Early Human Development 90 (2014) 781–785

Contents lists available at ScienceDirect

Early Human Development

journal homepage: www.elsevier.com/locate/earlhumdev

Review

Parents as practitioners in preterm care

Siyuan Jiang [a], Ruth Warre [a], Xiangming Qiu [a,b], Karel O'Brien [a,b], Shoo K. Lee [a,b,*]

[a] Maternal–Infant Care Research Centre, Mount Sinai Hospital, Toronto, Ontario, Canada
[b] Department of Paediatrics, University of Toronto, Toronto, Ontario, Canada

ARTICLE INFO

Keywords:
Neonatal intensive care
Infant
Premature
Care-by-parent
Care provision
Family-centred care
Family-integrated care

ABSTRACT

The very preterm birth of an infant is physiologically traumatic for the infant and physiologically and psychologically traumatic for the parents. The manner of care delivery in the first few days and weeks of the infant's life plays a large role in determining the impact of that trauma. For optimal outcomes parents need to be integrated into the care process as the primary practitioners of their infant's care in the neonatal intensive care unit. Supporting and enabling parents to be central to the care process establishes a consistent care environment where parents are in control and able to support their infant's physiological and psychological needs, thereby improving infant outcomes and reducing parent stress and anxiety. This article reviews the role of parents in the optimal development of preterm neonates, and discusses the elements crucial to promoting parent involvement in the neonatal intensive care unit and supporting parents following discharge.

Contents

1. Introduction

The very preterm birth of an infant is physiologically traumatic for the infant and physiologically and psychologically traumatic for the parents. The manner in which care is delivered in the first days and weeks of the infant's life plays a large role in determining the impact of that trauma. Parents experience significant stress following their infant's admission to the highly medicalized environment of the neonatal intensive care unit (NICU), particularly with regard to being separated from and unable to provide meaningful care for their child [1,2]. This experience can have a significant effect on the parent–infant attachment that is crucial to both infant and parent outcomes [3,4]. The current environment of family-centred care goes a long way to addressing this by educating parents, promoting care activities, such as skin-to-skin and breastfeeding, and considering the infant in the context of their family's wishes; [5] however, parents often remain passive

Abbreviations: FICare, Family Integrated Care; NICU, neonatal intensive care unit.

* Corresponding author at: 600, University Avenue Rm 19-231D, Toronto, Ontario, Canada. Tel.: +1 416 586 4800x6370; fax: +1 416 586 8745.
E-mail addresses: jane1350@163.com (S. Jiang), RWarre@mtsinai.on.ca (R. Warre), xqiu@mtsinai.on.ca (X. Qiu), KO'Brien@mtsinai.on.ca (K. O'Brien), sklee@mtsinai.on.ca (S.K. Lee).

http://dx.doi.org/10.1016/j.earlhumdev.2014.08.019
0378-3782/

observers, beholden to the healthcare team for information and acceptance, and restricted in the caregiving role they play [6,7].

As an extension of family-centred care, parents need to be integrated into the NICU care process as the primary practitioners of care for their infant [8]. Supporting and enabling parents to be central to the care process establishes a consistent care environment where parents are in control and able to support their infant's physiological and psychological needs, potentially improving infant outcomes and reducing parent stress and anxiety. It may also be helpful if the support that parents receive in the NICU is integrated with primary care and community services, as too often there is little or no support available to parents of premature infants following discharge.

This article briefly reviews the role of parents in the optimal development of neonates in the NICU, discusses our Family Integrated Care (FICare) model within the context of previous research as an example of how parents can be practitioners in preterm care, and suggests options for supporting parents following discharge.

2. The role of parents in optimal infant development in the NICU

2.1. Provision of external cues and moderation of environmental stressors

As their auditory and olfactory systems become functional during the last trimester of gestation, infants begin to form an awareness of their mother's voice and odour that then guides the infant's responses in the first days of life [9]. Even in preterm infants, where this awareness is still developing, maternal voice and odour play a role in feeding and physiological regulation following birth. Studies have demonstrated that stimulating preterm infants with their mother's voice either live or through recordings improves oral feeding rate, volume intake, feeds per day, and time-to-full oral feedings; [10,11] lowers heart rate; [12,13] produces a more stable skin colour; [13] improves oxygen saturation; [12] decreases the number of critical events (hypoxemia, bradycardia, apnoea); [12,14] and produces a calm alert state [12,15]. Similarly, the use of breast milk odour during gavage feeding or immediately prior to early breastfeeding attempts has been shown to reduce the transition time to oral feeding; lead to longer sucking bouts, more bursts of sucking movements, and increased milk consumption during breastfeeding; as well as reduce infant length of stay [16,17].

Even with external cues to guide and support an infant, the NICU environment can have further adverse effects on infant outcomes due to the risk of nosocomial infection and the presence of stressful stimuli (e.g. bright light, noise, painful procedures, handling, and monitoring) that disturb sleep and feeding, produce direct stress responses, and may have longer-term neurodevelopmental consequences [18–21]. For example, lighting in individual NICUs varies from continuous bright light through 12 h light/dark cycles to dim lighting. Specific lighting patterns, such as continuous bright light, have been shown to adversely affect outcomes such as weight gain, length of stay, and time spent crying in preterm infants [22]. Similarly, although there are published recommendations regarding a maximum noise level [23], units can rarely keep the noise below these limits [24,25]. Sources of noise include incubators, respiratory support, and external noises such as alarms and voices [24]. In the case of both light and sound, it is likely variability in conditions that are not attuned to the infant's needs that is most disruptive and stressful [26,27].

Although parents cannot influence the bed type, respiratory support, and light cycle used in the NICU, they can guard against unnecessary light sources and excessive noise from voices when they are present. Parental presence and touch can also influence infant responses to painful and stressful procedures. As such, the use of approaches including skin-to-skin contact, holding, gentle touch, and sensitive maternal caregiving has been shown to reduce infant response to procedural pain [28–30] and stress related to diaper changes [31]. The consistent presence of parents at the infant's bedside may also decrease the risk of nosocomial infection through a reduction in the number of people handling the infant, better control of the environment, and consistent hygiene practices [32].

2.2. Development of strong parent–infant interaction

Parental presence helps to build a strong parent–infant attachment, which in turn influences behavioural and emotional development. For example, a study of the frequency of parental visits indicated that infants whose mothers visited the NICU daily had fewer behavioural and emotional problems at school age [33]. Other studies of infants following discharge have also shown that maternal–infant interaction that is warm and sensitive, where the parent understands the child's cues and responds promptly and appropriately, is associated with improved behavioural outcomes in preterm infants [34–36]. Conversely, factors that inhibit parent–infant interaction, such as maternal depression and anxiety, have been shown to have an adverse effect on infant behaviour [37–40]. As such, ensuring that parent–infant interaction is encouraged in the NICU and that parents are provided with the means to reduce their stress levels and improve their knowledge and confidence is essential to the outcome of preterm infants.

3. Enabling parents to be practitioners in preterm care

3.1. The Family Integrated Care model

In considering the factors supporting optimal infant development it is obvious that parental presence in the NICU is vital to both the infant's and the parents' well-being. The Family Integrated Care (FICare) model takes a holistic approach to shift the paradigm of NICU care so that parents are the primary caregivers for their infant [8]. Participants in the program are required to commit to spending 6 to 8 h per day in the NICU caring for their infant, as well as attend daily medical rounds and small group education sessions. The education and support that parents receive enable them to perform daily caregiving activities, such as diaper changing, bathing, feeding, positioning, giving oral medication, and skin-to-skin care, as well as track their infant's progress, take part in rounds, and collaborate on their infant's care plan [41]. Parents, however, do not perform technical procedures and the overall responsibility for care remains with the healthcare team. In this scenario nurses become educators and coaches for parents and work in partnership with them, allowing for the development of a more therapeutic nurse–parent relationship. As such, nurses receive training on how to support and work with parents [42]. Parents also have access to psychosocial support, particularly from their peers and those that have lived through the same experience [43–45]. The final element in the program is a NICU environment that is conducive to parents spending extended hours there, including the provision of comfortable chairs at the bedside, parking or transit passes, and a space for rest and food preparation. By integrating parents into the care team, they gain more control of the situation and are able to participate meaningfully in their infant's care, which should decrease parental stress and also support the development of parent–infant attachment.

To date, FICare has been pilot tested in one NICU [46] and is currently undergoing a multi-centre nationwide cluster randomized controlled trial in 20 NICUs in Canada [47]. The pilot study included 42 mothers and their infants and showed that compared with retrospectively matched control infants, infants in the FICare program had a significantly improved rate of weight gain. In the FICare group there was also an 80% increase in breastfeeding at discharge and a 25% reduction in parental stress compared with mothers who were present on the ward at the same time but not enrolled in the program. Responses to a survey of both nurses and parents who participated in the program were overwhelmingly positive [46]. The cluster randomized controlled trial will evaluate the infant and parent outcomes examined in the pilot study on a wider scale [47].