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Communicu

Soft Skills Training

COURSE 1 - MODULE 1: EXTRA THEORY

Communicating Complex Medical Content

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In 2012, the World Health Organization identified prematurity as one of the world's public health problems. Premature infants, more accurately defined by the scientific community as preterm infants, are all babies born 37 weeks before gestation.[1]

This category of infants, especially if they are born before 32 weeks gestational age and with birth weight at or below the 10th percentile (infants small for gestational age), are not sufficiently developed to cope independently with life outside the womb and require additional care and attention.[1]

According to the gestational age, preterm infants can be classified into several categories[1]:

- Extremely preterm: born before 28 weeks of gestation.
- Very preterm: born between 28 and 31 weeks + 6 days.
- Moderately preterm: born between 32 and 33 weeks + 6 days.
- Late preterm: born between 34 and 36 weeks + 6 days.

Birth weight is another critical parameter for classifying preterm infants[2]:

- Low Birth Weight infant (LBW): weight between 1500g and 2499g at birth.
- Very Low Birth Weight infant (VLBW): weight between 1000g and 1499g at birth.
- Extremely Low Birth Weight infant (Extremely Low Birth Weight, ELBW): weight less than 1000g at birth.

Postnatal adaptation to extra-uterine life is a complex process in preterm infants. Therefore, appropriate neonatal resuscitation supports the transition, which promotes pulmonary respiration and cardiovascular development.[3]

The more severe the prematurity, the higher the number of interventions necessary at birth. Generally, a late preterm infant needs minimal procedures or may not need any interventions at all, whereas a moderately preterm infant may need more ventilation support. More extreme gestational ages, on the other hand, usually require resuscitative maneuvers starting with respiratory support.[4]

In the event of a possible preterm birth and before it occurs (if the birth does not happen in an emergency), parents are meant to receive counseling from healthcare professionals regarding the possibility of having to sustain neonatal adaptation through resuscitation. In addition, according to the European Resuscitation Council Guidelines, parents are invited to be present during the resuscitation process and will receive a report when this is concluded.[5]

It is beneficial to provide parents with clear and straightforward information about the diagnosis and prognosis, preferably with the assistance of a cultural mediator, if needed. As much time as possible should be dedicated to explaining the situation and collecting any concerns and expectations.

Therefore, it is strongly recommended to use 2 communication strategies with parents:

1. NICU consultations[4]
2. Department meetings: During these meetings, caregivers will receive cards with contact information for their newborn's healthcare team and details about the rotation system, ensuring they always know which clinician to contact[6]

Both of these strategies emphasize the importance of regular and structured communication opportunities between healthcare professionals and parents to improve satisfaction and collaboration in the NICU.

These activities should be co-managed by the NICU Health Coordinator, a neonatologist, and a psychologist experienced in managing trauma such as preterm birth.

The counseling activity is aimed at the parent or parents. Still, it can also include meetings dedicated to only one of the parents (due to the unavailability of the other or the higher sensitivity of one of the parents compared to the other); parents or the medical staff can request this.[7]

Often, in cases of risk of preterm delivery, psychological counseling is activated directly from the Obstetrics and Gynecology Department while the woman is still pregnant. Otherwise, it may be requested by the medical nursing team of the NICU for potential parental care at birth or in the subsequent hospitalization.[8]

Weekly meetings, on the other hand, usually target the group of parents who are about to have a preterm baby or who have their infant already admitted to the NICU. In the weekly meetings, information regarding the characteristics of premature infants is given, together with organizational and structural aspects of the ward, to foster a better understanding and ownership of the care process, from which, at times, parents may feel excluded.[7]

Meetings give parents a chance to socialize with other parents who may be experiencing similar situations in the NICU to get support from each other and the healthcare staff. This helps build strong connections. Medical and nursing staff should listen actively, but also ensure understanding of the information and behaviors presented.[8]

Premature birth is a traumatic experience for parent or parents as it disrupts the physiological journey of the pregnancy, the anticipation, and the idealization of the expected arrival. Prematurity brings with it an abrupt interruption of the fetus's growth and developmental processes and the psychological fluctuations underlying the transition to parenthood, characterized by continuous emotional and psychological transformations that result in the development of new mental models associated with the construction of the parental role.[9]

The nine months of pregnancy allow for complete fetus to newborn development while allowing the parent or parents to fully prepare for the upcoming role in childcare. Failure to carry the pregnancy to "full term" may induce feelings of self-blame, fear, and helplessness, at times undermining the emotional connection, the individual skills of the caregivers, and often the couple's relationship.[8]

The issues addressed in the counseling activities and weekly meetings can be revised from time to time with the parents to address their specific concerns and cope with their difficulties Still, at the same time, they should consider some "pivotal" points in the parents' experiences during their prematurity journey: the stress over their newborn's clinical condition and the fear of grief and loss, the highly technological and unfamiliar environment of the NICU; and the alteration of their parental role.[8]

Literature highlights the extreme pain experienced by parents of children with severe prematurity and an attitude focused on addressing the issues rather than taking care of their newborn. Still, it is equally valid that even parents of "traditional preterm infants" (34-36 weeks) present significant risks of emotional distress (anxiety and depression).[10]

There are some recurring feelings in the stories of parents who go through the NICU experience: fear of death, post-trauma stress, blame, perception of unmet expectations and difficulties in "bonding" with the child, separation from the child, and the possible sense of disconnection. Some words are recurrent in the stories of the parents of preterm infants, like fatigue, anxiety, inadequacy, unpreparedness, guilt, and helplessness. These feelings should be embraced and acknowledged. In each parent's experience, personal and family history should always be considered because both pregnancy history and birth experiences are key factors.[8]

The historical period of the COVID-19 health emergency also affected parents' perceptions and narratives. As much as the National Neonatology societies guidance is to leave the NICU open at all times so that parents can access it without hourly restrictions, difficulties have indeed emerged related to possible COVID-19 positivity, with forced removal from the NICU (even for mothers admitted to Obstetrics and Gynecology).[11]

To overcome these difficulties and in line with the evidence regarding the clinical effectiveness of remote interventions, the consultancy activity must not be interrupted but rather continued remotely.[12]

Along with addressing parents' well-being, clear medical information about preterm birth and the development of preterm children should be provided. It's important to give this information honestly to avoid misunderstandings or false hopes, but at the same time treated with extreme consideration.[8]

There is literature indicating that parents may experience stress while in the NICU. It is imperative to allow parents to express their feelings when interacting with their newborns, including their first impressions (visual and tactile), the ways they cope with barriers (such as the glass of the incubator, wires, and medical equipment), and the less visible obstacles, like fear and feelings related to the separation process. This process often involves a disconnection from their newborn.[4]

Remember that due to the diversity of personal clinical histories and clinical conditions of the fetuses, as well as issues related to language barriers and skills of each parent, an individual counseling setting, where people can have a dedicated space, is often more functional. We will cover this topic in more detail in Course 4. Remember, parents of preterm infants born before 28 weeks of gestation should be aware that their baby may appear more vulnerable and less developed than a full-term infant and will likely need substantial medical intervention, including machines, to help them survive and grow. Parents also need to be instructed about the risks of death or explained the long-term consequences concerning the child's premature condition. These very same issues are much better mitigated when described to parents of a baby born between 28 and 32 weeks, while they risk becoming unnecessary and misleading for parents of a premature baby born after 32 weeks, who, in the clear majority of cases, is guaranteed survival and absence of long-term consequences.[4]

All interventions should provide parents and their families with a feeling of safety by trying to reduce risk factors towards developing psychopathologies or dysfunctional relational dynamics that would negatively impact the development of the preterm infant.

Spaces in the NICU should be organized considering the healthcare professionals need to assist the parents and carefully consider the health needs of the infants and their families. As much as possible, close contact between parents and newborns is facilitated through access to the NICU during the day and by skin-to-skin contact. Psychologists are also present in the NICU to offer support to parents going through this new experience, which often happens in unexpected and difficult circumstances that involve a lot of emotional energy.

The NICU is known to be a stressful place for parents. The bright lights, the noise from the machines, and the smell of medication all add to their stress. This environment can make it hard for parents to connect with their newborn.[4]

Mothers often face a sudden and forced separation from their newborns, experiencing a postpartum period that is very different from what they expected. Many did not attend preparatory courses or receive counseling about preterm birth, which could have helped them cope better.[8]

Premature birth is a traumatic event that disrupts a woman's pregnancy and adds stress to the couple. Due to medical advancements and ongoing improvements in psychological support, efforts are being made to guide and support families through this challenging journey, which is often filled with feelings of inadequacy, guilt, anxiety, and high stress.[8]

From this perspective, the clarity regarding the newborn's condition and first moments of interaction between the baby and parent can increase the perceived sense of self-efficacy in order to facilitate deep connections with the newborn.[13]

Respecting each fragile and vulnerable newborn places them and their families at the heart of the care process. Neonatal care involves all the actions taken to look after newborns. A key part of this care is postural care, which means paying special attention to how the preterm infant is positioned (prone, supine, or otherwise on the side) since posture is of primary importance for neuromotor development, stimulation of respiratory function, prevention of stress and facilitation of sleep.[14]

Processing the trauma of preterm birth does not mean forgetting: the goal is to integrate this experience into one's life by considering it a family strength. All resources must be activated, supported, capitalized, and developed for this to happen.

In recent years, studies have focused not only on the mother's well-being but also on the parental couple and the triad, with a clinical perspective on recognizing psychopathologic signs, both maternal and paternal, that may develop in the experience of prematurity. Trends are moving toward understanding and involving the parents in screening and support activities.[8] In this way, the paternal emotional experiences are being taken into consideration, actively involving the father from the earliest stages of life, suggesting he perform various tasks (interfacing with healthcare professionals, making decisions, communicating with family members, having first contact with the newborn) since the mother is often bedridden to recover from a birth characterized by complications.

The latest trend is "zero separation", a campaign promoted by EFCNI (European Foundation for the Care of Newborn Infants), which aims to keep caregivers always close to their infants.[15]

The parents' continuous participation in the newborn care, their interaction with the baby, and the opportunity to achieve skin-to-skin contact significantly increase the health benefits of the newborn. Family-centered care reduces pain, stress, and sepsis incidence; it promotes better cardiovascular stability improves sleep, and breastfeeding rates. It increases parental confidence about their role and strengthens the parent-child relationship and bond; altogether, this promotes reduced length of hospitalization, lower incidence of re-hospitalization, and improves neurodevelopment.[16] The clinical practice then teaches that each parental couple and family is unique. Therefore, it should be approached differently, also taking into account that in the experience of prematurity, parents are not always biologically related to the newborn, just as families may include one or more parents and parents of the same or different gender.[17]

In 2015, in a special issue of the Journal of Perinatology, guidelines developed by the U.S. National Perinatal Association (NPA) focused on psychosocial support of parents with newborns in the NICU. These are recommendations developed by a working group including parents of hospitalized newborns and a multidisciplinary team of healthcare professionals. Although these guidelines are based on a U.S. perspective, it is believed that they can then be examined and used flexibility by different healthcare professionals in other parts of the world, considering the differences in their care system and the situation of their realities.[18]

From these recommendations emerges the need to make the dedicated mental health staff part of the team: NICUs with at least 20 beds should have a reliable and available psychologist (part-time or full-time) and consider involving the psychiatrist and psychiatric nurses.

At the same time, contact between these healthcare professionals and parents should take place from the first days of hospitalization to normalize the emotional distress they are experiencing.

The types of interventions envisioned go in the direction of a multi-level approach. From the systematic support and education/coaching that all these parents can benefit from - with respect towards their newborns' needs - to the structuring of interventions aimed at early detection of the risk of developing psychopathology during these experiences and also at the implementation and materialization of actual clinical treatments. The review presents suggestions on how to conduct the screening and, because of the continuous work, suggests psychological support for parents; it values telemedicine interventions that can be highly functional to the specific needs of these families who often use social media to seek comfort and information.[18]

When the assistance is focused on the family or a family-centered care model is introduced, parents take a leading role as better observers of their newborn and acquire skills in caring for their child.

A “frame” intervention that aims at parental welfare and the entire family system is the opening of NICU departments 24 hours a day.[19]

Kangaroo Mother Care (KMC) is the care of the preterm infant placed skin-to-skin on the parent’s chest, and its widespread use worldwide is a tangible example of the parents’ active role in neonatal care today. KMC is a simple and effective method for promoting the healthcare and well- being of the newborn. It was developed in 1978 in Bogotá by Dr. Edgar Rey Sanabria in response to the many premature births in healthcare facilities lacking incubators. The literature has highlighted the effectiveness of this approach in fostering parent-child bonding and early maternal involvement, early breastfeeding, good thermoregulation, fewer aspirations and regurgitations, improved stability of cardiorespiratory parameters, faster adjustment to extrauterine life, and enhanced humanization of neonatal care. Thus, KMC represents care for the infant. Still, at the same time, it helps facilitate parents’ contact with their newborn by fostering the connection that is often hindered by the rigid environment of the NICU.[16]

The development of the model of care centered on the newborn’s developmental needs and the family’s decisive role has also led to new organizational requirements in the NICUs.

Therefore, the role of design and management of spaces reserved for the care of tiny newborns is gaining increasing significance, introducing neonatology to architecture, the study of building materials, and the practical use of technology. The architectural design of a NICU that the FCC model inspires seeks to encourage privacy (e.g., through “single-family rooms,” that represent a space designated for the infant and their family, separated from other rooms) and the presence of dedicated areas for parents (relaxation room, kitchen, milk- pumping room) protected from visual and acoustic stress.[4]

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