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The Swedish approach to nurturing extremely preterm infants and their families: A nursing perspective

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ABSTRACT

Nurturing extremely premature infants is a complicated task that not only necessitates a systematic approach to the immature physiology and its medical management, but also to the needs of the family. Infants born at 22-24 weeks require many weeks of intensive care including a long duration of mechanical ventilation, numerous stressful medical interventions, and for the parents to spend a lot of time in the Neonatal Intensive Care unit (NICU). This paper aims to outline the Swedish nursing approach to nurturing these infants and their families. The nursing care is structured so the parents are the primary caregivers supported by the staff and is based on: timely expression and provision of mother's own breast milk, early and prolonged skin-to-skin contact and close collaboration with the family. While this presentation is based on a single-center's experience, it well represents the general features of nursing provided to extremely preterm infants in Swedish NICUs.

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Introduction

The neonatal intensive care unit (NICU) is a place of profound emotions, intense communication, important decisions, and the forming of life-long bonds and relationships. While decisions and management that are strictly medical are highly important, they interact with numerous care procedures and societal aspects to impact short- and long-term outcomes. Naylor et al.¹ wrote that "thinking about the NICU as a medical care unit is limiting and renders invisible the multiple and jointly enacted forms of care practice that occur in this space". The care of preterm infants has moved progressively from what we do to how we do it.²

In the last decade, around the world, infant-centered care has been replaced by family-centered and later by family-integrated care. In fact, family-integrated care has long been the norm in Sweden. The principles of family-integrated care include free unlimited parental access to the NICU, skin-to-skin contact (SSC), lactation and breastfeeding support, and staff-parent interaction.³ Although well established, the application of these principles are more challenging in the tiniest infants. The aim of this paper is to discuss selected aspects of family-integrated care that are relevant to extremely premature infants, in relation to various features of their medical management. The description is based on the nurses' perspective and on the authors' clinical experience from the NICU at Uppsala University Children's Hospital

The reported work was performed at University Children's Hospital, Neonatal Intensive Care, Uppsala, Sweden.

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in Sweden. The unit is a regional referral center covering all neonatal intensive care at the lowest gestations for a population of approximately 2.1 million and 23,000 annual births. The NICU has open-bay intensive care rooms with four care spaces, separated by privacy screens. Each care space has an adult bed encouraging parents to stay with their infants 24 h per day, and to be used for skin-to-skin care (SSC), interchangeably with a radiant warmer bed, or an incubator. Visits from siblings and/or other relatives are unrestricted. Both parents have the right to tax-financed compensation for lost income enabling them to stay with their infant for the duration of the hospital stay. Families (both parents and siblings) are, to the extent possible, offered accommodation at the NICU or at the assigned family hotel close by.

Early and prolonged skin-to-skin contact

The evidence supporting the use of SSC in preterm infants is solid.⁴ SSC promotes optimal brain development in preterm infants, facilitates supportive positioning, and parent–infant bonding.⁵ Although data is somewhat more limited in extremely preterm infants, it is reasonable to assume that the many benefits of SSC^{6,7} can be applied also to this group. Early initiation of SSC has been shown to increase the time parents spend in the NICU as well as the duration of SSC.^{8,9} Although extremely immature infants are at particular risk for hypothermia,¹⁰ SSC allows for thermal stability and normothermia when instituted as early as toward the end of the first week of life.¹¹ Parents of extremely preterm infants describe SSC as calming,¹² sincerely meaningful, supportive of their emotional ties to the infant, and critical to feeling like parents.^{13–15} Parents can also experience SSC as exhausting and stressful¹⁵ but most often find it worth the effort.¹⁵ Staff experience and attitude are critical to the support and encouragement parents need to be able to care for their extremely preterm infants' skin-to-skin. Staff in NICUs with an established tradition of applying continuous SSC are more positive and confident about this model of care, also in unstable infants.¹⁶

Our institutional guidelines for SSC with infants below 25 weeks' gestation (Table 1) stipulate:

- a) The attending neonatologist makes an individual assessment on when the infant's clinical status, particularly regarding skin condition, fluid balance, and thermal stability, allows initiation of SSC.¹¹ In selected cases, it is not

uncommon for SSC to be instituted as early as postnatal day 3. Umbilical lines don't restrict initiation of SSC;

- b) A standardized method to be used for the transfer between incubator and parent using a custom-made wool cape to swaddle the infant. The transfer between incubator and parent is critical for SSC performance in terms of both safety and heat maintenance.^{11,17} By lifting (rather than carrying) the infant, moving the incubator away and bringing in the parent bed, the risk of dislodging the endotracheal tube or umbilical lines, is minimized, without disconnecting the infant from respiratory support (Appendix 1). The prone position is preferred and, in most instances, the total time for transfer is 3 minutes or less;
- c) Continuous monitoring of skin temperature by a cutaneous temperature probe to limit any disturbance in the immediate care environment; and
- d) A minimum of 2 h of SSC. During SSC heat is exchanged via conduction with a small temperature gradient. Thus the efficiency of heat transfer is low; if hypothermia occurs, the return to normal body temperature will take time.¹¹

The infant is placed in the prone position (also with umbilical lines) to maximize the area of skin contact and continuous skin temperature monitoring enables keeping the cape snug around the infant, thereby limiting exposure to colder air.

With such measures undertaken it is our experience that SSC can be safely initiated towards the end of the first week also in infants born at 22–24 weeks of gestation.¹¹ The duration of SSC can gradually be increased and by the second week the mean duration of SSC in our unit is approximately 8 h per day (*unpublished data*). Thereafter SSC is unrestricted in most cases, infant status permitting. During incubator care, the infants are nursed in a nest to support a flexed posture, offer some resistance to movement, facilitate their hand-to-mouth activity, promote a state of calm, and reduce stress.¹⁸

Early feeding with breast milk

The provision of human milk for preterm infants has health benefits and the mother's own fresh milk is superior to pasteurized donor milk.^{19–22} To promote early expression of mothers own breast milk, both parents are informed, ideally at the prenatal consultation with the Neonatology team, about its value for the infant, and a "colostrum kit" with instructions and practical information is handed out.²³ The

Table 1 – Skin-to-skin care (SSC) guidelines for extremely preterm infants.

Pre-SSC	Transfer to SSC	During SSC
Infant prone in nest	Nest with infant lifted, placed on parent's chest	Nest removed
Swaddling in merino wool cape	Full cover by cape	Ensure maximal skin area exposed to parent, cape snug around body, head covered, two blankets added
Room temperature >24°C	Ventilator circuit remains connected. If sign of instability, allow time to recover	Button parents' shirt around infant, place large quilt on top
Parent positioned in adult bed at cot-side, dressed in front opening shirt		SSC continues minimum 120 minutes
Skin temperature probe placed; check axillary temperature >37°C	All monitoring (SaO ₂ , temp, ECG, ABP) stay on	Continuous skin temperature monitoring

mothers are encouraged and supported to express colostrum (and later, breastmilk) every 2 to 3 h as soon as possible after delivery. This support is provided both at the NICU and at the Maternity Unit, and electric breast pumps are readily available. A cotton swab is used to apply colostrum to the infant's lips and inside his/her mouth; once breastmilk production is established, it is fed fresh to the infant. Enteral feeding (every second hour) is started within 1-2 h after birth and parents are involved in colostrum care and tube feeding from birth. In most cases, parents are comfortable taking care of this task within a couple of days.

Collaborating with the family and the impact of the care team

Working closely with the family is important to our team (picture 1) and in our experience promotes infant as well as parental well-being.^{24,25} Maternal involvement has been associated with improved neurodevelopment, with SSC being the most important contributor, and reduces length of hospital stay.²⁶ We strongly believe that all health care professionals, individually and as a team, have a unique opportunity to "paint the picture" when they communicate with the families. In our experience, this picture will strongly influence parental presence, involvement, and minimize separation. We trust families to be their infants' primary caregivers (picture 2), while staff act as supporting mentors. The parents can and should be trusted with all tasks they would otherwise take care of at home such as feeding, hygiene, comforting, sharing closeness, baby talk, and love.²⁷ We have found it helpful to use a family checklist (appendix 2), adapted to parents' willingness, ability, and emotional readiness, to guide and keep track of their progress in taking over tasks assigned to them.²⁸ Our experience is that parents, regardless of age and educational level, take this responsibility and perform admirably well. A NICU team that believes that even the tiniest of babies can do well, will ultimately perform better,²⁹



Picture 1 – Collaboration with the family; parent holding his sick newborn, while an older sibling watches a children's show, and has a snack.



Picture 2 – Trust families to be their infant's primary caregivers; parents assisting during chest x-ray.

allowing parents to hope, and to endure the long and winding road of neonatal intensive care.

Pain and stress management - less invasive care

Exposure to painful stimuli during periods of brain maturation and growth is known to negatively impact on neurodevelopment.³⁰ To minimize harm, all aspects of care are reviewed and revised by the care team to avoid exposing the infant to pain. While separation negatively impacts infant development and parental well-being,^{31,32} skin-to-skin contact is an effective means to reduce both stress and pain. When pain is unavoidable, procedures should be planned and performed with parental involvement (picture 3), preferably during SSC.³³

Skin care

The immature skin barrier of extremely preterm infants requires precautions during routine care, particularly during the first weeks of life. The epidermis can be easily stripped by the removal of tape or other adhesives causing severe barrier disruption.³⁴ The delicate skin barrier is also a risk for absorption of toxic substances and/or being damaged by agents routinely used in health care for skin cleansing and/or disinfection.¹⁰ Even something as harmless as bathing/washing with water has been shown to delay the gradual postnatal decrease in pH³⁵ that might be important to barrier integrity.

The diaper region is wiped as needed with a soft cloth and water from birth and at the end of the second week parents are introduced to sponge bathing their infant regularly (most often daily). The first bath is considered when all lines are removed.

It is thus reasonable to avoid as much as possible the application of tape and adhesives to the skin and umbilical catheters are securely fastened by sutures only. While endotracheal and nasogastric tubes must be secured using tape, we routinely monitor the infants with pulse oximetry and indwelling arterial pressure monitoring, thereby avoiding



Picture 3 – Plan and perform procedures with the parents involved; mother holding, and comforting her son during peripheral intravenous cannulation.

skin trauma from electrocardiogram leads. Closed humidified incubators are used for initial care, with the relative humidity set to 85% during the first week. Thereafter, a relative humidity of 50% is used.³⁶ Umbilical lines are removed within 10 days and replaced with PICC if prolonged need is anticipated.

Discussion

It takes dedication to steer the care culture away from a paradigm where infants are to a large extent taken care of by staff with the parents as bystanders. True parental involvement requires a systematic approach whereby the parents actively participate in all aspects of their infant's care. It is our experience that such an involvement is greatly facilitated by focusing on early maternal provision of breast milk, skin-to-skin care, and step-by-step assignment of nursing tasks to the parents. Furthermore, small things matter in practice and the placement of an adult hospital bed in the center of each care space proved to dramatically change the way our NICU evolved. With parents present, there is an opportunity to build a partnership and further empower the parents to be the primary caregivers of their children, enabling extended SSC, feeding, caring, and sharing of information during rounds. The family includes siblings and any relatives the family chooses to involve. The benefits of parental involvement are numerous and independent of gestational age at birth.

Appendices

Appendix 1. Film clip; standardized method how to safely transfer infant between incubator and parent.

Appendix 2. Guide to parental participation.

Declaration of Competing Interest

None.

Supplementary materials

Supplementary material associated with this article can be found in the online version at [doi:10.1016/j.semperi.2021.151542](https://doi.org/10.1016/j.semperi.2021.151542).

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