Received: 21 October 2021 | Accepted: 21 October 2021

DOI: 10.1111/nicc.12727

GUEST EDITORIAL

BACCN Nursing in Critical Care WILEY

Parental involvement and empowerment in paediatric critical care: Partnership is key!

Parents of infants or children admitted to a critical care unit are themselves in a crisis situation. In this crisis, parents often feel out of control and are at a high risk of anxiety, depression, post-traumatic stress disorder, and other stress-related conditions challenging their parental role[1,2] They must deal with a new and disruptive situation that throws their entire life upside down. Post intensive care syndrome-family (PICS-F), also known as family intensive care unit syndrome (FICUS), are terms used to explain the psychological symptoms of the family of a patient in response to the patient's admission to the intensive care unit (ICU).[3] Critical illness is a family crisis and not only applicable to children but also to adults. When a child is admitted to the pediatric ICU, the family suffers considerably because of both the difficulty in seeing what their child is going through but also because of the "uncertainty of not knowing".[3] In this acute and distressing situation, they face many factors contributing to anxiety and stress, such as worries about the health and potential survival of their child, uncertainties about the future, helplessness, loss of control, and a huge change in their role as parent and caregiver.[1,2] Yet their role in the critical care unit is often viewed as a visitor or observer, which likely contributes to their feelings of helplessness and loss of control.[2,4] This editorial will discuss changes in roles of families and health care professionals, family involvement and empowerment in paediatric critical care, including neonatal critical care. The focus is on the role of families in daily paediatric critical care, the importance of empowering families, and the consequences for the changing balance in roles between health care professionals and family members.

Increasing awareness of the impact of this parental crisis and recognition of the role of parents has led to the development of models of care focusing on a more central role for parents. Established models are family-centred care (FCC) and family-integrated care (FICare).[5,6] FCC is an approach to planning, delivery, and evaluation of nursing and care, embracing the importance of the family in the patient's life, and thus focusing care not only on the child but also taking into account the family as the central and most important aspect in the child's life. The key components of FCC are partnership with family members and the recognition of parents as the experts concerning their child's abilities and needs.[7] FICare extends on the FCC model by placing families at the centre of care, and in addition, empowering them as primary caregivers, thus recognizing the importance of them being active in their parental role.[8] The FICare model has been developed in neonatal care, but the principles are relevant for all areas of paediatric care.[9,10] FICare invites and enables parents not only to become their infant's primary caregiver, but in addition to actively participate in the child's care. This involves being present most of the time on the unit, taking over some tasks previously undertaken by nurses, and being actively involved in ward rounds.[6,8,9] This then changes the dynamics of the parental role from passive observers to playing an active role in caregiving and making partnerships between families and health professionals possible.[6]

Increasingly, FICare is considered best practice in (neonatal) critical care, empowering parents and providing a consistent care environment in which a partnership is created.[6] This, in turn, can decrease parental stress and anxiety, and align the needs of the child (physiological and psychological) with those of the parents.[6,11] However, the implementation of this model in daily care may be challenging.[11] A major challenge is the focus primarily on the practical issues related to the presence and role of parents in the child's caregiving, thus neglecting the more fundamental shift in thinking regarding the consequences of these models for relationships and collaboration between families and health care professionals, including their roles. For example, the way health care professionals perceive parents' role as the primary caregiver must fundamentally change, and this influences the way FCC and FICare is delivered.[11]

As patient/parent participation in care is a growing discourse in health policy, health professionals need to consider different roles in caring for children and their parents. The focus on empowerment and partnership represents a shift from a paternalistic approach to care to a participatory way of thinking for all health care professionals.[12] Patient/parent empowerment, a crucial concept in this shift in the way of thinking, is described as the acquisition of motivation (self-awareness and attitude through engagement) and ability (skills and knowledge through enablement) that patients/parents might use to be involved or participate in decision-making, thus creating an opportunity for greater power in their relationship with professionals.[13] Central in understanding and translating this concept to critical care clinical practice is the recognition of empowerment as a *process*, in which health care professionals play a crucial role in enabling parents to develop skills and knowledge and to motivate them through engagement. It also emphasizes the importance of accommodating individual differences, as there are large differences in needs, wishes, and preferences. Indeed, to empower parents in paediatric critical care, we need to have insight in what individual parents need to fulfil their role.

FICare is not just physically involving families in care and tasks, it is a change in culture and relationships between health care professionals and the family, including an individualized approach to support and empower families. It is therefore not surprising that implementing FICare cannot take place rapidly or as a matter of course, and in fact is highly challenging. It requires a change in health care professionals' roles, which has not been part of their education, and they often already feel overburdened.[11] There may be institutional and organizational barriers, and there may be parental barriers too.[8] A large multicentre, cluster-randomized controlled trial into the effectiveness of FICare in neonatal intensive care units showed positive effects on infant and parent outcomes.[6] This study of O'Brien et al showed that it is safe to involve parents and families in the care of their infant. Subsequently, the results quantify the positive effect of parental-infant interaction on infant weight gain, breastfeeding rates at discharge, and FICare decreased levels of parental stress and anxiety.[6] However, it also became clear that substantial effort is required to implement the pillars of FICare. First, a parent education programme with small group education sessions, parent coaching at the bedside, and parent involvement in medical rounds is necessary. Secondly, there should be a staff training programme and tools for staff to mentor, coach, and support families. Furthermore, policies, procedures, and environmental resources to operationalize family involvement in caregiving and support prolonged parental presence in the NICU need to be established. Finally, a programme of psychosocial support that includes peer-to-peer and professional support for families while in the NICU is required.[6] The study by O'Brien et al[6] also showed that the implementation of FICare needs to be multidimensional, with interdependent components, to be successful. In fact, professionals need to be empowered too, and this takes time, enabling them to develop skills and knowledge and motivating them through engagement. It is clear that some (or, indeed, many) health care professionals may feel uncomfortable with letting go of some of "their power".

In summary, family-integrated care can empower families to re-gain control in a crisis situation. For nurses and others working in paediatric critical care, the challenge lies with us: how do we make sure all principles and pillars are implemented and secured, without cherry-picking the practical aspects related to presence and physically involving parents? We can only do this by partnering with families in this journey, acknowledging the challenges, considering it from a process perspective, at various levels of the organization, and by listening to experts-by-experience, the families themselves.

Agnes van den Hoogen PhD, RN[1,2]
Marjolijn Ketelaar PhD[3]

[1]*Department of Neonatology, University Medical Centre Utrecht, Wilhelmina Children's Hospital, Utrecht, The Netherlands*
[2]*Department of Clinical Health Science, Utrecht University, Utrecht, The Netherlands*
[3]*Centre of Excellence for Rehabilitation Medicine, Brain Centre University Medical Centre Utrecht and De Hoogstraat Rehabilitation, Utrecht, The Netherlands*

Correspondence
Agnes van den Hoogen, Department of Neonatology, University Medical Centre, Utrecht, The Netherlands.
Email: ahoogen@umcutrecht.nl

ORCID

Agnes van den Hoogen https://orcid.org/0000-0003-2032-2472
Marjolijn Ketelaar https://orcid.org/0000-0002-8324-518X

REFERENCES

1. Caporali C, Pisoni C, Gasparini L, et al. A global perspective on parental stress in the neonatal intensive care unit: a meta-analytic study. *J Perinatol*. 2020;40:1739-1752. doi:10.1038/s41372-020-00798-6
2. Al Maghaireh DF, Abdullah KL, Chan CM, Piaw CY, Al Kawafha MM. Systematic review of qualitative studies exploring parental experiences in the neonatal intensive care unit. *J Clin Nurs*. 2016;25(19–20):2745-2756. doi:10.1111/jocn.13259
3. Saeid Y, Salaree MM, Ebadi A, Moradian ST. Family intensive care unit syndrome: an integrative review. *Iran J Nurs Midwifery Res*. 2020;25(5):361-368. doi:10.4103/ijnmr.IJNMR_243_19
4. Lefkowitz DS, Baxt C, Evans JR. Prevalence and correlates of posttraumatic stress and postpartum depression in parents of infants in the neonatal intensive care unit (NICU). *J Clin Psychol Med Settings*. 2010;17(3):230-237. doi:10.1007/s10880-010-9202-7
5. Gooding JS, Cooper LG, Blaine AI, Franck LS, Howse JL, Berns SD. Family support and family-centered Care in the Neonatal Intensive Care Unit: origins, advances, impact. *Semin Perinatol*. 2011;35(1):20-28. doi:10.1053/j.semperi.2010.10.004
6. O'Brien K, Robson K, Bracht M, et al. Effectiveness of family integrated care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. *Lancet Child Adolesc Health*. 2018;2(4):245-254. doi:10.1016/S2352-4642(18)30039-7
7. Kokorelias KM, MAM G, Naglie G, Cameron JI. Towards a universal model of family centered care: a scoping review. *BMC Health Serv Res*. 2019;19(1):564. doi:10.1186/s12913-019-4394-5
8. Patel N, Ballantyne A, Bowker G, Weightman J, Weightman S, Helping Us Grow Group (HUGG). Family integrated care: changing the culture in the neonatal unit. *Arch Dis Child*. 2018;103(5):415-419. doi:10.1136/archdischild-2017-313282
9. Participation of parents of hospitalized children in medical rounds: a qualitative study on contributory factors. van Oort PJS, Maaskant JM, Smeulers M, van Oostrum N, Vermeulen E, van Goudoever JB. *J Pediatr Nurs*. 2019; 46:e44-e51. doi:10.1016/j.pedn.2019.02.033.
10. King G, Williams L, Hahn Goldberg S. Family-oriented services in pediatric rehabilitation: a scoping review and framework to promote parent and family wellness. *Child Care Health Dev*. 2017;43(3):334-347. doi:10.1111/cch.12435
11. Sabine Oude Maatman SM, Bohlin K, Lilliesköld S, et al. Factors influencing implementation of family-centered Care in a Neonatal Intensive Care Unit. *Front Pediatr*. 2020;6(8):222. doi:10.3389/fped.2020.00222
12. Halvorsen K, Dihle A, Hansen C, et al. Empowerment in healthcare: a thematic synthesis and critical discussion of concept analyses of empowerment. *Patient Educ Couns*. 2020;103(7):1263-1271. doi:10.1016/j.pec.2020.02.017
13. Fumagalli LP, Radaelli G, Lettieri E, Bertele' P, Masella C. Patient empowerment and its neighbours: clarifying the boundaries and their mutual relationships. *Health Policy*. 2015;119(3):384-394. doi:10.1016/j.healthpol.2014.10.017