there is a friend from the Group who talks, talks about what he has lived, which makes us happy, gives more hope, there is no way I am leaving this group... (Emotion).

The relationship of friendship established in the Support Group allows family members to configure it as a family space, providing the learning of living with different people, with different experiences before the baby's hospitalization process in the NICU, enabling significant support before the routine experienced in this sector.

The discourses of these family members reveal this configuration of the Group as a family space:

If had no support from the Group... because I am far from everything, away from family, from father, from mother, from everything... And then they support me a lot, we eat breakfast "together", have lunch "together", talk ... It is not our home, you know? But it ends up becoming it because we feel embraced, that is what matters and I only have to thank a lot [...] because I am not home, they end up being family, they get your phone number... (Love).

The feeling of belonging of an individual, as one of the elements related to the bond, is entitled as what characterizes him/her as an intimate part of a specific context or group, and is related to the bond by offering the establishment of relationships, exchange and bonds of care¹⁷.

An important factor that came from the bond formed in the Support Group was the strengthening of the bonds of friendship, even outside the hospital environment, through technological resources that provide contact between those who were discharged and those who are still in the NICU.

This Group promotes many friendships; after discharge, the person readily gets the "zap" (referring to the instant messaging phone application "WhatsApp"), they send photos from their home, like brothers here in the same hospital ... (Emotion).

This evidences the importance of contact between family members beyond the hospital routine, which can perpetuate the friendships made through the Group, which guarantees the quality and trust of the friendship relationships experienced, as it demonstrates the richness of the bonds established.

This mutual and family support network offered by the Support Group confirms altruism as a therapeutic effect for family members in the NICU. Altruism refers to the tendency or inclination that awakens people to worry about their peers, and, since the Group is a cohesive space, the bonds commonly tapper off through phone calls, visits and mutual assistance at difficulties, being a therapeutic benefit for the family that experiences the process of hospitalization of the baby in the Neonatal ICU¹⁸.

Although other discourses already demonstrated here have altruistic content, the report of a relative – in particular – more explicitly evidences its meaning:

See, I think after the Group, I became someone else, I started to see beyond the horizon, because I was never a selfish person, but I just saw within my limits [...] the Group made me look beyond what I was seeing [...] Over time, it made me help other people who are in the same situation as me, I am giving strength, because I keep wondering how the person is feeling, because I went through it. (Hope).

Hope's speech reveals that the Group enabled an altruistic way of seeing the world and people, which had repercussions on their attitudes. We also emphasize that the Support Group can strengthen the bond between the family member and the patient. In this case, the Gratitude's speech expresses how the Group helped in the formation/maintenance of the bond with her daughter in the NICU.

The group assisted in my development and of my daughter (...) So, I started to help my daughter more, because I used to feel cornered, I was afraid, I was sad about everything and after the Group I was no longer afraid, I became stronger and I wanted to help her more and more... (Gratitude).

It is possible to notice that the report of the family member evidences feelings emerging in the NICU environment: the fear of family members in establishing a bond with the baby, often due to the excess of devices, the suffering experienced or even the lack of incentive from professionals working in this sector. We noticed that the sadness emerged by the daughter's hospitalization in the NICU led Gratitude to be afraid to establish contact with her and that her participation in the Support Group promoted stimulation and emotional strengthening, culminating in the formation of a bond between mother and daughter.

Thus, participation in the Group was significant in the family members' life, because it allowed them circumvent the sadness felt by the hospitalization of their baby in the NICU and, consequently, the fear of being close to him/her, which ended up strengthening them to assume a reference role of care for the baby, based on bond and affection.

Support Group as an (non-)information scenario for family members in the NICU

The group's provision of information enables family members to perceive what they are living in real, through the knowledge of more concrete data about the problem, resulting in an environment that provides clarification of doubts and acquisition of indispensable guidance¹⁹.

The execution of activities in the context of the Support Group aims¹⁹ to mobilize its members for certain objectives, such as verbal orientations, playful resources (theater, games, paintings), construction of posters and brochures, dynamics, among others, strengthening the space as a scenario of construction and sharing of ideas. In addition, having information support works indirectly as emotional support, because the clarification of technical issues related to the NICU context promotes empowerment to family members to deal with this situation.

The discourses revealed the Support Group as a scenario that provides information, through activities such as dynamics, games and film sessions.

They work with various activities, every day, every week, it is always new... We end up learning... I mean, the activity of the Pink October, this thing we do not know about, we end up learning and passing to others (Miracle).

I learned from that little cord activity, it meant that we are no different from each other, each one has the aim to leave with their little child safe and sound (Emotion).

Family members denote that they assimilated the messages objectified by the Group's playful activities, expressing the increase in their knowledge and interest in the search and sharing of information.

Importantly, family members' concerns should be met, receiving information about the health status, treatment and devices used in the baby, since they have distress, due to a situation not understood by the parents. Thus, they signaled the need for the Support Group to address these issues:

I think it should explore more information about the ICU... the Group little addresses it; because there are times when we get stressed, crying, the machine keeps beeping, I do not know what is happening to the child, I get stressed, afraid of what can happen... (Emotion).

See, so far I have seen no information about things there (referring to the NICU)... I think it is very important, I have already suggested it. Because we do not understand everything, we do not know what might happen (Hope).

Thus, the Support Group can be a space to address specific issues experienced by family members and even have sessions elaborated based on the demands of these parents/family.

At this point, it is worth highlighting the importance of inter/multidisciplinary in the Group, because the presence of different professionals in their sessions would culminate in disclosures of information specific to their activities in the NICU, which would enable a diverse knowledge approach, configuring a more informative character to this scenario and, consequently, helping to address the doubts that arise from family members regarding the clinical condition and interventional practices performed in their babies in this sector.

The limitation of this study is the lack of scope in theoretical materials related to the theme, interfering in a better analysis of the possibilities, problems and consequences of such groups, at the time when a discussion is indicated that can permeate the different academic backgrounds in the health area, since we understand the Support Group as a humanized care strategy.

Conclusion

The Support Group presents itself as a scenario of support and care for family members in the NICU, minimizing the feeling of anguish and deprivation of liberty triggered by hospitalization, although the study was limited due to its development in only one sector.

In addition to emotional support, the information conveyed by recreational activities was beneficial, because some family members reported the need to expand their knowledge. However, the Support Group has not yet provided specific information on the baby's care and clinical condition in the NICU. Thus, the multidisciplinary team work together in the Support Group is reinforced, raising among the family members their doubts, questions about the clinical condition of the baby or other elements of the hospitalization unit. In this way, the configuration of the Support Group will be expanded as a scenario that allows a position of prominence for family members, as they choose the themes of the meetings.

It is noteworthy that the Family Support Group is an expanded strategy for various sectors and institutions, at different health care levels, involving patients, family members and professionals in inter and multidisciplinary.

Finally, we understand that this study gives visibility to the Group as a therapeutic effect to the relatives of babies hospitalized in the NICU, reinforcing the need for a sensitive look at the family in this sector.

Author contributions

Morais AC participated in the conception, design, analysis of research data, interpretation of the results and writing of the scientific article. Mascarenhas JS participated in the conception, design, search and analysis of research data, interpretation of the results, writing of the scientific article. Araújo JC, Souza MJ, Amorim RC and Lima IS participated in the analysis of the research data, interpretation of the results, writing of the scientific article.

Competing interests

No financial, legal or political conflict involving third parties (government, companies and private foundations, etc.) has been declared for any aspect of the work submitted (including, but not limited to grants and financing, participation in advisory board, study design, manuscript preparation, statistical analysis, etc.).

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