

The importance of parents in the neonatal intensive care units

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From the womb to the adult

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“We are premature parents... just like our premature baby”
Anonymous mother of a preterm newborn admitted in a NICU

Keywords

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The premature birth and the hospitalization in a neonatal intensive care unit (NICU) are potential risk factors for the development and behavior of the newborn, as has been shown in recent studies [1-11]. Premature birth of an infant is a distressing event for the family. Several feelings are experienced by parents during hospitalization of their baby in the NICU. Feelings of guilt, rejection, stress and anxiety are common. Also the attachment processes have the potential to be disrupted or delayed as a result of the initial separation of the premature newborn and the mother after the admission to the NICU. Added to these difficulties, there is the distortion of infant's "ideal image", created by the family, in contrast with the real image of the preterm. Family routines change, having impact on sisters and brothers, and on the relationship between the couple. In this way, the importance of assessing and giving support to the maternal feelings is fundamental.

This relationship-based family-centered approach, the Neonatal Individualized Developmental Care and Assessment Program (NIDCAP), promotes the idea that infants and their families are collaborators in developing an individualized program to maximize physical, mental, and emotional growth and health and to improve long-term outcomes for the high risk newborns. In this philosophy of care many practical aspects must be followed: to respect the babies and their families honoring the racial, ethnic, cultural, and socioeconomic diversity, to recognize and build on the strengths of each child and family, to share honest information, to collaborate with families at all levels of health care, and to empower each child and family to discover their own strengths, build confidence, and make choices and decisions about their health.

Although parents are viewed as playing a significant role in early intervention programs, little attention has been given to parenting beliefs, emotions and behaviors as either outcomes or mediating pathways to child development. The COPE (Creating Opportunities for Parent Empowerment) NICU Parent Program is an educational-behavioral intervention program for parents of preterm babies. It is designed to begin very early in the course of the NICU admission and extends after discharge. It consists of educational audio visual and written information and reinforcing activities for parents. Mothers receiving this program had less maternal stress as well as less anxiety and depressive symptoms

during the NICU stay and after discharge. COPE program might prevent more long-term negative developmental and emotional outcomes for prematurely born children as well as their parents.

Communication and information sharing have been underlined as critical needs of families in newborn care. Nowadays, in spite of many NICUs having adopted a family-oriented model care, parent's communication needs are not always successfully met by the professional team. Parents might remain dissatisfied with their involvement in care, physician-parent communication, and availability of information. So it is necessary to improve the parent-staff communication. The presence of parents on rounds emerges as a key component of Family Centered Care and is a strategy recommended by the professional organizations to improve communication and collaboration between families and professionals. It must be seen as an additional and complementary structure of communication.

The unlimited parents' presence is crucial in NICUs, to allow them to participate in the care of their children, improving their outcome. Other family members, namely siblings and grandparents should also visit the babies.

The participation of parents in care and decision making of their newborns is increasing in recent decades, changing between 8 and 20% in a recent European study. This rate is very low and all NICUs must develop efforts to include parents in decisions and discuss with them the clinical situation of their babies.

Neonatal palliative care is a developing model of care aimed at providing supportive services to families anticipating neonatal demise, providing an opportunity to alleviate suffering and stress. Studies show that end-of-life experiences are variable and inconsistent. In our NICU, in last decades we observed an improvement in practices of end-of-life care for newborns with terminal diseases. The offer of palliative care increased from 0.1% three decades ago to 30% recently. Usually death in NICU has a brief course, but consequences for parents and siblings (born before or after the death of an infant) can be life-long. The support of all health professionals including the psychologist, in the NICU and after discharge, is fundamental. Nowadays each NICU must develop the better methodology to offer neonatal palliative care.

When a death of a newborn occurs, parents experience one of the most profoundly distressing

events. It is not easy for professionals to face these situations; however respectful care for parents suffering neonatal loss is mandatory. NICU professionals with their knowledge and experience help parents to overcome these difficult moments. If parents wish may accompany their babies in death. The parental presence during the moment of death increased in our NICU from 26% to 78% in last three decades. Necropsy results must be discussed with parents, and all support must be given in NICU and after discharge. The NICU staff emotional support is fundamental. A psychologist must be a part of the NICU team, contributing to an accurate care in development and behavior of the infant. The empathy between the psychologist, medical team and families is the key of success to the best results in developmental care.

Parents to parents support is being more and more important and each country must develop efforts to create parents associations. They contact the families having a preterm baby in a NICU, promoting dialogue, and helping them to support moments of crisis. These organizations can be part and have an organizational support of the European Foundation of Care of the Newborn Infant (EFCNI).

Most of NICUs receive from families several gifts, namely photos, postcards, visits after discharge, and thank you letters, newspapers articles and praises, corresponding to the public recognition of the work of all professionals.

In conclusion, we can say that the presence of parents in NICUs and their involvement caring their babies, in a family centered care philosophy, is vital to improve the outcome of their infants and the relationships within each family.

Declaration of interest

The Author declares that there is no conflict of interest.

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