

Infant sisters and brothers of newborn babies hospitalized in neonatology units: A bibliographic review

Irmãos de bebês de recém-nascidos internados em unidades de neonatologia: revisão bibliográfica

Hermanas y hermanos infantiles de recién nacidos hospitalizados en unidades de neonatología: revisión bibliográfica

Valeria Alejandra Silva-Quintul¹  <https://orcid.org/0000-0002-3644-6456>

Carola Rosas^{1,2}  <https://orcid.org/0000-0001-7693-3278>

Patricia Triviño-Vargas¹  <https://orcid.org/0000-0002-6910-5092>

Tatiana Emperatriz Victoriano-Rivera¹  <https://orcid.org/0000-0002-2403-5756>

Abstract

Objective: To analyze the importance of visits by sisters and brothers of newborns hospitalized in Neonatology Units from the experiences reported in the literature.

Methods: To provide a reflection on the experiences in the world, a review of articles containing the theme of siblings is carried out, selected for the breadth of the study, whether it is quantitative, qualitative or mixed experience.

Conclusion: The importance of the implementation of sibling visits in the various hospital centers lies in its detection as a fundamental factor that reduces parental and family stress, improving the bonds between siblings and communication within the family. The impediments lie in the risk of transmission of microorganisms to patients who have an immature or weakened immune system, together with the internal policies of many centers, which prevent the entry of young children as visitors.

Resumo

Objetivo: Analisar a importância das visitas de irmãos de recém-nascidos internados em Unidades de Neonatologia a partir das experiências relatadas na literatura.

Métodos: Para proporcionar uma reflexão sobre as experiências no mundo, é realizada uma revisão de artigos que contenham a temática dos irmãos, selecionados pela amplitude do estudo, seja quantitativo, qualitativo ou experiência mista.

Conclusão: A importância da implementação da visita de irmãos nos diversos centros hospitalares reside na sua detecção como fator fundamental para a redução do estresse parental e familiar, melhorando o vínculo entre os irmãos e a comunicação dentro da família. Os entraves residem no risco de transmissão de microorganismos a pacientes com sistema imunológico imaturo ou debilitado, juntamente com as políticas internas de muitos centros, que impedem a entrada de crianças pequenas como visitantes.

Resumen

Objetivo: Analizar la importancia de las visitas de hermanas y hermanos de los recién nacidos hospitalizados en las Unidades de Neonatología desde las experiencias que se relatan en la literatura.

Métodos: Para proporcionar una reflexión de las experiencias en el mundo, se realiza una revisión de artículos que contienen la temática de hermanos, seleccionados por amplitud del estudio ya sea experiencia cuantitativa, cualitativa o mixta.

Conclusión: La importancia de la implementación de las visitas de los hermanos en los diversos centros hospitalarios radica en su detección como un factor fundamental que permite disminuir el estrés parental y familiar, mejorando los lazos entre hermanos y la comunicación en el interior de la familia. Los impedimentos radican en el riesgo de transmisión de microorganismos a pacientes que poseen un sistema inmune inmaduro o debilitado, junto con las políticas internas de muchos centros, que impiden el ingreso de niños pequeños como visitas.

Keywords

Siblings; Neonatology; Infections; Pediatric nursing

Descritores

Irmãos, Neonatologia; Infecções; Enfermagem pediátrica

Descriptores

Hermanos; Neonatología; Infecciones; Enfermería pediátrica

Como citar:

Silva-Quintul VA, Rosas C, Triviño-Vargas P, Victoriano-Rivera TE. [Irmãos de bebês recém-nascidos internados em unidades de neonatologia: revisão bibliográfica]. Rev Soc Bras Enferm Ped. 2021;21(1):51-6. Portuguese.

¹Universidad Austral de Chile, Valdivia, Chile.

²Universidade Estadual de Campinas, SP Brazil.

Conflicts to interest: none to declare.

Submitted: January 4, 2021 | Accepted: July 30, 2021

Corresponding author: Carola Rosas | E-mail: carolaros@gmail.com

DOI: <http://dx.doi.org/10.31508/1676-3793202100008>

Introduction

Hospitalized newborn care has evolved. In the past, care units allowed little time for parents to stay and the measures were even more restricted for the rest of the family due to the risk of transmitting infections to newborns, prioritizing health over affective attachment. Currently, several studies have progressively shown that the inclusion of the family⁽¹⁾ is not an additional risk of infections per se and it favors the continuity of the family bond and the subsequent care of the infant.

The mother's visit was first included, mainly for breastfeeding, then the father and grandparents were allowed to visit, but there is still a lag in the case of siblings. The manner in which the family is included in the recovery of newborns varies greatly⁽²⁾ according to the characteristics of infrastructure, number, and training of the personnel, in addition to the conditions of the premature infant.

The presence of both mother and father causes an evident improvement, but the inclusion of the siblings could have further positive repercussions on the family dynamics after discharge, such as lower levels of paternal stress and better bonding between the siblings.⁽³⁾

In Chile, different experiences have been reported on this subject, and each healthcare center allows or restricts the visit of siblings according to its regulations. The Health Ministry recommends to scheduling visits for both siblings and relatives in the event of prolonged hospitalizations.⁽⁴⁾ However, the health center may decide whether to allow it or not and there is little documentation on the experiences in the country. On the other hand, the characteristics of newborn babies always make health centers fear the risk of infections, which is why visits tend to be limited.

This research is part of a project that aims to include family visitation to hospitalized newborn babies in the neonatology unit of a hospital in Chile and consists of a bibliographic review of the available literature that analyzes the evidence and discusses the evolution of the meaning of hospitalization for a child (sister/brother) and their family.

Methods

To reflect on worldwide experiences, a review of literature on the subject of siblings was performed using

as parameters the date of publication, the extent of the study and whether it was a quantitative, qualitative or mixed experience.

The selected descriptors are siblings, neonatology, and infections. Full-text databases such as ScienceDirect and reference databases such as Medline (PubMed) and Scopus were used for the search. All articles were available open access.

The presentation of results was carried out considering five points which have been deductively identified, after literature review. The point regarding the pandemic has also been included as it causes major restriction regarding hospital visits.

Thirty-six out of 45 studies reviewed were included in this work due to their greater affinity with the objective of the review.

Discussion

Evolution of the meaning of newborn hospitalization for a child and his family

Since its appearance in France in 1880 with the invention of the incubator and until today, neonatology has been an area in continuous evolution. The knowledge, equipment, treatments and techniques introduced in the care of newborn infants contributed to the decrease in neonatal mortality rate. At present, the focus is also to guarantee an adequate quality of future life.⁽¹⁾

However, the hospitalization of a child is a complex and, in many cases, unexpected situation which confronts the family with a process that fills them with doubts, making it difficult to predict its course. This mainly affects the parents and they are expected to suffer from some mood alteration such as "symptoms of anxiety and stress through feelings of fright fear due to the events that are experienced in the Neonatal Intensive Care Unit (NICU)".⁽⁵⁾

Parents have the ethical and legal authority to make decisions about the health status of their children, which they can make with professional assessment,⁽⁶⁾ therefore, they must be informed of possible conditions or adverse diagnoses for newborns and their families in a practical way. In turn, the health team should allow parents to participate in "setting goals, decisions, transitions and planning for the fu-

ture”, considering the results that are most important to them⁽⁷⁾ since many times they expect results that are different from those aimed by the health team, related to the quality of care provided.⁽⁸⁾

Both parents have the child’s health status as their main concern, but they also have the added stress of the NICU care and the anguish due to the separation from the rest of their children. The mother’s participation during hospitalization is considered essential for the recovery and evolution of the newborn and it implies long hospital stays, forcing her to distance herself from the rest of her children and the family organization.⁽⁹⁾ Besides, the participation of the parents is influenced not only by the presence of other children at home, but also by personal limitations such as working time, distance from the hospital, and travel expenses.⁽¹⁰⁾

In this way, the parents, especially the mother, are the axis around which the various strategies aimed at promoting the achievement of better care, development, and a better quality of life in the future of newborns and their families are developed. This is encompassed by family-centered care (FCC), an approach to medical care that is based on the association of patients, families, and health professionals whose objective is to empower the patient’s family by promoting direct participation in their care.⁽¹¹⁾ “Participation as a caregiver can take many forms and will vary according to the baby’s medical condition.”⁽¹²⁾

Currently, there are models of care that formalize the implementation of family-centered care and have similarities and differences among themselves, with the joint leadership of the parents being key for their design, evaluation, implementation and expansion.⁽¹³⁾

The inclusion of the rest of the family group has been more restricted, as is the case of siblings, who according to their age have to bear the various consequences of the early hospitalization of the newborn baby due to some serious condition or prematurity, therefore, it is necessary to consider this option within health care because a programmed and assisted inclusion aims to humanize care practices.⁽⁹⁾

Sisters and brothers: their inclusion in hospital visits

Sibling visitation favors family integration and strengthens ties interrupted by hospitalization, reduc-

ing anxiety levels. On the other hand, it allows the development of resilience in the siblings, allowing them to find meaning in the lived experiences and bringing them closer to the particular reality of each family. Similarly, it facilitates the emergence of psycho-social-affective support networks for both children and their parents. In this way, the neonatal care unit can be perceived as a space where the family is given the opportunity of facing the newborn’s hospitalization together.⁽³⁾

Family inclusion in the different healthcare centers varies according to structural characteristics, their particular regulations and the characteristics of the staff. However, despite difficulties related to infrastructure and operating modalities, it has been shown that family-centered practices are not related to the availability of material resources, for example, the skin-to-skin care. On the other hand, there is great variability in the attitudes of the nurses themselves. “It has been argued that each NICU is, in some way, similar to a culture and in some of these Units there are also subcultures in different nursing shifts. Changing a culture is not something simple, if attitudes and personal approaches are not modified”.⁽²⁾

In the same way, leadership is necessary at both hospital and unit level, to allow the development and support of consistent institutional policies and avoid variability in the care provided. The creation of continuing education and training programs for the staff to implement and support family-centered clinical practices is a way to promote it,⁽¹⁴⁾ considering the continuity of staff as an important factor. The use of these strategies should be complementary and the context in which the implementation occurs should be considered.⁽¹⁵⁾

According to the above mentioned, it should be considered that the organizational culture of each establishment has a major influence on any implementation of a new care system since “it allows identifying the barriers and facilitators of change, evaluating its feasibility and designing strategies to promote and sustain it”, at the same time evaluating the “results and impacts on work processes and relationships within the organization”.⁽¹⁶⁾ An important role is played by the individual behavior of health personnel and the quality of the parent-provider relationship, directly influencing the experience of the parents during hospitalization.⁽¹⁷⁾

To do this, the role of the Nursing professional is considered essential throughout the hospitalization. "The nurse is the fundamental link and pillar for the bond between parents and newborn to be produced during the hospitalization process."⁽¹⁸⁾ The caring culture could be a key facilitator for both the presence and participation of the parents, allowing the construction of a family-centered "neonatal care" environment,⁽¹⁹⁾ which is associated with positive impacts on their relationships and well-being.^(20,21)

There are structured visitation programs for siblings in intensive care areas in order to increase the comfort levels of the staff in dealing with children and decrease their resistance to them. "A sibling policy allows the nurse to make sound clinical decisions based on knowledge of growth and development, family systems theory, and the current literature applied in a skilful, supportive, consistent, and individualized way, not only bending the rules when it seems to be justified".⁽²²⁾

An integral part of ensuring high quality services under the approach of the FCC is to provide educational and emotional resources to siblings, who may have the opportunity to receive direct assistance through support groups, storytelling, interactive games, among other activities. A particularly effective approach to support sibling understanding is the social story, which narrates the newborn's hospitalization process from the sibling's perspective, being especially effective for preschool and school-age children. It is intended to be descriptive and explanatory, and it aims to educate siblings about the NICU, help them express their feelings, and improve understanding of why their new sibling cannot return home.⁽²³⁾

One of the most frequently arising questions among parents is what information they should share with their children so as to not increase their anxiety, and the answer is to use a language that is clear according to the age and characteristics of each minor, verifying what the child already knows. "Children should be told the truth or at least they shouldn't be lied to."⁽²⁴⁾ Parents can always be more careful with very young siblings and check on how the visit affects them, as they may have fantasies about the looks of the newborn.⁽²⁵⁾ Another factor to consider is the duration of the hospital stay which could last weeks or months, producing progressive stress on the family.⁽²⁴⁾

Visitation and their relationship with the appearance of nosocomial infections

Nosocomial infections are those that occur during hospitalization and were not present or incubating at the time of hospital admission. They are among the most relevant causes of morbidity, prolonged hospital stay, increased hospital costs and mortality in newborns, especially for premature infants who are at high risk of exposure to infection during hospitalization due to their vulnerable condition and the presence of antibiotic-resistant microorganisms that are common in these settings.⁽²⁶⁾ This risk increases the lower the weight and gestational age at birth. The improvement in survival makes them highly susceptible to infections,⁽²⁷⁾ since prematurity itself is associated with incomplete maturation and/or function of the immune system.⁽²⁸⁾

The importance of balancing sibling visitation with the regulations for infection control is an issue that has been reviewed in some studies, suggest the implementation of forms that allow for the timely detection of any alteration in the health status of visiting siblings. In this sense, the involvement of the families is essential because they are responsible for completing the forms and keeping them up to date.^(29,30) Visits should be encouraged but those who have been exposed to contagious diseases or show symptoms of infectious diseases should be restricted, regardless of their age, and visiting siblings should be up to date with their immunizations.⁽³¹⁾ On the other hand, it is important to explain the basic techniques of infection prevention, such as hand washing.⁽³⁰⁾

Impact of the death of a hospitalized newborn

The saddest and most brutal process of hospitalization is when the newborn cannot survive. The impact of their death on the surviving siblings should be considered because although the experience may have a relatively short time frame, its consequences can last a lifetime, with effects on family communication or greater anxiety. "Professional assistance can be a powerful addition to the range of coping strategies available to families."⁽³²⁾

Creating memories is an important part of the grieving process, and siblings may want to help their

parents create memories in the neonatal unit before or even after the moment of death. "It is important not to miss this bonding time for siblings, as well as for parents and extended family members."⁽³³⁾ Even its consideration in the annual memorial services held by some centers could be beneficial.⁽³⁴⁾

Pandemic 2020

The entire world scenario changed radically during this year due to the global pandemic caused by the SARS Cov-2 virus. Most confirmed COVID-19 cases have been reported in adults, especially older people with comorbidities. According to the available literature to date, children have had a relatively lower rate and a less severe course of infection. In turn, among pediatric patients, the most vulnerable are those cared for in the neonatal intensive care unit, with limited data on the effect of the virus at the fetal level and after birth. Therefore, efforts have been focused on adequate planning and preparation to protect patients, their families, and healthcare staff, and visitor restrictions become relevant. The obtention of the medical history of the visitors must be enforced to ensure that they are healthy, also, they must follow the infection control indications and use the personal protection elements necessary for this.⁽³⁵⁾ In this sense, visitors should follow certain protocols which may vary depending on the evolution of the current situation but will imply a restriction on the continuity of family ties.

The current pandemic is likely to add further stress to both newborns and their families. "Mental health problems are not unique to parents in the home and can affect siblings and other caregivers."⁽³⁶⁾

Conclusion

The reviewed literature provides an account of the transformations undergone by neonatal units. Currently, the approach is to improve the quality of life of the newborn by maintaining the continuity of family ties during hospitalization which requires role transformation, with the nursing professional being a key actor. Staff, family and institutional barriers need to be considered, as they can be overcome if both staff and families are allowed to lead the change. The most

relevant aspects found are the detection and reduction of parental and family stress, the strengthening of ties between siblings and better family communication, which makes space for the expression of feelings and concerns that siblings may have. On the other hand, the main reasons that prevent the implementation of visits are summarized in the danger posed by the transmission of microorganisms and external infections to newborns. It is also considered that many health centers have internal policies that prevent the entry of young children as visitors to their facilities. The evidence shows the need to implement these visits in a targeted manner as a priority of health care, and further informed talks with a solid basis should be carried out to adapt visitation to the regulations of each healthcare center. Finally, the current conditions of the neonatology unit where this approach is intended to be implemented optimally allow its development, perhaps still subject to the evolution of the COVID-19 pandemic.

References

1. Sá Neto J, Rodrigues BM. Tecnologia como fundamento do cuidar em neonatologia. *Texto Contexto Enfermagem*. 2010;19(2):372-7.
2. Montes M, Quiroga A, Rodríguez S, Sola A. Acceso de las familias a las unidades de internación de Neonatología en Iberoamérica: una realidad a mejorar. *An Pediatr*. 2016;85(2):95-101.
3. Balaguer MS, Nieto MA, Peressutti SN. Acercando las Unidades Neonatales Mediante Vínculos Saludables: Visitas Programadas de Hermanos en Neonatología. *Anu investig*. 2018;3(3):128-33.
4. Chile. Ministerio de Salud. Orientaciones Técnicas para la Atención Psicosocial de los Niños y Niñas Hospitalizados en Servicios de Neonatología y Pediatría. Santiago: Ministerio de Salud, Programa de Apoyo al Desarrollo Biopsicosocial; 2011.
5. Guanuchi Y. Nivel de ansiedad en padres/madres de neonatos hospitalizados en neonatología del hospital vicente corral moscoso [tese]. Cuenca: Universidad de Cuenca, Facultad de Ciencias Médicas; 2018.
6. Larcher V. Ethical considerations in neonatal end-of-life care. *Semin Fetal Neonatal Med*. 2013;18(2):105-110.
7. Janvier A, Farlow B, Baardsnes J, Pearce R, Barrington KJ. Measuring and communicating meaningful outcomes in neonatology: A family perspective. *Semin Perinatol*. 2016;40(8):571-7.
8. Webbe J, Brunton G, Ali S, Longford N, Modi N, Gale C. Parent, patient and clinician perceptions of outcomes during and following neonatal care: a systematic review of qualitative research. *BMJ Paediatr Open*. 2018;2:e000343.
9. Lozano D. Control del estrés en los padres de neonatos internados en la unidad de cuidados intensivos neonatales del servicio de neonatología-Hospital Nacional Ramiro Prialé Prialé (EsSalud Huancayo) en el período 2017- 2019 [tesis]. Huancayo: Universidad Continental, Repositorio Institucional - Continental; 2017.
10. Greisen G, Mirante N, Haumont D, Pierrat V, Pallás-Alonso C, Warren I, et al. Parents, siblings and grandparents in the Neonatal Intensive Care Unit. A survey of policies in eight European countries. *Acta Paediatr*. 2009;98(11):1744-50.
11. Susmani K. Certified Child Life Specialists' Perspectives On Supporting Siblings Of Infants In The Neonatal Intensive Care Unit [thesis]. Michigan: Mills College, Education; 2015.

12. Treherne S, Feeley N, Charbonneau L, Axelin A. Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU. *J Obstet Gynecol Neonatal Nurs*. 2017;46(5):737-47.
13. Franck LS, O'Brien K. The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care. *Birth Defects Res*. 2019;111(15):1044-59.
14. Dall'Oglio I, Mascolo R, Tiozzo E, Portanova A, Fiori M, Gawronski O, et al. The current practice of family-centred care in Italian neonatal intensive care units: A multicentre descriptive study. *Intensive Crit Care Nurs*. 2019;50:36-43.
15. Naef R, Kläusler-Troxler M, Ernst J, Huber S, Dinten-Schmid B, Karen T, et al. Translating family systems care into neonatology practice: A mixed method study of practitioners' attitudes, practice skills and implementation experience. *Int J Nurs Stud*. 2020;102:103448.
16. Ramos S, Romero M, Ortiz Z, Vanessa B. Maternidad Segura y Centrada en la Familia: la cultura organizacional de maternidades de la provincia de Buenos Aires. *Arch Argent Pediatr*. 2015;113(6):510-8.
17. Dall'Oglio I, Fiori M, Tiozzo E, Mascolo R, Portanova A, Gawronski O, et al. Neonatal intensive care parent satisfaction: a multicenter study translating and validating the Italian EMPATHIC-N questionnaire. *Ital J Pediatr*. 2018;44:5.
18. Utrilla A, Sellán M, Ramos A, Mateo G. La relación enfermera - padres - neonato desde la perspectiva enfermera. *Rev Cubana Enferm*. 2018;34(3):637-48.
19. Aija A, Toome L, Axelin A, Raiskila S, Lehtonen L. Parents' presence and participation in medical rounds in 11 European neonatal units. *Early Hum Dev*. 2019;130:10-16.
20. Thomson G, Flacking R, George K, Feeley N, Haslund-Thomsen H, De Coen K, et al. Parents' experiences of emotional closeness to their infants in the neonatal unit: A meta-ethnography. *Early Hum Dev*. 2020;149:105155.
21. Flacking R, Breili C, Eriksson M. Facilities for presence and provision of support to parents and significant others in neonatal units. *Acta Paediatr*. 2019;108(12):2186-91.
22. Rozdilsky J. Enhancing Sibling Presence in Pediatric ICU. *Crit Care Clin*. 2005;17(4):451-61.
23. Morrison A, Gullón-Rivera Á. Supporting Siblings of Neonatal Intensive Care Unit Patients: A NICU Social Story™ as an Innovative Approach. *J Pediatr Nurs*. 2017;33:91-3.
24. Beavis AG. What about brothers and sisters? Helping siblings cope with a new baby brother or sister in the NICU. *Infant*. 2007;3(6):238-42.
25. Latva R, Lehtonen L, Salmelin R, Tamminen T. Visits by the family to the neonatal intensive care unit. *Acta Paediatr*. 2006;96(2):215-20.
26. Civardi E, Tzialla C, Baldanti F, Strocchio L, Manzoni P, Stronati M. Viral outbreaks in neonatal intensive care units: what we do not know. *Am J Infect Control*. 2013;41(10):854-6.
27. Legeay C, Bourigault C, Lepelletier D, Zahar JR. Prevention of healthcare-associated infections in neonates: room for improvement. *Journal of Hospital Infection*. *J Hosp Infect*. 2015;89(4):319-23.
28. Cortese F, Scicchitano P, Gesualdo M, Filaninno A, De Giorgi E, Schettini F, et al. Early and Late Infections in Newborns: Where Do We Stand? A Review. *Pediatr Neonatol*. 2016;57(4):265-73.
29. Ivany A, LeBlanc C, Grisdale M, Maxwell B, Langley JM. Reducing infection transmission in the playroom: Balancing patient safety and family-centered care. *Am J Infect Control*. 2016; 44(1):61-5.
30. Horikoshi Y, Okazaki K, Miyokawa S, Kinoshita K, Higuchi H, Suwa J, et al. Sibling visits and viral infection in the neonatal intensive care unit. *Pediatr Int*. 2018;60(2):153-6.
31. Polak JD, Ringler N, Daugherty B. Unit Based Procedures: Impact on the Incidence of Nosocomial Infections in the Newborn Intensive Care Unit. *Newborn Infant Nurs Rev*. 2004;4(1):38-45.
32. Fanos J, Little G, Edwards W. Candles in the Snow: Ritual and Memory for Siblings of Infants Who Died in the Intensive Care Nursery. *J Pediatr*. 2009;154(6):849-53.
33. Jackson C, Vasudevan C. Palliative care in the neonatal intensive care unit. *Paediatr Child Health*. 2020;30(4):124-8.
34. Sandler C, Robinson E, Carter B. Loss in the NICU: sibling matters. *Am J Hosp Palliat Care*. 2012;30(6):1-3.
35. Verma S, Lumba R, Lighter JL, Bailey SM, Wachtel EV, Kunjumon B, et al. Neonatal intensive care unit preparedness for the Novel Coronavirus Disease-2019 pandemic: A New York City hospital perspective. *Curr Probl Pediatr Adolesc Health Care*. 2020;50(4):100795.
36. Lemmon ME, Chapman I, Malcolm W, Kelley K, Shaw RJ, Milazzo A, et al. Beyond the First Wave: Consequences of COVID-19 on High-Risk Infants and Families. *Am J Perinatol*. 2020;37(12):1283-8.