REVIEW ARTICLE

A Review of the Mental Health Care of Families in the Neonatal Intensive Care Unit

María Aurelia González[1] and Jazmín Alfie[2]

1. Servicio de Salud Mental del Hospital Materno Infantil Ramón Sardá. Buenos Aires, Argentina
2. Ministerio de Salud, CABA, Argentina

ABSTRACT

Introduction: This paper reviews practices addressing the perinatal mental health of families hospitalized in Neonatal Intensive Care Units (NICU). Achievements in increased survival of high-risk newborns involve prolonged hospitalization and emotional care of their families.

State of the art: the conceptual framework refers to person-centered care and its perinatal expression in the Safe and Family-Centered Maternity Model (SFCMM). It includes experiences of local and international referents that guide interventions in the field.

Conclusions: the importance of emotional care in highly stressful scenarios is highlighted, given its impact on the care and construction of early bonds between hospitalized newborns (NB) and their primary referents. It mentions psychological risk factors and possible approaches. We propose actions for promotion, prevention, and assistance in this context.

Key words: NICU, family, mental health, perinatal care, neonatology, MSCF.Review.

INTRODUCTION

The family-centered care approach marks a shift from the traditional professional model to care centered on individuals and their family groups. That became visible in the 1980s with Bronfebrenner's ecological theory[1] and consolidated in the 1990s with the Family Centered Care proposal for infants, toddlers, and adolescents[2]. In the local scenario, early contributions in the 1960s by Drs. Carlos A. Gianantonio and Florencio Escardó, heads of pediatric hospitalization areas at the R. Gutiérrez Pediatrics Hospital, set the course positively.

In perinatal care, this paradigm shift manifests itself in the Safe and Family-Centered Maternity Care (FCMC)[3] approach, which recognizes the family as the protagonist during pregnancy, delivery, and puerperium care. The arrival of a child requiring specialized care in neonatology is part of step 5 of the FCMC model[4]. The model proposes to bring back the protagonism of families in highly technological scenarios to: "Facilitate the inclusion of the mother, father and the rest of the family in the neonatal hospitalization" without neglecting the safety component. The increasingly frequent recovery of very premature children, or those with different pathologies, requires the assembly of personalized care from the beginning of life and medical assistance and technological support.

The survival of high-risk newborns (NB) has increased notably, and parental care is consequently a necessary variable to include in this context. According to figures from the Dirección de Estadísticas e Información de Salud (DEIS)[5] that year, 1.1% of live newborns were preterm babies weighing less than 1500 g, which corresponds to 8078 children in that year. The shift in the limit of viability and the implementation of perinatal regionalization[6]

Author for correspondence: jazalfie@gmail.com, Alfie J.

Received: 04/17/23 Accepted: 07/26/23 Online: 09/29/2023

DOI: http://doi.org/10.51987/revhospitalbaires.v43i3.270

How to cite: González Review of the Mental Health Care of Families in the Neonatal Intensive Care Unit. Rev. Hosp. Ital. B.Aires. 2023;43(3).134-138.

ISSN (Online) 2314-3312

entail a particular challenge: the work of Mental Health with high-risk patients.

The gestation and birth of a child are momentous events in personal and family history, with cultural and social resonance. The high obstetric and neonatal risk implies an additional impact and emotional demands[7]. Families are confronted with their expectations of health and integral well-being when facing a Neonatal Intensive Care Unit (NICU) admission. Parental ideals appear threatened, and adaptation to the new situation implies a great challenge of personal and family adaptation. Parents face new demands arising from the challenging process of getting to know their child, governed by personal schedules that vary according to each individual's history. As explained by Gonzalez et al., "The family and social ideal gets shaken, and the expectations of celebration turn into uncertainty about survival" [8].

On the occasion of prenatal diagnoses capable of anticipating neonatal hospitalization or premature birth, families face a disruptive process with emotions that integrate fear, guilt, anxiety, stress, and anguish, among others. These emotions vary in their occurrence according to the personal coping strategies put in place, the defense mechanisms involved, and the new and pre-existing symbolic resources. It is essential to consider the presence or absence of a social or family network, or both, the socio-environmental context and perinatal antecedents, bereavement, previous hospitalizations in the NICU, and similar diagnoses of other children and or family members. It is necessary to know the history of mental health conditions, such as postpartum depression and or anxiety, individual and family, to accompany families in this transition.

Institutions can contribute to better coping according to the practices they adopt and the space they give to the family. Trust in the healthcare team, with timely and adequate information on the baby's condition, are some of the dimensions to consider here.

A newborn's fragility calls for the continuous availability of its caregivers. The baby admitted to the NICU is in an even more vulnerable conditions, as well as his parents and the extended family, who must reorganize their responses in the face of uncertainty. This paper aims to reflect on the family care practices of the hospitalized newborn as a practical guide to thinking about perinatal mental health interventions in the NICU setting.

Lemus Alcántara et al. [9] point out that "health care has been the object of multiple initiatives to improve it, with the particularity of placing quality at the center (...). The approaches, described as innovative and avant-garde, propose changes in form and their interest in modifying the notion of 'patient' (...). Thus, the term 'user' introduces the idea of someone with decision-making capacity". Thus, it is not a simple choice of vocabulary; on the contrary, the terminology used derives from a conceptualization and a way of thinking about the health system, its effectors, and the relationships framed therein.

DEVELOPMENT: MOST FREQUENT PROBLEMS AND MENTAL HEALTH INTERVENTIONS

Various actions aim at caring for the baby and its family environment during hospitalization. Firstly, to facilitate entry and continuous stay of parental caregivers in the NICU.

However, within the framework of child's rights protection and perinatal care, restrictions and visiting hours within these units express institutional barriers based on hospital-centric models[10,11]. Many institutions have the "Mothers' Hospital Residence" device, which allows physical proximity and promotes initial attachment between mothers and their hospitalized children. This action is based on the observation made by R. Sptiz[12], described as hospitalism syndrome, and later by J. Bowlby[13], regarding the impact of isolation and lack of emotional support in institutionalized children or those lacking parental care.

An early example of this preventive action in Argentina is the first Mothers' Residence, organized at the Hospital Materno Infantil Ramón Sardá, around 1986 [3,14,15]. This space-inspired public policy led to similar devices in the main perinatal centers, as is the case today. Mothers thus see the possibility of being involved in the care routines according to the needs of each newborn. Their autonomous status places them as users, not as "patients" of the institution, inaugurating a care category in line with the family-centered approach. In other institutions, without reaching this level of organization, families have physical spaces for meeting and resting during the long hospitalization days.

Parental stress in the NICU is still of interest to neonatology teams today as a factor of impact on the initial development of the NB and the quality of the bond with the parents. The Parental Stressor Scale[16], designed for this purpose, makes it possible to know the degree of stress of the families and the development of strategies for its containment. In studies carried out in our country, there are high scores in perceived stress, particularly in mothers[17,18]. We observed that the highest score in parental stress corresponds to the subscale that measures parental role alteration, a trend confirmed in the multicenter study carried out in twenty-four neonatology units in the South American area[19].

Some recognized authors such as Klaus and Kennell20 and Fava Vizziello21 assign importance to the care of the emotional aspects of parents and primary caregivers in the context of hospitalization at the beginning of life. Gonzalez et al., 22 detailed the topics that most frequently arise in the context of weekly meetings with parents in the NICU, which are interestingly relevant today. They detected the following as recurring themes: the impact of the arrival of a child with difficulties;

concern about weight; reactions such as feelings of unreality, guilt, and narcissistic wounding for a child who requires support from others; the need to reassemble the life project (given the differences between the real baby

and the imagined one); and difficulties communicating with the health team.

The milestones that mark the transition to less complex areas, the achievement of autonomy in their primary functions, such as breathing without support or feeding and discharge from the institution, are difficult to anticipate in timelines. It is essential for parents to feel informed on issues related to their child's progress on an ongoing basis and in accessible language. Konikoff et al.,23 places routine as a crucial element of comfort for adults. The mentioned authors explain that, in the context of hospitalization, adequate information and accompaniment contribute to the possibility of establishing routines inherent to the new dynamics, providing the family with a feeling of greater predictability in a context of concern and uncertainty, which would also contribute to reducing parental stress in the face of the situation. Among the Perinatal Mental Health interventions in conjunction with the health team and within the framework of SFCMM practices, we can mention:

To provide strategies for parental involvement and active participation in the care of the NB during hospitalization.

It is a joint intervention with the entire health team: the Perinatal Mental Health professional and all health team members take care of the parents' mental health by promoting active participation in caring for their children and their continued stay in the hospitalization sector. These actions reduce stress, depression, and anxiety[24] while favoring a better relationship between the child and parents in the inpatient setting. In a context of high medical complexity, parents may believe that the care provided by nurses and doctors is more efficient than their own. The health team, especially Mental Health, accompanies parents in recovering their protagonism, recognizing them as a fundamental part of the care team, starting with simple yet valuable actions such as "gavage" feeding, skin-to-skin contact, and comfort care. As Gonzalez et al.8 explain about care functions: "This transfer of competencies is only transitory and doctors, machines and nurses can never replace the intensity of affection for the young child. The desire for life that animates every newborn human being must always rely on someone else who is not just anyone, someone else who has a fundamental value in their life (...), that is to say, a mother and a father or whoever fulfills this function".

Prioritize the inclusion and accompaniment of the extended family.

There are several actions to rearrange the family dynamics, especially when the family has other children. Admission programs for adult relatives and siblings are a privileged instance to accompany the extended family in the impact caused by premature birth and neonatal hospitalization25. The health team can promote these arrangements with the coordination of the mental health professional. Prolonged hospitalization provides the opportunity to maintain fluid contact with family members and to detect the moment when vulnerability factors that require specific interventions from the mental health point of view are present.

Provide emotional support to the immediate family and assist in finding coping resources.

Inclusion of the Mental Health professional in the NICU contributes to mitigating the initial negative impact of hospitalization. Uncertainty regarding diagnosis and prognosis is a source of confusion and anxiety for parents. The role of this professional in the team is to provide skilled listening to the emotional aspects involved, with the necessary support and accompaniment of these. As mentioned above and in conjunction with the efforts of the entire health team in this direction, the Mental Health professional collaborates in the recognition of the parents in their role as primary emotional referents for the NB in the NICU, highlighting the non-transferable quality of their emotional care for the child while receiving medical care and technological assistance.

In addition, the Mental Health professional offers as a mediator to identify (and in other cases discover) the subjective resources of each caregiver or family, which can sustain the needs of an infant with vulnerabilities at such an early stage by assisting in the search for coping resources. Often, including the extended family is a protection factor for the parents, overwhelmed by the urgency and the institutional routine. In close relationships, they find the containment or support they need.

It also facilitates the representation of shared family care and medium and long-term support actions, which involves raising infants with specialized follow-up needs, as is the case of prematurity and various pathological conditions.

Early identification of situations of psychological distress in primary caregivers of the NB.

Intervention is not limited to the short-term; it also produces its effects in the "long term" by facilitating the basis for a healthy early bond between parents and children. The timely listening to warning signs is fundamental in the clinic with families in the NICU and contributes to preventing more severe psycho-pathological conditions.

Detection of mothers with psycho-social risk factors.

Among those most frequently mentioned are prior perinatal mourning (especially those with emotional compromise); mood disorders (e.g., perinatal depression or anxiety as the most prevalent); personal and or family history of psychiatric disorders; violent situations of different categories (requiring specific intervention); adolescent motherhood, unplanned pregnancy, and absence of family or community networks.

Teamwork among the different services of the institution and intersectoral articulation favor the protection of rights and intervention in social and

health conditions when necessary and or appropriate before discharge. The identified risk factors are not per se indicators of psychopathology. They require identification and development of proposals with a preventive and health promotion approach. An integrated approach is essential for planning family care since it is helpful for perinatal care. The MSCF model establishes this with the proposal of interdisciplinary teams in the different instances of prenatal care, care of the healthy newborn, neonatal hospitalization, and specialized pediatric follow-up programs (especially in at-risk newborns).

Accompaniment during bereavement and articulation with networks.

The death of a child is an event that shocks the family in the first place and the health team as well. Parents and relatives may resort to denial as a first defensive reaction; grief is a process that goes through different stages or steps through which they can acknowledge their pain and concern for the newborn's suffering 26,27. The participation of the Mental Health professional accompanies this process, articulating the communication of the health team with the parents and their close environment. The intervention is of respectful accompaniment of the cultural and religious beliefs and the psychic times of the persons involved. Siblings, grandparents, and emotional references are involved in the farewell that begins in the NICU. The Mental Health professional coordinates these actions with nursing and medical support in the context of the care required by the hospitalization service. It is advisable to provide the contact information of the Mental Health Service in case they later opt for a therapeutic space. Another resource to consider is the articulation as a network with other providers.

CONCLUSION

We can conclude that comprehensive follow-up in perinatal mental health is essential, particularly during NICU hospitalizations. The keys to care listed in this article include active listening and respect for each family's uniqueness, cultural frame of reference, and any particularities resulting from it. The model framework for research and therapeutic intervention with these families is the positioning of an organizational culture of Safe and Family Centered Maternities, which proposes humanized, personalized care, hand in hand with scientific and technological progress, a proposal that overcomes false antinomies28. Parents are not visitors in the NICU; their role as protagonists in their r children's recovery requires health teams that are increasingly involved in this philosophy of care.

Conflict of interests: the authors declare no conflict of interests

REFERENCES

1. Bronfenbrenner U. The ecology of the family as a context for human development. Dev Psychol. 1986;22(6):723-742. https://doi.org/10.1037/0012-1649.22.6.723.
2. Shelton TL. Family-centered care in pediatric practice: when and how? J Dev Behav Pediatr. 1999;20(2):117-119. https://doi.org/10.1097/00004703-199904000-00008.
3. Larguía AM, Lomuto CC, González MA, eds. Guía para la transformación de maternidades convencionales en maternidades centradas en la familia [Internet]. Buenos Aires: Fundación Neonatológica para el Recién Nacido y su Familia; 2006 [citado 2023 abr 17]. Disponible en: http://www.funlarguia.org.ar/Herramientas/Guia-para-transformar-maternidades-tradicionales-en-maternidades-centradas-en-la-familia.
4. Ortiz Z, Larguía AM, González MA, et al. Maternidad segura y centrada en la familia (MSCF), con enfoque intercultural [Internet]. 2ª ed. Buenos Aires: UNICEF Argentina; 2012 [citado 2023 abr 17]. Disponible en: https://www.unicef.org/argentina/media/346/file/MSCF.pdf.
5. Argentina. Ministerio de Salud. Natalidad y mortalidad infantil: Argentina – año 2021 [Internet]. Buenos Aires: el Ministerio; 2023 [citado 2023 abr 17]. Disponible en: https://www.argentina.gob.ar/sites/default/files/natalidad_mortalidad_infantil_2021.pdf.
6. Argentina. Ministerio de Salud. Recepción, estabilización, traslado y admisión en la unidad neonatal: recomendaciones y lineamientos prácticos [Internet]. Buenos Aires: el Ministerio; 2019 [citado 2023 abr 17]. Disponible en: https://bancos.salud.gob.ar/sites/default/files/2020-09/atencion-prematuros-1.pdf.
7. Alfie J. Una reflexión sobre la diversidad en las maternidades y los servicios de neonatología: acerca de la diversidad en las maternidades. En: Trimboli A, Grande E, Fridman P, comps. Amor y deseo: clínica y política de la diversidad en salud mental. Buenos Aires: Asociación Argentina de Profesionales de Salud Mental – AASM; 2022. p. 36-38.
8. González MA, Larguía M, Lomuto C. Contención de padres en crisis: comunicación y manejo de los padres de recién nacidos en riesgo de morir. Rev Hosp Matern Infant Ramón Sardá. 2007; 26(4):177-181.
9. Lemus Alcántara S, Hamui Sutton A, Ixtla Pérez M, et al. Una mirada crítica sobre la noción: paciente/usuario/cliente desde la antropología en salud. Rev CONAMED. 2017;22(2):98-103.
10. Argentina. [Ley Nacional 27.611]: de atención y cuidado integral de la salud durante el embarazo y la primera Infancia. Bol Oficial Rep Argentina. 2021 ene 15.
11. Argentina. [Ley Nacional 25.929]: derechos de padres e hijos durante el nacimiento. Bol Oficial Rep Argentina. 2004 sept 21.
12. Spitz RA. Hospitalismo: solicitud de la génesis de condiciones psiquiátricas en temprana niñez. Estudio Psicoanalítico de Niño. 1945;1:53-74.
13. Bowlby J. Los cuidados maternos y la salud mental. Washington, DC: Oficina Sanitaria Panamericana; 1954.
14. Dunst C, Trivette CM. Capacity-building family-systems intervention practices. J Fam Social Work. 2009;12(2):119-143.
15. González MA, Scarpello YP, Borra ME, et al. Dispositivo de planificación familiar en la residencia hospitalaria para madres de niños internados. Rev Hosp Matern Infant Ramón Sardá [Internet]. 2018; [citado 2023 abr 17];2(3):80-90. Disponible en: https://www.sarda.org.ar/images/2018/2.%20Original.pdf.
16. Miles MS, Funk SG, Carlson J. Parental Stressor Scale: neonatal intensive care unit. Nurs Res. 1993;42(3):148-152.
17. Ruiz AL, Ceriani Cernadas JM, Cravedi V, et al. Estrés y depresión en madres de prematuros: un programa de intervención. Arch Argent Pediatr. 2005;103(1):36-42.
18. González MA, Naddeo SJ. Niños internados desde el comienzo de la vida: internación neonatal y salud mental. Rev Hosp Matern Infant Ramón Sardá. 2007;26(4):155-158.
19. Wormald F, Tapia J, Torres P, et al. Estrés en padres de recién nacidos prematuros de muy bajo peso hospitalizados en unidades de cuidados intensivos neonatales: estudio multicéntrico. Arch Argent Pediatr. 2015;113(4):303-309.
20. Klaus M, Kennell JH. La relación madre-hijo. Impacto de la separación o

pérdida prematura en el desarrollo de la familia. Buenos Aires: Médica Panamericana; 1978.
21. Fava Vizziello G, Zorzi C, Bottos M. Los hijos de las máquinas. Buenos Aires: Nueva Visión; 2003.
22. González MA, Dinerstein A, Boccacio C, et al. Problemática de los padres de recién nacidos asistidos en unidades de cuidados intensivos: abordaje interdisciplinario. Arch Argent Pediatr. 1996;94(3):178-182.
23. Konikoff L, Triluzi, B. La comunicación con los padres de recién nacidos internados en la unidad de cuidados intensivos neonatales. Buenos Aires: PRONEO. Programa de actualización en Neonatología; 2019. Ciclo 20. Módulo 2. Unidad 5, p. 135-152.
24. González MA. Cuantificación del estrés, depresión y ansiedad en madres de recién nacidos internados en UCIN. Presentado en: 1º Congreso Argentino de Neonatología. Sociedad Argentina de Pediatría; 2010 sept 9- oct 2; Buenos Aires, Argentina.
25. Balconi F, Álvarez M, Pastorino M, et al. Visita de familiares a una unidad de cuidados intensivos neonatales en un hospital público materno infantil de la Ciudad de Buenos Aires. Rev Hosp Matern Infant Ramón Sardá [Internet]. 2022 [citado 2023 abr 17];7(1):e1-16. Disponible en: https://www.sarda.org.ar/images/2022/3_original_Visita.pdf.
26. Ruiz AL. El bebé prematuro y sus padres: creación de un Programa de Intervención Psicológico implementado en las Unidades de Cuidados Intensivos Neonatales. Buenos Aires: Miño y Dávila; 2005.
27. Mariani G, Arimany M. Decisiones en reanimación y cuidados de fin de vida en neonatos: aspectos bioéticos (parte I). Arch Argent Pediatr. 2023;121(1):e202202635. https://doi.org/10.5546/aap.2022-02635.
28. Larguía AM, González MA, Dinerstein NA, et al. Perinatal programming prevention measures. Adv Neurobiol. 2015;10:425-441. https://doi.org/10.1007/978-1-4939-1372-5_20.