Empowerment of parents in neonatal level 2 care

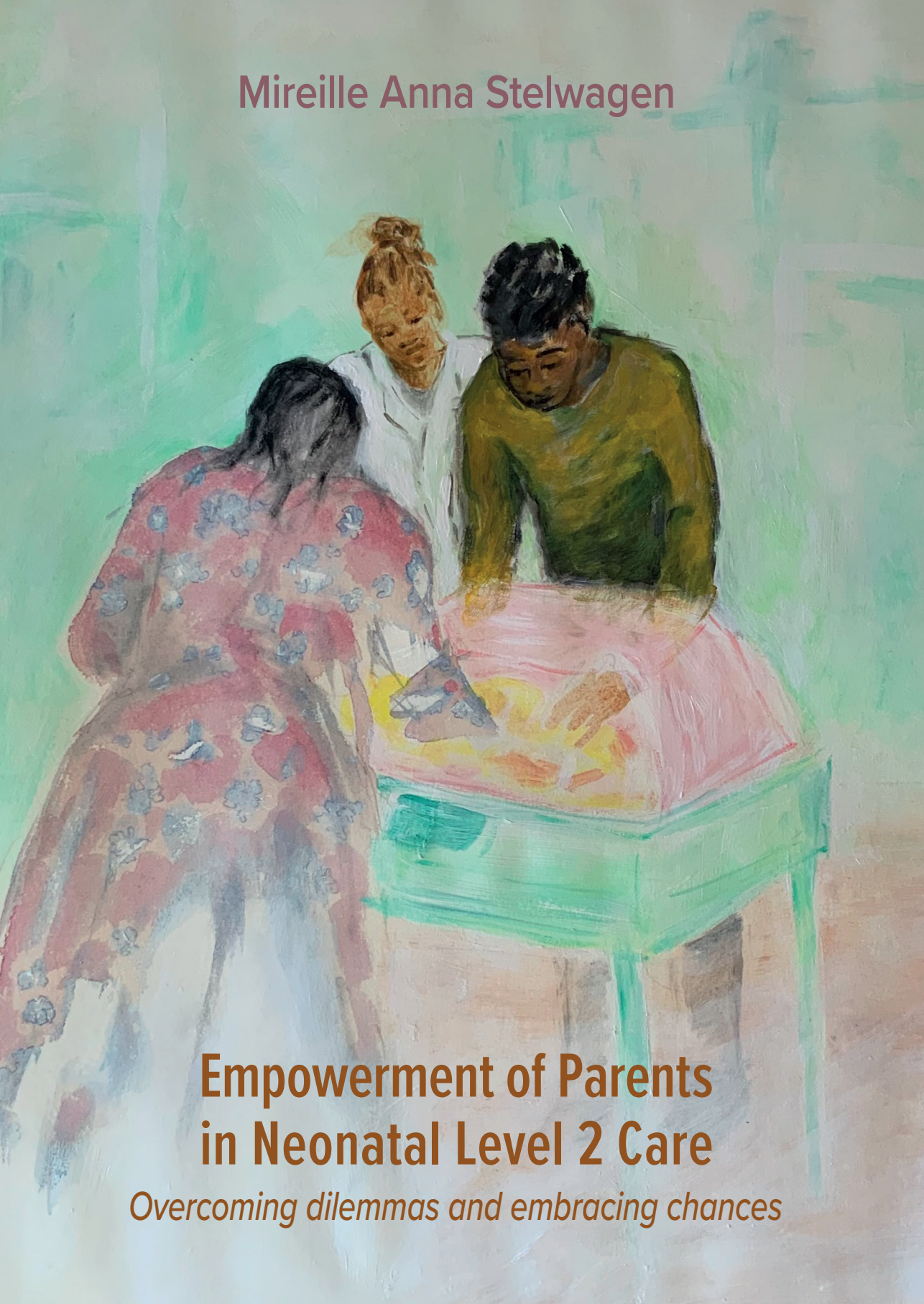
Stelwagen, Mireille Anna

2023

DOI (link to publisher)
10.5463/thesis.52

document version
Publisher's PDF, also known as Version of record

Mireille Anna Stelwagen



Empowerment of Parents in Neonatal Level 2 Care

Overcoming dilemmas and embracing chances

Empowerment of Parents in Neonatal Level 2 Care

Overcoming dilemmas and embracing chances

Mireille Anna Stelwagen

ISBN
978-90-832951-0-7

Cover
Machteld Wijnbergh Kunst en Cultuureducatie, Amsterdam

Lay out and print
proefschriftenprinten.nl

The printing of this thesis was financially supported by
Stichting Wetenschap OLVG.

VRIJE UNIVERSITEIT

Empowerment of Parents in Neonatal Level 2 Care

Overcoming dilemmas and embracing chances

ACADEMISCH PROEFSCHRIFT

Ter verkrijging van de graad Doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. J.J.G. Geurts
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de Faculteit der Geneeskunde
op dinsdag 17 januari 2023 om 13.45 uur
in een bijeenkomst van de universiteit,
Boelelaan 1105

door

Mireille Anna Stelwagen
geboren te Wijdewormer

promotor:	prof.dr. F. Scheele
copromotoren:	dr. A.A.M.W. van Kempen dr. A.H. Westmaas
promotiecommissie:	prof.dr. C. Boer prof.dr. M.J.E. van Dijk prof.dr. J.A.M. Kremer prof.dr. I.H.M. Steenhuis prof.dr. J.M. Latour prof.dr. W.B. de Vries

Table of Contents

'The very first requirement in a hospital is that it should do the sick no harm.'

Florence nightingale

1

General introduction

Many barriers still exist for the parents of hospitalized newborns (Ashcraft et al., 2019) to be empowered towards autonomous, independent parents. One of the major barriers is that parents are physically, socially and/or emotionally separated from their newborns, due to the traditional organization and the paternalistic culture of hospital care (Dykes et al., 2016; Feeley et al., 2016; Flacking et al., 2012; Mäkelä et al., 2018; Niela-Vilen etal., 2017; Treherne et al., 2017).

It is very stressful for both the newborn and the parents if sick newborns are separated from their parents on a neonatal ward when they must undergo procedures that may or may not be painful (Campbell-Yeo et al., 2022; Caporali et al., 2020; McNair et al., 2020). Newborns with a high stress level have higher mortality risks and a higher occurrence of medical complications (Van Dokkum et al, 2021). In parents of NICU infants, possible consequences of stress are anxiety and depressions (Cyr-Alves et al., 2018; De Paula Eduardo et al., 2019; Salomè et al., 2022; Soghier et al., 2020). Other consequences of stress are that parents and newborns do not bond well and that the success of breastfeeding is hampered. As a result, parents are not able to develop properly their parental role. (Baia et al., 2016; Bouet et al., 2012; Diffin et al., 2016; Ionio et al., 2016; Prouhet et al., 2018). Both the parents and the involved health professionals face these stress-related consequences in daily practice.

Multiple interventions have been developed to address the barriers that prevent parent empowerment and that cause health-related problems of parents and newborns. Most of these interventions have been independently evaluated, particularly for neonatal level 3 care, known as specialized neonatal intensive care units (NICU's) of academic hospitals (American Academy of Pediatrics, 2012). This thesis contributes to filling the gap of knowledge about how parents can be empowered toward autonomous and independent parenting during admission to a neonatal level 2 ward in teaching hospitals where newborns receive post-intensive care or high care by using multiple interventions simultaneously.

Empowerment in health care

The concept of 'empowerment' is used in several aspects of health care. Firstly, it is used to describe a relationship between health and power, based on the assumption that empowered individuals are healthier than those who are not empowered. Patient empowerment is a concept that gives the patient a central and equal position in their relation to health professionals in order to improve the quality and the efficiency of health care (Bravo et al., 2015). Secondly, the concept of empowerment is used to describe a certain type of patient, for example, a patient who can be empowered by health education programs, or a patient who

can be empowered by interactions with health professionals (Holmstrom & Roing, 2010). Thirdly, empowerment as an outcome refers to self-efficacy; active patients who take part in their own health care are capable of self-management and make informed autonomous decisions about their health care (Chen et al., 2016; Wallerstein, 2006).

The process of empowerment in health care requires the fulfilment of two fundamental conditions: patient participation and a patient-centered care vision (Castro et al., 2016). These conditions are reflected in the most effective empowerment strategies, namely strategies that are built on and reinforce authentic participation, that ensure autonomy in decision-making, and that are sensitive to the patients' self-defined health needs (Wallerstein, 2006). Examples of these strategies are the concepts of *shared decision-making* and *self-management*.

Shared decision making (SDM) has been defined as an approach in which clinicians and patients share the best evidence when faced with decisions and in which patients are supported to consider options to develop informed preferences (Elwyn et al., 2012). Health professionals should provide clear information on the diagnosis, the prognosis and the treatment options, as well as on the advantages and disadvantages of each option. Patients should express their personal preferences regarding treatment and they should be able to inform the health care workers to what extent they want to be involved in the decision-making process. In addition, patients should be able to make choices, mentally and cognitively, and should not experience hierarchical relationships with health professionals (Dy & Purnell, 2012).

Self-management is a concept and a component of self-care, which refers to an iterative process of patient strategies that meet their self-defined needs to cope with illness within the context of their daily lives (Tulu et a., 2021). Self-care is defined as "the ability to take care of oneself through awareness, self-control, and self-efficacy in order to achieve, maintain, or promote optimal health and well-being" (Martínez et al., 2021). Effective interventions to support self-management are multifaceted. They must be tailored to each individual, their culture and their beliefs, and they require a collaborative and communicative relationship between the patient and the health care professional. Components of self-management support include patient education, psychological support for life changes as well as treatment adherence support and practical support (Taylor et al., 2014). It requires educational skills of health professionals in self-management and in problem solving to increase the patients' understanding of their situation and to support lasting changes in their lives (Jiang et al., 2014).

Empowerment in neonatal care

A newborn depends on its parents and is inextricably linked to them for its health. Rather than empowering the newborn, empowerment of the parents is required for the quality of health and life of hospitalized newborns (Latour, 2011; Umberger et al., 2018). Intervention strategies for the empowerment of parents of hospitalized newborns can be divided into two major categories: striving for *proximity between parents and newborns* and *involving parents as primary caregivers* in the care of their newborn during hospital admission.

Proximity between parents and newborns

A key intervention for close proximity between parents and newborns is *skin-to-skin contact*, which is also called *kangaroo care*. It has been proven to have positive effects on stress and pain experiences in newborns, on the cortisol levels of parents and newborns, on the attachment of parents and the newborn, on successful breastfeeding and on the reduction of perceived relationship problems between parents (Conde-Agudelo & Díaz-Rossello, 2016). Parents and even other family members can easily practice skin-to-skin contact, but if the intervention is embedded in neonatal care, one is still faced with adherence to traditional practices (Siraneh et al., 2021; Smith et al., 2017).

A concept that was developed to facilitate a quiet, safe, and private environment for parents and newborns around births in hospitals is the *single-family room* (SFR). (Brown & Taquino, 2001; Janssen et al., 2000; Reed & Schmid, 1986). In these rooms, parents and other family members can remain in proximity with the newborn and take part in the care of the newborn without disruption of the development of attachment or of the parental role by other parents and newborns or by having to move repeatedly to another room. Single-family rooms were found to be associated with positive effects on outcomes for newborns and parents. For newborns, these effects were a lower incidence of neonatal sepsis and improved rates of exclusive breastfeeding (Van Veenendaal et al., 2019). For parents, these effects were lower levels of stress and higher levels of attendance, engagement, skin-to-skin care, empowerment, and family-centered care (Feeley et al., 2020; Van Veenendaal et al., 2020). Feeley et al. (2020) concluded that mothers of newborns who were cared for on an open bay ward experienced greater stress due to images and sounds and that they felt more restricted in their parental role. Mothers of newborns who were cared for in an SFR perceived their infant to be more ready for discharge, and they attended maternal education for significantly more hours per week than mothers of newborns who were cared for on an open

ward (Feeley et al., 2020). Single-family rooms appear to have a greater impact on the father's involvement in activities of care and comforting than on the mother's involvement (Campbell-Yeo et al., 2021).

It has been reported that both the staff and the parents had positive experiences with single-family rooms in maternity and neonatal care (Ali et al., 2020). Parents experienced the privacy to express joys and sorrows; they felt more like a parent than like a visitor. They felt shielded from the emotional expressions of other parents, and both their newborns and they themselves experienced less over-stimulation by noise and light. Besides, they experienced better access to the pediatrician or the neonatologist. Finally, they felt supported by the entire team, and they felt they were leaving the hospital as a family rather than only the newborn being discharged from the hospital (Domanico et al., 2010; Maben et al., 2016; Shahheidari & Homer, 2012; Stevens et al., 2011; Stevens et al., 2010; Walsh et al., 2006). Health professionals preferred single-family rooms in relation to quality of care, control of primary workspace, privacy, and reduced interruptions (Winner-Stoltz et al., 2018).

However, more recent studies also reported disadvantages for parents, newborns and health professionals regarding their experiences with single-family rooms. Health professionals experienced being more isolated from colleagues, and they reported mixed satisfaction and concerns about newborn safety (Ali et al., 2020; Doede & Trinkoff, 2020). In a survey on the ideal environment for parents of hospitalized children, parents said that they preferred a room at the Ronald McDonald House to single-family rooms because they could rest better there and could distance themselves from the hospital context (Franck et al., 2015). Although single-family rooms increased parental attendance, researchers found no association with increased skin-to-skin care (Kainiemi et al., 2021).

Another intervention that was developed to prevent separation of mothers and newborns during postnatal care is *couplet care,* also called *co-care* (Brenneman, 2014; Cottrell & Grubbs, 1994; Crenshaw, 2019; De Salaberry et al., 2019; Elliott-Carter & Harper, 2012; Erlandsson & Fagerberg, 2005; Flacking et al., 2013; Mahlmeister, 2005). This means that both mother and newborn are cared for together, side by side, independent of the design of the accommodation. Sick mothers and newborns usually are admitted to separate maternity and neonatal wards. Health professionals who are especially trained for neonatal care usually are not equipped or trained to provide care for the mother who has recently given birth and who requires postnatal care, and conversely, the health professionals who were especially trained for maternity care are usually not equipped or trained to provide neonatal care for sick newborns. Flacking et al. (Flacking et al., 2013) found that mothers whose infants were cared for in a NICU with co-care facilities reported significantly lower levels of stress in the dimension of 'incompetence' than mothers whose infants had been cared for in non-co-care NICUs.

Rooming-in for parents is an intervention facilitating and allowing parents to stay overnight to care for and support their hospitalized child. In contrast to couplet care or co-care in maternity and neonatal care, rooming-in means that a 'healthy' parent spends the night next to the newborn (Cottrell & Grubbs, 1994; Jaafar et al., 2016). In contrast to single-family rooms (Van Veenendaal et al., 2019), there is no evidence that rooming-in leads to better breastfeeding results (Ng et al., 2019). In maternity care, rooming-in means that a partner stays overnight to support the women.

Involving parents as primary caregivers

Active family involvement in care has also been shown to have a positive effect on quality of care (Celenza et al., 2017). In 1994, Levin was one of the first to report the outcomes of a so-called *patient-centered care model* within neonatal care (Levin, 1994). He investigated the effects of a "Truly Baby-Friendly Unit" that had been established in 1979. The premise of this unit was that mothers cared for their hospitalized newborns 24 hours a day, with minimal use of technology, along with only brief contact between the newborns and the medical and nursing staff. Today, these principles can still be found in the care model of *family-centered care* (FCC) (Committee on Hospital Care and Institute for Patient-and Family-Centered Care (2012); Levin & Chalmers, 2014; Ramezani et al., 2014) and in the model of *family-integrated care* (FICare) (Franck & O'Brien, 2019). These care models are associated with newborn outcomes of higher weight gain and a lower readmission rate and with parental outcomes of higher satisfaction and better newborn care skills and knowledge and less anxiety and stress (Ding et al., 2019). Parental stress was reduced because they could gain more control over the situation and they could meaningfully take part in the care of their newborn, which supported the development of their parental attachment to the newborn (Cheng et al., 2021; Heo & Oh, 2019; Ortenstrand et al., 2010) and improved the parents' partnership with the nurses (Heo & Oh, 2019).

FCC focuses on the planning, delivery, and evaluation of health care that is based on mutually beneficial partnerships between health professionals, patients, and families. It redefines health care relationships and includes (a) caring for family members, such as recognizing and meeting family members' needs, (b) equal family participation in decision-making on care as well as on planning and providing care, (c) inter-professional and management-organizational collaboration with family members, (d) respecting family members, and (e) knowledge transformation (Gooding et al., 2011; Griffin, 2013; Gustavsson, 2016).

FICare is a model which embraces FCC principles and, by design, integrated families as part of their newborn's care team at a level 3 NICU (Franck et al., 2020; Waddington et al., 2021). The goal of FICare is to achieve a total integration of parental care in neonatal care by changing NICU care in such a way that parents are the primary caregivers for their newborns instead of the NICU staff (Jiang et al., 2014; Lee & O'Brien, 2014). It means that parents spend 6 to 8 hours in the NICU caring for their newborn with the support of staff, besides attending education sessions in small groups and participating in daily medical rounds (O'Brien et al., 2015; O'Brien et al., 2018). The four pillars of FICare are 'staff education and support' (Galarza-Winton et al., 2013), 'parent education' (Bracht et al., 2013), 'NICU environment', and 'psychosocial support' (Macdonell et al., 2013). Health professionals treat parents as the primary caregivers for their newborns and support them by means of special education programs to empower parents in their parental role. Simultaneously, they stimulate and facilitate interaction and proximity between parents and newborns.

For *shared decision-making* between parents and health professionals, medical rounds are held with the parents, also known as *family-centered rounds* (FCRs) (Harris, 2014; Rosenthal et al., 2021; Voos et al., 2011). In these FCRs, health professionals involve parents in decision-making processes to achieve parental autonomy in newborn care (Bouet et al., 2012; Diffin et al., 2016; Manning, 2012). However, inhibiting factors exist, such as a lack of effective communication, a lack of clear professional expectations, and problems with autonomy in power and control (Alves et al., 2014; Bedells & Bevan, 2016; Thomas, 2008; Weiss et al., 2016). In Europe, there is significant variation across neonatal wards in how they involve parents in medical rounds. This variation is likely due to cultural differences in welcoming parents to take part in the care of their newborns and due to differences in the willingness of health professionals to work together with the parents (Aija et al., 2019; Axelin et al., 2018). Other important factors are contextual factors, such as the room and seating arrangements, and support and coaching of parents in participating in medical rounds and in evaluating the rounds (Van Oort et al., 2019).

Since supporting parents in making shared decisions and self-management requires collaboration, communication, and educational skills of health professionals, health professionals should be able to *communicate and negotiate equally* and effectively with parents, particularly in decision-making situations (Aarthun et al., 2018). In neonatal wards, these aspects still need improvement in terms of parental empowerment (Beck et al., 2015; Idso & Basir, 2019; Labrie et al., 2021; Lorié et al., 2021; Wreesmann et al., 2021). Health professionals must surrender their need for control and autonomy and their habit of deciding for the patients, and they must accept that parents are in control (Codsi et al., 2021; Kilbride & Joffe, 2018; Lindberg

et al., 2018; Ubel et al., 2018). They must provide ongoing information and education to parents as important interventions for empowering parents (Franck et al., 2020; Gehl et al., 2020; Hunter et al., 2019; Platonos et al., 2018). Parent education should be well monitored, considering the reasons why parents do not always attend parent education groups, such as personal, self-interested reasons, and lack of awareness of the availability of the education groups (Forslund Frykedal et al, 2019). Various parental education programs exist, but individualized programs were found to be the most effective (Zhang et al.,2021). Parents need to negotiate with healthcare providers about their roles in the care of their sick newborns (Bedells & Bevan, 2016; Coyne, 2015; Pellikka et al., 2020). This negotiation includes determining what their participation in their newborns' care will comprise (Bedells & Bevan, 2016). Parents need to have the ability and the intellectual capacity to decide and act in complex care situations (Aarthun et al., 2018; Aarthun et al, 2019, 2020; Weiss et al., 2016).

Problem definition and research area

In our daily practice, health professionals experienced many obstacles when FICare was implemented as a model of care in our former traditionally designed maternity and neonatal level 2 ward. Due to the open-bay design of the traditional ward, there was little opportunity for parents to bond with their sick or preterm newborn, to have skin-to-skin contact, to breastfeed their newborn, or to pump in proximity to their newborn in a comfortable private setting. Some mothers of newborns admitted to the neonatal ward experienced psychosocial problems because they were admitted to the traditional maternity ward amidst other mothers with their healthy newborns in the same room, which meant that they were missing their own newborns. Mothers in their post-partum period had to be transferred repeatedly from the maternity ward to the neonatal ward, in bed, walking or in a wheelchair, depending on their own medical condition, and for help, they were dependent on the availability of the nursing staff, or on the presence of their partner, for whom there were no 'rooming-in' facilities. As a result, parents could only visit their newborns a few times per day. Because of the many transfers, the situation also caused communication and continuity problems between the parents, the health professionals of the neonatal ward and the health professionals of the maternity ward regarding the care needs of the mothers and the newborns. Shared decision making with the parents and parent education were limited to the scarce moments when parents would visit their newborns on the neonatal ward. As a result, parents could not bond properly with their newborns, nor could they develop their role as primary caregivers, and consequently they often were not ready to care for their child independently at the time of their newborns' discharge.

To address these problems, health professionals implemented the design of a new ward, called The Anna Pavilion, which combined FICare, couplet-care, single-family rooms, and rooming-in options, based on evidence of positive health outcomes for parents and newborns. The present research was initiated because there was a lack of insight into the experiences of parents and health professionals with such a combination of interventions to empower parents in neonatal level 2 care.

The aim of this thesis is to answer the following questions:

1. What can we learn from empowering parents in a neonatal level 2 setting after implementing FICare in combination with couplet-care, single-family rooms and rooming-in options?
2. What does this combination of care interventions mean for parents and health professionals?

The specific context of this thesis

The setting of the studies described in this thesis is an integrated ward for complex maternity and neonatal level 2 care, which was designed to empower parents as primary caregivers from admission to the hospital onwards by implementing and integrating the concepts of FICare, single-family rooms, couplet care, and rooming-in options. This setting supports the goal of keeping parents and their newborns together 24/7 during hospital admission by providing rooming-in facilities for partners during the hospital stay of the mother. If the newborn needs to remain in hospital after discharge of the mother, sleeping facilities are available for one parent, called rooming-in facilities. Both parents are welcome to visit their newborn 24/7, and they are encouraged to stay as often and for as long as their personal situation allows, but they are never obligated to stay or sleep in the hospital.

Overview of the studies

We used several qualitative research methods (Colorafi & Evans, 2016; Gale et al, 2013; Powson, 2013; Ritchie J, 2003) to better understand the phenomenon of parent empowerment within neonatal level 2 care and what parent empowerment means for parents and health professionals. Given that this thesis comprises articles published in peer-reviewed journals, some repetitions in several chapters were unavoidable.

The following chapters will answer the following sub-questions:

Chapter 2 describes a document and interview study on a hospital's organisational transition aimed at parental empowerment. This study answers the question, 'What changes took place in transforming traditional separated maternity and neonatal level 2 wards into an infrastructure to improve empowerment for parents of sick newborns?'

In *Chapter 3,* we explore the experiences of parents with empowerment regarding single-family rooms, rooming-in and couplet care of mothers and newborns, based on the FICare model with the fundamental principle of "the parent as primary caregiver". This study was conducted in the infrastructure described in Chapter 2. This study helped us to understand what parents experienced in this infrastructure and what they need to develop their parental role during hospitalization.

In *Chapter 4,* we explore the experiences of health professionals with empowerment through the education of parents in a setting built for parental empowerment. This study helped us to understand what can be improved in parent education to empower parents toward independent parenthood.

In *Chapter 5,* we explore the perceptions and experiences of health professionals regarding their changing role and identity within the context of a hospital infrastructure to empower the parents of sick newborns.

In *Chapter 6,* the findings of the thesis are discussed, followed by recommendations for further research.

References

Aarthun, A., Øymar, K. A., & Akerjordet, K. (2018). How health professionals facilitate parents' involvement in decision-making at the hospital: A parental perspective. *J Child Health Care, 22*(1), 108-121.

Aarthun, A., Øymar, K. A., & Akerjordet, K. (2019). Parental involvement in decision-making about their child's health care at the hospital. *Nurs Open, 6*(1), 50-58.

Aarthun, A., Øymar, K. A., & Akerjordet, K. (2020). Health professionals' involvement of parents in decision-making in interprofessional practice at the hospital. *J Interprof Care, 34*(3), 297-306.

Aija, A., Toome, L., Axelin, A., Raiskila, S., & Lehtonen, L. (2019). Parents' presence and participation in medical rounds in 11 European neonatal units. *Early Hum Dev, 130*, 10-16.

Ali, E., Norris, J. M., Hall, M., & White, D. E. (2020). Single-room maternity care: Systematic review and narrative synthesis. *Nurs Open, 7*(6), 1661-1670.

Alves, E., Amorim, M., Fraga, S., Barros, H., & Silva, S. (2014). Parenting roles and knowledge in neonatal intensive care units: protocol of a mixed methods study. *BMJ Open, 4*(7), e005941.

American Academy of Pediatrics (2012). Levels of neonatal care. Pediatrics, 130(3),10. Retrieved from https://pediatrics.aappublications.org/content/130/3/587.

Ashcraft, L. E., Asato, M., Houtrow, A. J., Kavalieratos, D., Miller, E., & Ray, K. N. (2019). Parent empowerment in pediatric healthcare settings: A systematic review of observational studies. *The Patient*.

Axelin, A., Outinen, J., Lainema, K., Lehtonen, L., & Franck, L. S. (2018). Neonatologists can impede or support parents' participation in decision-making during medical rounds in neonatal intensive care units. *Acta Paediatr.*

Baia, I., Amorim, M., Silva, S., Kelly-Irving, M., de, F. C., & Alves, E. (2016). Parenting very preterm infants and stress in Neonatal Intensive Care Units. *Early. Hum. Dev, 101*, 3-9.

Beck, J., Meyer, R., Kind, T., & Bhansali, P. (2015). The Importance of Situational Awareness: A Qualitative Study of Family Members' and Nurses' Perspectives on Teaching During Family-Centered Rounds. *Academic Medicine*.

Bedells, E., & Bevan, A. (2016). Roles of nurses and parents caring for hospitalised children. *Nurs Child Young People, 28*(2), 24-28.

Bouet, K. M., Claudio, N., Ramirez, V., & Garcia-Fragoso, L. (2012). Loss of parental role as a cause of stress in the neonatal intensive care unit. *Bol Asoc Med P R, 104*(1), 8-11.

Bracht, M., O'Leary, L., Lee, S. K., & O'Brien, K. (2013). Implementing family-integrated care in the NICU: a parent education and support program. *Advances in Neonatal Care, 13*(2), 115-126.

Bravo, P., Edwards, A., Barr, P. J., Scholl, I., Elwyn, G., & McAllister, M. (2015). Conceptualising patient empowerment: a mixed methods study. *Journal of Biomedical Science Health Service Research, 15*, 252.

Brenneman, & Price, K. M., (2014). Couplet Care: The Magic Within. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 43*(1).

Brown, P., & Taquino, L. T. (2001). Designing and delivering neonatal care in single rooms. *J. Perinat. Neonatal Nurs, 15*(1), 68-83.

Campbell-Yeo, M., Eriksson, M., & Benoit, B. (2022). Assessment and Management of Pain in Preterm Infants: A Practice Update. *Children (Basel), 9*(2).

Campbell-Yeo, M., Kim, T., Disher, T., Richardson, B., Dol, J., Bishop, T., et al. (2021). Do Single-Family Rooms Increase Parental Presence, Involvement, and Maternal Well-Being in Neonatal Intensive Care? *J Perinat Neonatal Nurs, 35*(4), 350-361.

Caporali, C., Pisoni, C., Gasparini, L., Ballante, E., Zecca, M., Orcesi, S., et al. (2020). A global perspective on parental stress in the neonatal intensive care unit: a meta-analytic study. *J Perinatol, 40*(12), 1739-1752.

Committee on Hospital Care and Institute for Patient-and Family-Centered Care (2012). Patient- and family-centered care and the pediatrician's role. *Pediatrics*. Feb;129(2):394-404. doi: 10.1542/peds.2011-3084.

Castro, E. M., Van, R. T., Vanhaecht, K., Sermeus, W., & Van Hecke, A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient. Educ. Couns, 99*(12), 1923-1939.

Celenza, J. F., Zayack, D., Buus-Frank, M. E., & Horbar, J. D. (2017). Family Involvement in Quality Improvement: From Bedside Advocate to System Advisor. *Clin Perinatol, 44*(3), 553-566.

Chen, J., Mullins, C. D., Novak, P., & Thomas, S. B. (2016). Personalized Strategies to Activate and Empower Patients in Health Care and Reduce Health Disparities. *Health Educ. Behav, 43*(1), 25-34.

Cheng, C., Franck, L. S., Ye, X. Y., Hutchinson, S. A., Lee, S. K., & O'Brien, K. (2021). Evaluating the effect of Family Integrated Care on maternal stress and anxiety in neonatal intensive care units. *J Reprod Infant Psychol, 39*(2), 166-179.

Codsi, M. P., Karazivan, P., Rouly, G., Leclaire, M., & Boivin, A. (2021). Changing relationships: how does patient involvement transform professional identity? An ethnographic study. *BMJ Open, 11*(7), e045520.

Colorafi, K. J., & Evans, B. (2016). Qualitative Descriptive Methods in Health Science Research. *HERD, 9*(4), 16-25.

Conde-Agudelo, A., & Díaz-Rossello, J. L. (2016). Kangaroo mother care to reduce morbidity and mortality in low birthweight infants. *Cochrane Database Syst Rev, 2016*(8), CD002771.

Cottrell, B. H., & Grubbs, L. M. (1994). Women's satisfaction with couplet care nursing compared to traditional postpartum care with rooming-in. *Res. Nurs. Health, 17*(6), 401-409.

Coyne, I. (2015). Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles. *Health Expect, 18*(5), 796-808.

Crenshaw, J. T. (2019). Healthy Birth Practice #6: Keep Mother and Newborn Together-It's Best for Mother, Newborn, and Breastfeeding. *J Perinat Educ, 28*(2), 108-115.

Cyr-Alves, H., Macken, L., & Hyrkas, K. (2018). Stress and Symptoms of Depression in Fathers of Infants Admitted to the NICU. *J Obstet Gynecol Neonatal Nurs, 47*(2), 146-157.

De Paula Eduardo, J. A. F., de Rezende, M. G., Menezes, P. R., & Del-Ben, C. M. (2019). Preterm birth as a risk factor for postpartum depression: A systematic review and meta-analysis. *J Affect Disord, 259*, 392-403.

De Salaberry, J., Hait, V., Thornton, K., Bolton, M., Abrams, M., Shivananda, S., et al. (2019). Journey to mother baby care: Implementation of a combined care/couplet model in a level 2 neonatal intensive care unit. *Birth Defects Research*.

Diffin, J., Spence, K., Naranian, T., Badawi, N., & Johnston, L. (2016). Stress and distress in parents of neonates admitted to the neonatal intensive care unit for cardiac surgery. *Early. Hum. Dev, 103*, 101-107.

Ding, X., Zhu, L., Zhang, R., Wang, L., Wang, T. T., & Latour, J. M. (2019). Effects of family-centred care interventions on preterm infants and parents in neonatal intensive care units: A systematic review and meta-analysis of randomised controlled trials. *Aust Crit Care, 32*(1), 63-75.

Doede, M., & Trinkoff, A. M. (2020). Emotional Work of Neonatal Nurses in a Single-Family Room NICU. *J Obstet Gynecol Neonatal Nurs, 49*(3), 283-292.

Domanico, R., Davis, D. K., Coleman, F., & Davis, B. O., Jr. (2010). Documenting the NICU design dilemma: parent and staff perceptions of open ward versus single family room units. *J. Perinatol, 30*(5), 343-351.

Dy, S. M., & Purnell, T. S. (2012). Key concepts relevant to quality of complex and shared decision-making in health care: a literature review. *Soc Sci Med, 74*(4), 582-587.

Dykes, F., Thomson, G., Gardner, C., Hall, M., V, & Flacking, R. (2016). Perceptions of European medical staff on the facilitators and barriers to physical closeness between parents and infants in neonatal units. *Acta Paediatr, 105*(9), 1039-1046.

Elliott-Carter, N., & Harper, J. (2012). Keeping mothers and newborns together after cesarean: how one hospital made the change. *Nurs Womens Health, 16*(4), 290-295.

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., et al. (2012). Shared decision making: a model for clinical practice. *J Gen Intern Med, 27*(10), 1361-1367.

Erlandsson, K., & Fagerberg, I. (2005). Mothers' lived experiences of co-care and part-care after birth, and their strong desire to be close to their baby. *Midwifery, 21*(2), 131-138.

Feeley, N., Genest, C., Niela-Vilen, H., Charbonneau, L., & Axelin, A. (2016). Parents and nurses balancing parent-infant closeness and separation: a qualitative study of NICU nurses' perceptions. *BMC. Pediatr, 16*, 134.

Feeley, N., Robins, S., Genest, C., Stremler, R., Zelkowitz, P., & Charbonneau, L. (2020). A comparative study of mothers of infants hospitalized in an open ward neonatal intensive care unit and a combined pod and single-family room design. *BMC Pediatr, 20*(1), 38.

Flacking, R., Lehtonen, L., Thomson, G., Axelin, A., Ahlqvist, S., Moran, V. H., et al. (2012). Closeness and separation in neonatal intensive care. *Acta Paediatrica, 101*(10), 1032-1037.

Flacking, R., Thomson, G., Ekenberg, L., Lowegren, L., & Wallin, L. (2013). Influence of NICU co-care facilities and skin-to-skin contact on maternal stress in mothers of preterm infants. *Sexual & Reproductive Healthcare, 4*(3), 107-112.

Forslund Frykedal, K., Barimani, M., Rosander, M., & Berlin, A. (2019). Parents' reasons for not attending parental education groups in antenatal and child health care: A qualitative study. *J Clin Nurs, 28*(17-18), 3330-3338.

Franck, L. S., Ferguson, D., Fryda, S., & Rubin, N. (2015). The Child and Family Hospital Experience: Is It Influenced by Family Accommodation? *Med Care Res Rev, 72*(4), 419-437.

Franck, L. S., & O'Brien, K. (2019). The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care. *Birth Defects Res, 111*(15), 1044-1059.

Franck, L. S., Waddington, C., & O'Brien, K. (2020). Family Integrated Care for Preterm Infants. *Crit Care Nurs Clin North Am, 32*(2), 149-165.

Galarza-Winton, M. E., Dicky, T., O'Leary, L., Lee, S. K., & O'Brien, K. (2013). Implementing family-integrated care in the NICU: educating nurses. *Adv Neonatal Care, 13*(5), 335-340.

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol, 13*, 117.

Gehl, M. B., Alter, C. C., Rider, N., Gunther, L. G., & Russell, R. B. (2020). Improving the Efficiency and Effectiveness of Parent Education in the Neonatal Intensive Care Unit. *Adv Neonatal Care, 20*(1), 59-67.

Gooding, J. S., Cooper, L. G., Blaine, A. I., Franck, L. S., Howse, J. L., & Berns, S. D. (2011). Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. *Semin. Perinatol, 35*(1), 20-28.

Griffin, T. (2013). A family-centered "visitation" policy in the neonatal intensive care unit that welcomes parents as partners. *Journal of Perinatal & Neonatal Nursing, 27*(2), 160-165.

Gustavsson, S. (2016). *Patient Involvement in Quality Improvement.*, Department of Technology Management and Economics, Chalmers University of Technology, Gothenburg.

Harris, G. M. (2014). Family-centered rounds in the neonatal intensive care unit. *Nursing for Womens Health, 18*(1), 18-27.

Heo, Y. J., & Oh, W. O. (2019). The effectiveness of a parent participation improvement program for parents on partnership, attachment infant growth in a neonatal intensive care unit: A randomized controlled trial. *Int J Nurs Stud, 95*, 19-27.

Holmstrom, I., & Roing, M. (2010). The relation between patient-centeredness and patient empowerment: a discussion on concepts. *Patient. Educ. Couns, 79*(2), 167-172.

Hunter, M. L., Blake, S., Simmons, C., Thompson, J., & Derouin, A. (2019). Implementing a Parent Education Program in the Special Care Nursery. *J Pediatr Health Care, 33*(2), 131-137.

Idso, J. M., & Basir, M. A. (2019). Errors in Clinician-Parent Communication during Neonatal Hospitalization. *Children (Basel), 6*(6).

Ionio, C., Colombo, C., Brazzoduro, V., Mascheroni, E., Confalonieri, E., Castoldi, F., et al. (2016). Mothers and Fathers in NICU: The Impact of Preterm Birth on Parental Distress. *Eur. J. Psychol, 12*(4), 604-621.

Jaafar, S. H., Ho, J. J., & Lee, K. S. (2016). Rooming-in for new mother and infant versus separate care for increasing the duration of breastfeeding. *Cochrane. Database. Syst. Rev*(8), CD006641.

Janssen, P. A., Klein, M. C., Harris, S. J., Soolsma, J., & Seymour, L. C. (2000). Single room maternity care and client satisfaction. *Birth, 27*(4), 235-243.

Jiang, S., Warre, R., Qiu, X., O'Brien, K., & Lee, S. K. (2014). Parents as practitioners in preterm care. *Early. Hum. Dev, 90*(11), 781-785.

Kainiemi, E., Hongisto, P., Lehtonen, L., Pape, B., & Axelin, A. (2021). Effects of single family room architecture on parent-infant closeness and family centered care in neonatal environments-a single-center pre-post study. *J Perinatol, 41*(9), 2244-2251.

Kilbride, M. K., & Joffe, S. (2018). The New Age of Patient Autonomy: Implications for the Patient-Physician Relationship. *Jama, 320*(19), 1973-1974.

Labrie, N. H. M., van Veenendaal, N. R., Ludolph, R. A., Ket, J. C. F., van der Schoor, S. R. D., & van Kempen, A. (2021). Effects of parent-provider communication during infant hospitalization in the NICU on parents: A systematic review with meta-synthesis and narrative synthesis. *Patient Educ Couns, 104*(7), 1526-1552.

Latour, J. M. (2011). *Empowerment of Parents in the Intensive Care. A journey discovering parents' experiences and satisfaction with care.* Rotterdam.

Lee, S. K., & O'Brien, K. (2014). Parents as primary caregivers in the neonatal intensive care unit. *CMAJ, 186*(11), 845-847.

Levin, A. (1994). The Mother-Infant unit at Tallinn Children's Hospital, Estonia: a truly baby-friendly unit. *Birth, 21*(1), 39-44, discussion.

Levin, A., & Chalmers, B. (2014). Family-centered neonatal intensive care. *Birth, 41*(3), 300.

Lindberg, C., Fagerström, C., & Willman, A. (2018). Patient autonomy in a high-tech care context-A theoretical framework. *J Clin Nurs, 27*(21-22), 4128-4140.

Lorié, E. S., Wreesmann, W. W., van Veenendaal, N. R., van Kempen, A., & Labrie, N. H. M. (2021). Parents' needs and perceived gaps in communication with healthcare professionals in the neonatal (intensive) care unit: A qualitative interview study. *Patient Educ Couns, 104*(7), 1518-1525.

Maben, J., Griffiths, P., Penfold, C., Simon, M., Anderson, J. E., Robert, G., et al. (2016). One size fits all? Mixed methods evaluation of the impact of 100% single-room accommodation on staff and patient experience, safety and costs. *BMJ Qual Saf, 25*(4), 241-256.

Macdonell, K., Christie, K., Robson, K., Pytlik, K., Lee, S. K., & O'Brien, K. (2013). Implementing family-integrated care in the NICU: engaging veteran parents in program design and delivery. *Advances in Neonatal Care, 13*(4), 262-269, quiz.

Mahlmeister, L. R. (2005). Couplet care after cesarean delivery: creating a safe environment for mother and baby. *J. Perinat. Neonatal Nurs, 19*(3), 212-214.

Mäkelä, H., Axelin, A., Feeley, N., & Niela-Vilén, H. (2018). Clinging to closeness: The parental view on developing a close bond with their infants in a NICU. *Midwifery, 62*, 183-188.

Manning, A. N. (2012). The NICU experience: how does it affect the parents' relationship? *J Perinat. Neonatal Nurs, 26*(4), 353-357.

Martínez, N., Connelly, C. D., Pérez, A., & Calero, P. (2021). Self-care: A concept analysis. *Int J Nurs Sci, 8*(4), 418-425.

McNair, C., Chinian, N., Shah, V., McAllister, M., Franck, L. S., Stevens, B., et al. (2020). Metasynthesis of Factors That Influence Parents' Participation in Pain Management for Their Infants in the NICU. *J Obstet Gynecol Neonatal Nurs, 49*(3), 263-271.

Ng, C. A., Ho, J. J., & Lee, Z. H. (2019). The effect of rooming-in on duration of breastfeeding: A systematic review of randomised and non-randomised prospective controlled studies. *PLoS One, 14*(4), e0215869.

Niela-Vilen, H., Feeley, N., & Axelin, A. (2017). Hospital routines promote parent-infant closeness and cause separation in the birthing unit in the first 2 hours after birth: A pilot study. *Birth, 44*(2), 167-172.

O'Brien, K., Bracht, M., Robson, K., Ye, X. Y., Mirea, L., Cruz, M., et al. (2015). Evaluation of the Family Integrated Care model of neonatal intensive care: a cluster randomized controlled trial in Canada and Australia. *BMC Pediatr, 15*, 210.

O'Brien, K., Bracht, M., Robson, K., Ye, X. Y., Mirea, L., Cruz, M., et al. (2015). Evaluation of the Family Integrated Care model of neonatal intensive care: a cluster randomized controlled trial in Canada and Australia. *BMC. Pediatr, 15*(1), 210.

O'Brien, K., Robson, K., Bracht, M., Cruz, M., Lui, K., Alvaro, R., et al. (2018). 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, 2*(4), 245-254.

Ortenstrand, A., Westrup, B., Brostrom, E. B., Sarman, I., Akerstrom, S., Brune, T., et al. (2010). The Stockholm Neonatal Family Centered Care Study: effects on length of stay and infant morbidity. *Pediatrics, 125*(2), e278-e285.

Pellikka, H. K., Pölkki, T., Sankilampi, U., & Kangasniemi, M. (2020). Finnish Parents' Responsibilities for Their Infant's Care When They Stayed in a Single Family Room in a Neonatal Intensive Care Unit. *J Pediatr Nurs, 53*, e28-e34.

Platonos, K., Aloysius, A., Banerjee, J., & Deierl, A. (2018). Integrated family delivered care project: Parent education programme. *Journal of Neonatal Nursing, 24*(1), 29-34.

Powson, R. (2013). *The sciene of evaluation: A realistic manifesto*. London: SAGE.

Prouhet, P. M., Gregory, M. R., Russell, C. L., & Yaeger, L. H. (2018). Fathers' Stress in the Neonatal Intensive Care Unit: A Systematic Review. *Adv Neonatal Care, 18*(2), 105-120.

Ramezani, T., Hadian, S. Z., Sabet, S. R., & Moattari, M. (2014). Family-centered care in neonatal intensive care unit: a concept analysis. *Int. J. Community Based. Nurs. Midwifery, 2*(4), 268-278.

Reed, G., & Schmid, M. (1986). Nursing implementation of single-room maternity care. *J Obstet Gynecol Neonatal Nurs, 15*(5), 386-389.

Ritchie J, L. J. (2003). *Qualitative research practice: a guide for social science students and researchers*. London: Sage.

Rosenthal, J. L., Sauers-Ford, H. S., Williams, J., Ranu, J., Tancredi, D. J., & Hoffman, K. R. (2021). Virtual Family-Centered Rounds in the Neonatal Intensive Care Unit: A Randomized Controlled Pilot Trial. *Acad Pediatr, 21*(7), 1244-1252.

Salomè, S., Mansi, G., Lambiase, C. V., Barone, M., Piro, V., Pesce, M., et al. (2022). Impact of psychological distress and psychophysical wellbeing on posttraumatic symptoms in parents of preterm infants after NICU discharge. *Ital J Pediatr, 48*(1), 13.

Shahheidari, M., & Homer, C. (2012). Impact of the design of neonatal intensive care units on neonates, staff, and families: a systematic literature review. *J. Perinat. Neonatal. Nurs, 26*(3), 260-266.

Siraneh, Y., Berhane, M., Abraham, G., Feyissa, G. T., & Morankar, S. (2021). Compliance to kangaroo mother care best practice: an evidence-based implementation project. *JBI Evid Implement, 19*(3), 228-235.

Smith, E. R., Bergelson, I., Constantian, S., Valsangkar, B., & Chan, G. J. (2017). Barriers and enablers of health system adoption of kangaroo mother care: a systematic review of caregiver perspectives. *BMC Pediatr, 17*(1), 35.

Soghier, L. M., Kritikos, K. I., Carty, C. L., Glass, P., Tuchman, L. K., Streisand, R., et al. (2020). Parental Depression Symptoms at Neonatal Intensive Care Unit Discharge and Associated Risk Factors. *J Pediatr, 227*, 163-169.e161.

Stevens, D. C., Helseth, C. C., Khan, M. A., Munson, D. P., & Reid, E. J. (2011). A comparison of parent satisfaction in an open-bay and single-family room neonatal intensive care unit. *HERD, 4*(3), 110-123.

Stevens, D. C., Helseth, C. C., Khan, M. A., Munson, D. P., & Smith, T. J. (2010). Neonatal intensive care nursery staff perceive enhanced workplace quality with the single-family room design. *J. Perinatol, 30*(5), 352-358.

Taylor, S. J. C., Pinnock, H., Epiphaniou, E., Pearce, G., Parke, H. L., Schwappach, A., et al. (2014). Health Services and Delivery Research. In *A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic Review of Self-Management Support for long-term conditions*. Southampton (UK): NIHR Journals Library

Thomas, L. M. (2008). The changing role of parents in neonatal care: a historical review. *Neonatal Netw, 27*(2), 91-100.

Treherne, S. C., Feeley, N., Charbonneau, L., & Axelin, A. (2017). Parents' Perspectives of Closeness and Separation With Their Preterm Infants in the NICU. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 46*(5), 737-747.

Tulu, S. N., Cook, P., Oman, K. S., Meek, P., & Kebede Gudina, E. (2021). Chronic disease self-care: A concept analysis. *Nurs Forum, 56*(3), 734-741.

Ubel, P. A., Scherr, K. A., & Fagerlin, A. (2018). Autonomy: What's Shared Decision Making Have to Do With It? *Am J Bioeth, 18*(2), W11-w12.

Umberger, E., Canvasser, J., & Hall, S. L. (2018). Enhancing NICU parent engagement and empowerment. *Seminars in Pediatric Surgery, 27*(1), 19-24.

Van Dokkum, N. H., de Kroon, M. L. A., Reijneveld, S. A., & Bos, A. F. (2021). Neonatal Stress, Health, and Development in Preterms: A Systematic Review. *Pediatrics, 148*(4).

Van Oort, P. J. S., Maaskant, J. M., Smeulers, M., van Oostrum, N., Vermeulen, E., & van Goudoever, J. B. (2019). Participation of Parents of Hospitalized Children in Medical Rounds: A Qualitative Study on Contributory Factors. *J Pediatr Nurs, 46*, e44-e51.

Van Veenendaal, N. R., Heideman, W. H., Limpens, J., Van der Lee, J. H., Van Goudoever, J. B., Van Kempen, A., et al. (2019). Hospitalising preterm infants in single family rooms versus open bay units: a systematic review and meta-analysis. *The Lancet. Child & Adolescent Health*.

Van Veenendaal, N. R., van Kempen, A., Franck, L. S., O'Brien, K., Limpens, J., van der Lee, J. H., et al. (2020). Hospitalising preterm infants in single family rooms versus open bay units: A systematic review and meta-analysis of impact on parents. *EClinicalMedicine, 23*, 100388.

Voos, K. C., Ross, G., Ward, M. J., Yohay, A. L., Osorio, S. N., & Perlman, J. M. (2011). Effects of implementing family-centered rounds (FCRs) in a neonatal intensive care unit (NICU). *J Matern. Fetal Neonatal Med, 24*(11), 1403-1406.

Waddington, C., van Veenendaal, N. R., O'Brien, K., & Patel, N. (2021). Family integrated care: Supporting parents as primary caregivers in the neonatal intensive care unit. *Pediatr Investig, 5*(2), 148-154.

Wallerstein, N. (2006). What is the evidence on effectiveness of empowerment to improve health? retrieved from www.euro.who.int/__data/assets/pdf_file/0010/74656/E88086 .pdf

Walsh, W. F., McCullough, K. L., & White, R. D. (2006). Room for improvement: nurses' perceptions of providing care in a single room newborn intensive care setting. *Adv. Neonatal Care, 6*(5), 261-270.

Weiss, E. M., Barg, F. K., Cook, N., Black, E., & Joffe, S. (2016). Parental Decision-Making Preferences in Neonatal Intensive Care. *J. Pediatr, 179*, 36-41.

Winner-Stoltz, R., Lengerich, A., Hench, A. J., O'Malley, J., Kjelland, K., & Teal, M. (2018). Staff Nurse Perceptions of Open-Pod and Single Family Room NICU Designs on Work Environment and Patient Care. *Adv Neonatal Care, 18*(3), 189-198.

Wreesmann, W. W., Lorié, E. S., van Veenendaal, N. R., van Kempen, A., Ket, J. C. F., & Labrie, N. H. M. (2021). The functions of adequate communication in the neonatal care unit: A systematic review and meta-synthesis of qualitative research. *Patient Educ Couns, 104*(7), 1505-1517.

Zhang, Q., Wu, J., Sheng, X., & Ni, Z. (2021). Empowerment programs for parental mental health of preterm infants: A meta-analysis. *Patient Educ Couns*.

'There comes a point where we need to stop just pulling people out of the river.
We need to go upstream and find out why they're falling in.'

Desmond Tutu

2

Integration of maternity and neonatal care to empower parents

Mireille A. Stelwagen
Anne A.M.W. van Kempen
Alvin H. Westmaas
Yvonne J. Blees
Fedde Scheele

Journal of Obstetrics, Gynecologic & Neonatal Nursing, 49(1), 12; 2020

Abstract

Objective: To describe the transition from a traditional hospital design with separate maternity and neonatal departments to a design in which maternity and neonatal health care infrastructures are integrated to empower parents.
Design: A descriptive, qualitative analysis.
Setting: A mother and child center in a teaching hospital in Amsterdam.
Participants: Six staff members who were involved in the transition.
Methods: We analyzed the content of all relevant policy reports and other related documents that were produced during the transition from April 2010 to October 2014. This content was supplemented with in-depth, semi-structured interviews with the six participants. We used thematic analysis and Bravo et al.'s model of patient empowerment to analyze the documents and the qualitative interview data.
Findings: We identified eight themes. At the health care system level, the four themes were *Joint Vision and Goal*, *Integration of Three Wards into One with Single Family Rooms*, *Reorganization of the Health Care Team*, and *New Equipment*. At the health care provider level, the three themes were *Training for Extension of Professional Goals*, *Intensified Coaching for Parents*, and *Implementing Patient Centeredness*. The single theme at the patient level was *Opinions and Experiences of Parents*.
Conclusion: We found a good fit between the new design and Bravo et al.'s model of patient empowerment. Challenges that remain include the adaptation of staff training programs and further development of the infrastructure in collaboration with staff and parents. The experiences of parents and staff members will be evaluated in future studies.

Introduction

The empowerment of parents indisputably improves the quality of health care for newborns and parents, and is conducive to successful development of the parental role (Latour, 2011). A common goal in neonatal units is to increase parents' participation in daily care and decisions regarding the health care of their infants (Ashcraft et al., 2018). In health care, empowerment is the process of giving power to individuals and supporting them to make their own decisions; through this process, they gain greater control over decisions and actions that affect their health (World Health Organization, 1998). In the context of high-risk maternity care, women are patients and parents of newborns who may require care in the NICU.

Women experience many physical and psychological problems when their newborns are admitted to separate neonatal units, such as breastfeeding problems, powerlessness, and stress (Al Maghaireh et al., 2016). A prerequisite for the empowerment of parents is the close physical proximity to their newborns (Makela et al., 2018). Traditional hospital designs with separate wards for mothers and newborns who need specialized care prohibit close physical proximity and thereby impede the empowerment of parents (Flacking et al., 2012).

In addition, it is essential for all health care professionals to acknowledge that parents are their newborns' primary caregivers from birth, even during hospitalization (Read & Rattenbury, 2018). To facilitate and promote close physical proximity and participation of parents in specialized maternity and neonatal care, specific care models have been described, such as family-centered maternity care (Zwelling & Phillips, 2001), single-room maternity care (Harris et al., 2004; Janssen et al., 2005), family-centered developmental care (Craig et al., 2015; McGrath, 2013), and family-integrated care (Bracht et al., 2013; Macdonell et al., 2013; O'Brien et al., 2013). All models imply parents should be closely involved as primary caregivers for their newborns, but the first two models are aimed at sick women and their partners on maternity wards, whereas the latter two are specifically aimed at parents of newborns admitted to NICUs. Important interventions and principles related to these models include shared decision-making (Harris, 2014), a welcoming visitation policy for parents (Griffin, 2013), and inclusion of parents as equal partners on the newborn's health care team (Ramezani et al., 2014).

Single-family rooms and family-integrated care models to empower parents have been successful in various ways, including reduced complications and readmissions (Bastani et al., 2015), improve survival, and shortened lengths of hospital stay of infants (Melnyk & Feinstein, 2009; Ortenstrand et al., 2010; White-Traut et al., 2015, van Veenendaal et al., 2019). Parents who participated also reported improved satisfaction with their infants' care; more confidence in their parental roles (Jones et al., 2016), and lower level of stress (Mianaei et al., 2014), depression, and anxiety (Bastani et al., 2015).

Couplet care of women and newborns in single-family rooms is a desirable and increasingly common practice in maternity care (Brenneman, 2014; Brockman, 2015; Elliott-Carter & Harper, 2012). In neonatal units, family-centered or integrated-care and single-family rooms are also increasingly used to improve care and to achieve a high level of parent empowerment (Stevens et al., 2015; Stichler, 2012). However, it has not yet become common practice for hospitals to provide couplet care in the same ward for mothers and newborns who both need specialized care for prolonged periods of time (Flacking et al., 2013). Neonatal units that provide couplet care frequently exclude women who need complex maternity care (De Salaberry et al., 2019; Mann, 2016). In addition, the woman's partner may have to adhere to visiting hours, and often no rooming-in facilities are available for partners who want to stay with their families (Hildingsson et al., 2009). The purpose of this article is to describe one hospital's transition from a traditional design with separate maternity and neonatal departments to a design in which maternity and neonatal health care infrastructures are integrated to empower parents.

Methods

Design

We used a descriptive, qualitative analysis in this study (Colorafi & Evans, 2016). The medical ethical review board of OLVG hospital, Amsterdam, The Netherlands approved the design and ethics of the study (MEC number WO.14.018).

Setting

We conducted this study at the Mother and Child Center of OLVG hospital, Amsterdam East, the Netherlands, at which approximately 3,000 births occur each year. Specialized maternity nurses provide care up to and including complex maternity care and up to and including level 1 neonatal care (American Academy of Pediatrics, 2012) for stable term and preterm infants born at more than 35 weeks' gestation. Specialized neonatal nurses provide level 2 neonatal care (American Academy of Pediatrics, 2012) for around 400 newborns each year. In the Netherlands, level 3 neonatal care is provided in the specialized NICUs of academic hospitals nearby. Pregnant women are transferred in the antepartum period to the specialized NICU centers if they are expected to give birth before 32 weeks' gestation or if the estimated birth weight is less than 1200 grams. Infants convalescing after intensive care are transferred to teaching hospitals with certified, neonatal, post-intensive care beds after they attain the postconceptional age of 30 weeks or more and body weights greater than 1000 g. Each year, approximately 70 of these premature newborns are admitted to the five certified, neonatal, post-intensive care beds

at the Mother and Child Center of OLVG hospital. They often require noninvasive respiratory support for prolonged periods.

Participants

We recruited participants for semi-structured interviews with the use of a purposeful sampling approach until we reached data saturation. Health care staff of the neonatal and maternity wards who participated intensively from the start of the project to the opening of the new ward were included. The intended sample included at least one participant from each discipline of each specialty area. The first author (M.S.), who was involved in the transition process as a nurse educator, interviewed six participants: the head nurse and the head midwife of the maternity ward, the head nurse of the neonatal ward (fourth author; Y.B.), the manager of the Mother and Child Center, an obstetrician-gynecologist, and a neonatologist (second author; A.v.K).

Data sources and procedures

Between September 2016 and April 2017, we collected all the relevant filed documents that were produced during the transition process between April 2010 and October 2014, such as policy reports, education programs, annual reports, information materials, presentations, and minutes of regular meetings related to the changes that were made to create the new infrastructure. We included documents if they described interventions or conditions to achieve the empowerment of parents of sick newborns. First, the first and fourth authors (M.S. and Y.B.) independently selected the documents; in case of disagreement, we consulted the second author (A.v.K) to determine the final selection. We stored all the collected documents electronically and processed the data in MaxQDA 2007 (VERBI Software, 2007), a qualitative data analysis software.

We also included qualitative data from semi-structured interviews. The aim of the interviews was to refine, confirm, and further explain data extracted from the documents reviewed. To structure the interviews, we used infrastructure-related categories extracted from the analysis of the documents. The researchers informed the participants about the purpose of the interview and told them that additional information would be processed anonymously as notes in an electronic environment, meaning that other researchers could not see who had provided specific information. All participants provided informed consent before starting the interviews.

Analysis

We used thematic analysis with an inductive and deductive coding approach (Fereday & Muir-Cochrane, 2006). Independently, two authors (M.S. and Y.B)

inductively open coded the data extracted from the documents and categorized these codes into categories. Uncertainties and gaps within these categories were supplemented by the data from the interviews. Next, we used the model of Bravo et al. (2015; see Figure 1) for deductive thematic analysis of the categories that emerged from the inductive thematic analysis (Bergdahl & Bertero, 2015; Neale, 2016). We chose this model because themes from models of parent and patient empowerment show many similarities and because it was the most recent and likely the most complete model of patient empowerment. Bravo et al.'s model distinguishes themes of moderators and interventions that can influence the process of patient empowerment at three different levels: the health care system level, the health care provider level, and the patient level. We allocated the categories that emerged from our data to the themes of the three levels of Bravo et al.'s model to check if and how the emerging categories fit with the themes of patient empowerment. As the primary researcher, the first author (M.S.) regularly discussed her findings with the second and fourth authors (A.v.K and Y.B.) as a member check. In case of disagreements, they consulted the third and fifth author (A.W. and F.S).

Findings

We identified 207 electronically filed documents and selected 38 key documents for analysis. In addition, we conducted six interviews. Most of the documents were policy documents and minutes of working groups. All the identified interventions and conditions for the new infrastructure fit within themes at the three levels of Bravo et al.'s (2015) patient empowerment model. We identified four themes at the health care system level, three themes at the health care professional level, and one theme at the patient level.

Health care system level

We identified four themes at the health care system level: *Joint Vision and Goal*, *Integration of Three Wards into One with Single-Family Rooms*, *Reorganization of the Health Care Team*, and *New Equipment*.

Joint vision and goal

In the OLVG hospital, the changes began with the renovation of the outdated maternity and neonatal wards. In the process of planning this renovation, the Hospital Board of Directors allowed the operational managers of the units, obstetrics and pediatrics, to design a future-oriented Mother and Child Center. The initial design adhered to the extant model, with one ward for maternity care

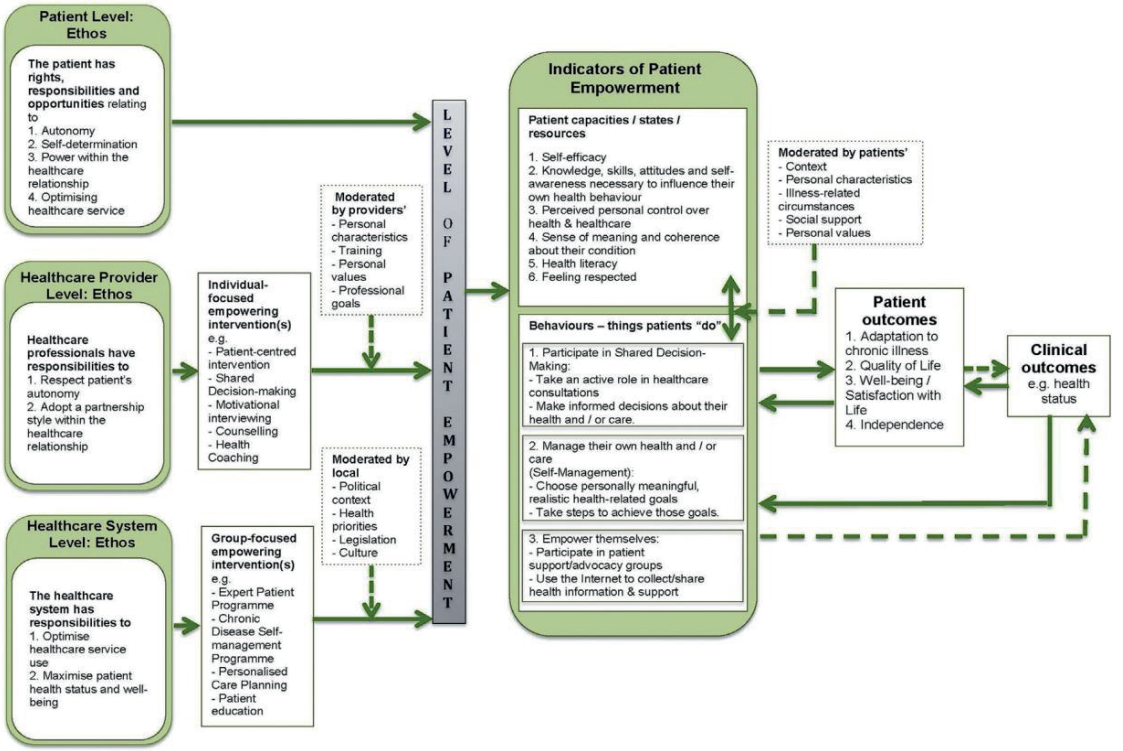


Figure 1. The conceptual model of patient empowerment. Categories, indicators, and moderators of patient empowerment at three levels: patient, health care provider and health care system. Reprinted with permission from "Conceptualising Patient Empowerment: A Mixed Methods Study," by P. Bravo, A. Edwards, P. J. Barr, J. Scholl, G. Elwyn, and M. McAllister, 2015, BMC Health Service Research, 15, 252. Licensed under the Creative Commons Attribution 4.0 International License, which permits unrestricted use, distribution, modification, and reproduction in any medium (http://creativecommons.org/licenses/by/4.0). Published by Springer Nature.

during labor and birth, one ward for maternity care during pregnancy and the postpartum period with level 1 neonatal care, and one level 2 neonatal ward for newborns. It was proposed that both maternity care wards be modified to two separate departments with single-family rooms that had rooming-in facilities for partners, whereas the neonatal ward would remain an open-bay unit, with separated rooming-in facilities for the parents.

Meanwhile, resistance had grown among maternity and neonatal health care professionals against any kind of separation of mothers from newborns who need specialized care. Their plea resulted in a joint vision and goal for the new Mother and Child Center: Mothers (parents) and their newborns can always stay together during hospitalization to optimize bonding between the newborns and their parents. The awareness of this collective goal generated new ideas among the involved health care professionals and led to fundamental choices for the organization of integrated maternity and neonatal care.

Integration of three wards into one with single-family rooms

Maternity and neonatal health care professionals realized that a traditional floor plan with separate wards for maternity care and an open-bay unit for neonatal level 2 care would be a suboptimal design. Because the necessary level of care for the mother and the newborn can change during hospitalization, frequent transfers from one ward to another were expected. In light of the goal of 'always keep mother and newborn together', the new Mother and Child Center also had to facilitate couplet care in the same room if both the mother and the newborn need specialized care. One of the head nurses formulated the solution as follows: "If we do not want to separate mothers and newborns, then we will literally need to integrate the wards." From this perspective, the units designed one integrated ward with 53 single-family rooms equipped for complex maternity care and levels 1 and 2 neonatal care, where mother and newborn can stay together for the entire hospitalization, even after one of them has been discharged administratively. Rooming-in facilities for the partner are included in the single-family room. Three types of suites were designed (see Table 1) and evenly distributed throughout the ward, so there is no separate neonatal or maternity ward, and there is no open-bay unit. With this infrastructure, the designers aimed to facilitate the consistent physical proximity of parents and newborns during hospitalization to facilitate all opportunities for parents to assume their parental responsibilities and to guarantee that newborns are never separated from their parents.

Reorganization of the health care team

To keep mother and newborn together while providing the necessary medical care for both, the health care teams needed to reorganize their work processes.

Table 1 Design of three types of single-family rooms

Characteristics	Type 1 (22)	Type 2 (18)	Type 3 (13)[b]
Patients	Women in labor, during birth and the postpartum period/newborns	Pregnant women or women in the postpartum period and newborns	Newborns
Medical equipment[a]	Maternity care (all levels) and neonatal care (all levels)	Maternity care (all levels) and neonatal care (standard and level 1 care)	Neonatal care (levels 1 and 2)
Hospitalization/ discharge	Women and newborn will stay in this suite as long as both need specialized medical care	Transferred from a type 1 single-family room	Transferred from academic hospitals or from a type 1 single-family room
Rooming-in facilities for	One partner	One partner	Both parents all day, one parent during the night
Number of square meters	29	22	20

Note. Extracted with permission from the policy report Notitie veranderplan Anna Paviljoen OLVG, juli 2012, versie 2.

[a] Portable resuscitation equipment is available for all suites for neonatal life support or if a woman needs basic or advanced life support. [b] In case of twins, two neonatal suites can be connected by opening a double door.

The former teams were reorganized and integrated into a combined maternity-neonatal team. A calculation was made to predict the extent of care differentiated according to all couplet care combinations (see Table 2). Before the transition, couplet care for mothers who needed maternity care and their newborns who needed level 1 neonatal care was provided on 57,75% of hospital days by specialized maternity nurses, even in the case of standard maternity care (28,42%). With the new layout, the staff expected that 60,14% of hospital days would be needed to provide care for newborns with level 1 or non-complex level 2 care combined with women who need standard maternity care; 35,31% combined with women who need medium complex maternity care; and 4,55% combined with women who need high complex maternity care.

To organize the work in the new, integrated center and assign the appropriate educated health care professionals to the different couplets, a matrix was drawn

Table 2 Expected number of hospitalization days per year for each patient category at the new ward

	Maternity Care			
Neonatal Care	Standard	Medium Complex	High Complex	Total
Level 1	4.453 28.42	4.219 26.94	375 2.39	9.047 57.75
	375 2.39%	600 3.83%	225 1.44%	1.200 7.66%
Noncomplex Level 2				
Level 2	4.594 29.33%	712 4.54%	113 0.72%	5.419 34.59%
Total	9.422 60.14%	5.531 35.31%	713 4.55%	15.666 100%

Note. Expected hospitalization days and percentage per year based on the expected 3,100 births per year. Level 1 ¼ care for stable full-term newborns who need screening and/or treatment for neonatal hypoglycemia; observation and/or treatment for perinatal infection; or observation because of maternal medication use during pregnancy, phototherapy for hyperbilirubinemia, or (short-term) nasogastric tube feeding. Noncomplex Level 2 = care for clinically stable preterm infants at ≥ 34 weeks' gestation and birth weight ≥ 1,700 g who may need incubator care, cardiorespiratory monitoring, and/or double phototherapy. Level 2 = care for preterm newborns < 34 weeks gestation or birth weight < 1,700 g or newborns who need respiratory support with nasal continuous positive airway pressure or high- or low-flow therapy, parenteral nutrition, central venous lines, or intensive phototherapy; newborns convalescing after intensive care at ≥ 30 weeks postconceptional age and birth weight ≥ 1000 g or newborns who need to be stabilized, born before 32 weeks gestation and weighing less than 1,200 g; or newborns who need mechanical ventilation, vasopressor support, therapeutic hypothermia, or other intensive care treatments until transferred to a neonatal intensive care facility (level 3). Maternity care: standard ¼ uncomplicated maternity care. Medium complex = care for women with stable preeclampsia, diabetes gravidarum (no insulin), hyperemesis, abortion, birth of twins, pain-relief interventions, cesarean birth, and postpartum hemorrhage. High complex = care for women with HELLP syndrome and preeclampsia, diabetes (with insulin), or serious complications based on infections. Women are transferred to the intensive care unit if they need mechanical ventilation or intra-arterial blood pressure monitoring. Extracted with permission from the policy document, PVE Nieuwbouw 2e etage. Units Gynaecologie/verloskunde & Kindergeneeskunde. November 2009 definitief.

with all couplet care combinations for the different levels of health care needs of mothers and newborns. The care that can be provided includes neonatal level 2 care and all maternity care, unless women need mechanical ventilation or intra-arterial blood pressure monitoring (see Table 3).

The aim was to assign one nurse to one mother-newborn couplet. The rationale for this choice was to limit the number of different nurses a family would meet, allow for a more personal approach, and improve coaching for parents. Only if the mother and newborn both needed specialized care at the highest level (0,72% of hospital days, see Table 2) would they each be assigned to a specialized nurse with both nurses working together in the single-family room.

Table 3 Assigning patients in different levels of care situations to nurse functions at the new integrated ward

	Maternity Care		
Neonatal Care	**Standard**	**Medium Complex**	**High Complex**
Level 1	Registered nurse	Specialized mother and newborn nurse	Specialized maternity nurse
Noncomplex Level 2	Specialized mother and newborn nurse	Specialized mother and newborn nurse	Specialized maternity nurse
Level 2	Specialized neonatology nurse	Specialized neonatology nurse	2 nurses: maternity nurse and a neonatology nurse

Note. Neonatal care: Level 1 ¼ care for stable full-term newborns including newborns who need screening and/or treatment for neonatal hypoglycemia; observation and/or treatment for perinatal infection; or observation because of maternal medication use during pregnancy, phototherapy for hyperbilirubinemia, or (short-term) nasogastric tube feeding. Noncomplex Level 2 ¼ care for clinically stable preterm infants at ≥ 34 weeks' gestation and birth weight ≥ 1,700 g who may need incubator care, cardiorespiratory monitoring, and/or double phototherapy. Level 2 = care for preterm newborns < 34 weeks gestation or birth weight < 1,700 g or newborns who need respiratory support with nasal continuous positive airway pressure or high- or low-flow therapy, parenteral nutrition, central venous lines, or intensive phototherapy; newborns convalescing after intensive care at ≥ 30 weeks postconceptional age and birth weight ≥ 1,000 g or newborns who need to be stabilized born before 32 weeks gestation and weighing less than 1,200 g; or newborns who need mechanical ventilation, vasopressor support, therapeutic hypothermia, or other intensive care treatments until transfer to a neonatal intensive care facility (level 3). Maternity care: standard = uncomplicated maternity care. Medium complex = care for women with stable preeclampsia, diabetes gravidarum (no insulin), hyperemesis, abortion, birth of twins, pain-relief interventions, cesarean birth, and postpartum hemorrhage. High complex = care for women with HELLP syndrome and preeclampsia, diabetes (with insulin), or serious complications based on infections. Women are transferred to the intensive care unit if they need mechanical ventilation or intra-arterial blood pressure monitoring.

Most mother-newborn couples in the OLVG hospital need standard or medium complex care (61,58%; see Table 2). In the previous situation, the wards only employed specialized maternity or neonatal nurses. Integrating the care for mother and newborn required the creation of a new nurse position: a nurse who can provide level 1 and noncomplex level 2 care for the mother and the newborn, as detailed in Table 3 (see also health care professionals' level section). Hence, the new integrated maternity-neonatal nursing team addresses four functions of health care professionals.

To prepare the organization and the staff for the different workflows in the integrated center, special working groups outlined clinical workflows and prospective risk assessments for all possible care situations, a classification model for the workload, and an adjudication system for the health care professionals. Nurse coordinators were appointed to plan and organize hospitalization and to allocate the appropriate health care professional to each single-family room.

All working groups consisted of staff members of all the involved disciplines at every level of the organization of the units. The progress of the working groups was presented and discussed in several meetings for the entire staff. During these sessions, feedback was collected on all plans to refine the infrastructure. Staff supported the changes because the changes ensured that families and newborns would always stay together, and the staff expected that the privacy of the single-family rooms would facilitate bonding and breastfeeding and resolve communication problems between staff and parents.

Although most staff members had positive attitudes towards the new training and personal development opportunities, some staff members were more reluctant and mentioned that rest might be a problem for mother and newborn if both were very sick. Other concerns were that the large team and the even larger department with single-family rooms might make work conditions less personal, leading to more communication problems with colleagues and increased workload. Some staff members mentioned uncertainties about competence profiles, duties and responsibilities of all nurse positions and about how to supervise all the newborns, especially if newborns were alone in the single-family rooms.

New equipment

Each single-family room is fully equipped with standard equipment and supplies for maternity care and neonatal care. Moreover, each single-family room is equipped with facilities that were specifically requested by the parents and the staff, such as cameras that enable the parents to see the newborn when they are at home (see Table 4). Because nurses take care of patients in different suites, additional safety procedures were necessary besides the standard nurse call system. All neonatal monitors are connected to an alarm system for the nurses. Monitor alarms in any of the suites can be reviewed on all the other neonatal monitors and in the central nursing stations. Cameras enable the nurses to observe newborns in real time without having to enter the family suite. The rationale for the design and the choice of equipment was to create an environment that facilitates the parenting role and ensures sufficient nursing supervision and safety for the newborn.

Health care provider level

We identified three themes at the health care provider level: *Training for Extension of Professional Goals*, *Intensified Coaching of Parents*, and *Implementing Patient Centeredness*.

Table 4 Wishes of parents for the new ward

Wish	Measures Taken
Good preparation and insight into dismissal (date)	Daily medical rounds at the single-family room with parents; a whiteboard for daily notes, such as questions and suggestions to discuss
Room to meet other parents[a]	A meeting place for parents centrally located at the ward with a vending machine for drinks
A bath to give birth in[a]	Portable bath
Cameras in the rooms so parents can see their child from home	Cameras aimed at the incubator. Parents or other family members can watch the newborn at home with webcam technology on the Internet with a login code and a safety code.
Closets and storage room near the woman's bed	Closets installed, as well as a sofa bed for rooming-in partners, a locker with a safe, and a small refrigerator.
Security, access to the room, and supervision when the newborn is alone in the room[a]	When the parents are not present, the doors of the suite are locked. Staff members and parents can unlock them. Newborns who are alone in the suite are always connected to an oxygen saturation monitor to alarm the nurse in case of an emergency. Cameras connected to monitors at the back office provide nurses with a real-time image of all newborns without having to enter the suites.
Television and Internet connection in the room[a]	All suites have a television and a computer terminal with connections to the Internet and the hospital's intranet.
Transparent windows with curtains[a]	The front wall and the entrance door of each suite are made of clear glass to create a sensation of light and space and to prevent the occupants from feeling locked up. For privacy, two curtains are provided, one of semitransparent material and one of nontransparent material.

Note. Extracted with permission from the minutes Bijeenkomst d.d. 15-02-10 focusgesprekken van 26 november 2009 en 10 december 2009 and an unpublished research report: "Hoe ervaren moeders de opnameperiode van hun zieke pasgeborenen op de afdeling neonatologie (voorjaar 2014) ten aanzien van de uitgangspunten van Family Integrated Care?".

[a] Concerns and wishes of the staff extracted with permission from minutes from Informatieavonden Anna Paviljoen mei 2011.

Training for extension of professional goals

Before the transition, the team did not include a specialized nurse who could provide medium complex care for mothers and newborns (see Table 3). Therefore, a new nurse position was created, the specialized mother and newborn nurse. Because the extant training programs for nurses focus on maternity or neonatal

care, the training for the new nurse position had to be developed to enable nurses to provide health care for mothers and newborns. This specialized training program (see Table 5) for the new nurse position was developed first as an in-hospital training for registered nurses before it was transferred to a nationally recognized vocational training institute. After this training, the nurse can work in the position of specialized mother and newborn nurse or can specialize further in complex care for mothers or newborns (level 2).

Besides training new mother and newborn nurses, extra training courses were organized for all specialized maternity and neonatal nurses (see Table 5) to allow them to refresh and expand their professional capacities in the area of the other specialty. Once the units were integrated, this was followed by training on the job through peer support and nurse-to-nurse coaching. In the new situation, newly hired nurses are trained as mother and newborn nurses. Newly hired, specialized nurses are trained according to an individual professional training plan.

Intensified coaching of parents

The working groups anticipated that health care professionals would need to expand their roles as coaches and adopt a partnership style when working with parents in the single-family rooms. In these single-family rooms, parents are the most constant factors in the care of their well or ill newborns and act as equal partners on the health care team. In preparatory team sessions, the staff discussed how to coach and encourage parents to participate in all situations related to the care of their sick or preterm infants and to take gradually over from the nurses.

The rationale for the strong focus on coaching was the belief that coaching is conducive to the empowerment of parents. Although nurses were already accustomed to coaching parents to take on their roles as parents on the open-bay ward, the staff had no experience with working more intensively with parents within the single-family rooms, especially when the mother needed specialized/complex maternity care. Hence, it was not clear beforehand which specific training the staff would need to support the parent empowerment process. Therefore, the staff planned to develop an advanced training program for coaching after the transition.

Implementing patient centeredness

In the single family rooms, parents can remain with their newborns constantly. This enables the staff to implement family-integrated care further. Members of the working groups expected that open communication and close collaboration between parents and health care professionals would increase and result in improvements to the exchange of information and shared decision making. The steering group held several team meetings to discuss the concept of family-

Table 5 Training program for nurses

Theory lessons for mother and newborn nurses (6 days)	
Theory lessons for neonatology nurses (2 days)	**Theory lessons for maternity nurses (2 days)**
Information on women in the postpartum period	Development and growth and transition intrauterine-extrauterine
Pregnancy	Neurologic development and care
Hypertensive disorders (postpartum)	Neurologic diseases
Resuscitation of a pregnant woman	Neonatal life support
Physiology of birth	Infections and neonatal icterus[a]
Pathology of birth	Moisture, nutrition, and electrolytes[a]
Physiology and pathology of the postpartum period	Oxygen therapy and monitoring[a]
Psychiatric disorders and psychiatric diseases	Thermoregulation, early feeding skills[a]
Cardiotocogram	Observation of newborns[a] Discharge of newborns
Training on the job	
Specialized mother and newborn nurse (before and after the new ward opened)	Specialized neonatology nurse and maternity nurse (after the new ward opened)
4 months: pregnant women and women giving birth 4 months: women in the postpartum period and neonates	Peer support and coaching each other at the suites

Note. Newly hired registered basic nurses after the new ward opened were scheduled to be trained as mother and newborn nurses. Newly hired specialized nurses were scheduled to be trained according to an individual professional training plan. Extracted with permission from Training Syllabi: Syllabi scholing Neonatologie Verpleegkundigen, Obstetrieverpleegkundigen en Verpleegkundige Moeder en Pasgeborene, maart, 2014.

[a] Newborns > 34 weeks gestation.

integrated care in single-family rooms, with the aim of increasing respect for parents' autonomy and for the parents' roles as primary caregivers of their infants. The meetings underscored the importance of facilitating and encouraging parents to stay close to their newborn and of encouraging parents to act as equal partners of the health care team.

In the preparatory sessions with the entire staff, the team also agreed that the staff would invite parents in the single-family rooms to participate in the development of the personal care plans for mother and newborn. Medical rounds were planned to take place only in the single-family rooms, to invite the parents to

be present during the rounds and promoting active participation in discussion and decision-making. Members of the working groups expected parents would spend more time with their newborns and would intensify their participation in daily care (e.g. changing diapers, bathing, supporting the newborn during medical rounds or nursing procedures, and feeding [including tube feeding]). Parents, in collaboration with the nurses, would control visiting hours and determine their own rules for visits from family members and friends. The rationale for these measures was that all the routines of the ward must support the principle of intensive patient participation and the aim of accelerating the development of parents in their roles as primary caregivers.

Patient level

We identified one theme at the patient level: *Opinions and Experiences of Parents*.

Opinions and experiences of parents

Before the transition to the new infrastructure, the staff asked parents to share their views on the necessary requirements for the new ward. The rationale for requesting and incorporating the parents' input was that the parents themselves know best what they need for their own empowerment process. While designing the new ward, the staff invited parents who were discharged recently from the conventional wards to participate in two focus groups on equipment for the future single-family rooms. In five other sessions, the staff invited parents to express their views on how to organize the future infrastructure to enhance family-integrated care.

Parents' opinions informed the choice of the equipment for the family rooms (see Table 4) and the design of the routines for communication between parents and health care professionals. The most important wish parents expressed was to be better informed by the physicians, especially before the health care plan for the newborn was established and implemented. The staff expected to be able to solve this problem by scheduling daily medical rounds in the single-family rooms with the parents present.

Furthermore, parents were mainly very positive about the fact that they could always stay close to each other and their newborns to experience a real family feeling. Parents saw good opportunities for privacy, rest, bonding, breastfeeding, getting to know their newborns, and comforting their newborns and each other. Parents mentioned they also believed the single-family room design would solve experienced problems caused by the separate wards. For example, transport problems, communication and coordination problems between the separate neonatal and maternity staffs, and problems that arose on the open-bay maternity ward from being confronted with the suffering of other mothers or with the earlier discharge of women with their well newborns.

Discussion

The purpose of our study was to describe the transition from a traditional hospital design with separate maternity and neonatal departments to a design in which maternity and neonatal health care infrastructures are integrated to empower parents. The change process began with a staff of the maternity and neonatal units developing the shared vision that mothers (parents) and their newborns should always stay together during hospitalization to optimize bonding between newborns and parents. The primary changes pertained to the health care system level. The renovation of the outdated maternity and neonatal wards made it possible to organize couplet care on a single integrated ward for sick mothers and sick newborns in single-family rooms.

The changes at the health care provider level consisted of training programs for health personnel and new work routines that support a climate of patient or parent empowerment. These included the creation of a new nurse position, the specialized mother and newborn nurse, and supplemental training programs for specialized personnel. In addition, the staff planned time for shared decision making during the daily medical visiting rounds at the single-family rooms. In addition, they implemented several patient-centered routines, such as regulating visiting hours for friends and family by the parents themselves, with guidance from the nurses on request. Moreover, the teams agreed to focus more on coaching the parents in caring for their newborns.

Analysis of the infrastructure changes with the help of the patient empowerment model of Bravo et al. (2015) showed that most of the changes occurred at the health care system level and the health care professional level, whereas fewer changes occurred at the patient level. This suggests that once the new infrastructure has been implemented, an evaluation is needed to co-create (Israilov & Cho, 2017) changes for empowerment with the parents.

Although it was clear from the start that personnel would require training to be able to adopt coaching roles with the parents, it was difficult to design an effective training before the actual change took place because the staff had no experience in working more intensively with parents within single-family rooms. Hence, the management postponed the design of this training until the staff knew what specific training they needed to be able to empower the parents in the care of their infants.

We are aware that besides high complex maternity care, this case focuses on level 1 and level 2 neonatal care. Integrating maternity care and level 3 neonatal care will be an even greater challenge because of the complexity of care. However, NICUs with single-family rooms and family-integrated care are becoming more common. They are designed and implemented in various ways, and health care

professionals are aware of the importance of creating better conditions to empower parents (Hall et al., 2017; Ottosson & Lantz, 2017; Umberger et al., 2018).

We propose that the new integrated infrastructure of family-integrated care in single-family rooms should be evaluated by all stakeholders, particularly parents, as should the effect on parent empowerment (Denham, et al., 2018). In our case, the parents' opinions informed the design of the new infrastructure. We recognize the importance of focusing on the perspectives of patients to optimize health care infrastructures. Exploration and identification of these needs may help to bridge the gap between current professional practice and the needs of parents in new infrastructures for parent empowerment. Co-creation of health care at the system level and optimal use of the patients' views are relatively new in the context of health care infrastructure design and should be topics for future research.

Other specific themes to be explored include the experiences of parents with the environmental context of hospital wards related to close physical proximity and separation (Benoit & Semenic, 2014; Butt et al., 2013; Gaboury, et al., 2017; Raiskila et al., 2016; Treherne et al., 2017) and parents' experiences regarding the cooperation with the professionals and their feelings about their empowerment. To optimize the empowerment of parents, insights into the experiences of nurses and physicians regarding the cooperation with parents are also required, especially during shared decision-making (Beck et al., 2015). Furthermore, there is a need to explore the changes in the nurses' roles (focused more on coaching) and their newly experienced needs for training. The results of such studies may provide guidance for closing the perceived gaps between parents, health care professionals, and managers related to neonatal care (Butt et al., 2013; Lantz & Ottosson, 2014).

In this context, evaluation of how the new infrastructure affects collaboration between parents and health care professionals is important (Cleveland, 2008). It is likely that the new infrastructure will cause changes in the professional identity of the health care professionals, and future research may identify emerging training needs, particularly for nurses. Our research group is currently evaluating the new infrastructure regarding to the health outcomes of parents and newborns. The preliminary results are positive but will also provide guidance for further improvements.

To support the comparison of designs of infrastructures for parent empowerment in hospitals, to inform the discussion, and to increase the awareness of the need for change, there is a need for research on other examples of empowering infrastructures that prevent the separation of parents from newborns who need higher levels of neonatal care (Dall'Oglio et al., 2019; White, 2016). The literature provides some descriptions of couplet care for women with their sick newborns (De Salaberry et al., 2019; Mann, 2016), but we believe it is necessary to reflect on how these infrastructures are related to parent empowerment.

A strength of the current study is that we used a model of patient empowerment to structure our results. This enabled us to gain systematically insights into which aspects have already been considered and which still deserve attention in the further development of the new design to empower parents. A limitation of our study is the minimal description of the implementation strategy and the cost.

Conclusion

Our description of the design and implementation of an integrated infrastructure for maternity care and neonatal care to facilitate parent empowerment showed that health care professionals and systems could move away from traditional ideas and structures within each specialty in order to optimize the integration of maternity and neonatal care. Achieving parent empowerment in hospitals requires a readiness for change (Bank et al., 2017). Furthermore, our case study demonstrated that the design of this infrastructure showed a good fit with the themes for patient empowerment, as described in the model of Bravo et al. (2015). Therefore, this infrastructure appears to optimize and promote parent empowerment, but challenges remain. Training programs for staff need to be modified to match their changed role in coaching of parents and making shared decisions with parents who are present 24 hours a day. Co-creation with staff and parents is needed to empower parents optimally with the new design.

References

Al Maghaireh, D. F., Abdullah, K. L., Chan, C. M., Piaw, C. Y., & Al Kawafha, M. M. (2016). Systematic review of qualitative studies exploring parental experiences in the neonatal intensive care unit. *Journal of Clinical Nursing, 25*(19-20), 2745-2756. https://doi.org/10.1111/jocn.13259

Ashcraft, L. E., Asato, M., Houtrow, A. J., Kavalieratos, D., Miller, E., & Ray, K. N. (2018). Parent empowerment in pediatric healthcare settings: A systematic review of observational studies. *Patient*, *12*(2), 199-212. https://doi.org/10.1007/s40271-018-0336-2

American Academy of Pediatrics. (2012). Levels of neonatal care. *Pediatrics, 130*(3), 10. Retrieved from https://pediatrics.aappublications.org/content/130/3/587

Bank, L., Jippes, M., Leppink, J., Scherpbier, A. J., den, R. C., van Luijk, S. J., & Scheele, F. (2017). Are they ready? Organizational readiness for change among clinical teaching teams. *Advances in Medical Education and Practice, 8*, 807-815. https://doi.org/10.2147/AMEP.S146021

Bastani, F., Abadi, T. A., & Haghani, H. (2015). Effect of family-centered care on improving parental satisfaction and reducing readmission among premature infants: A randomized controlled trial. *Journal of Clinical & Diagnostic Research, 9*(1), SC04-SC08. https://doi.org/10.7860/JCDR/2015/10356.5444

Beck, J., Meyer, R., Kind, T., & Bhansali, P. (2015). The importance of situational awareness: A qualitative study of family members' and nurses' perspectives on teaching during family-centered rounds. *Academic Medicine*, *90*(10), 1401-1407. https://doi.org/10.1097/ACM.0000000000000810

Benoit, B., & Semenic, S. (2014). Barriers and facilitators to implementing the Baby-Friendly Hospital Initiative in neonatal intensive care units. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 43*(5), 614-624. https://doi.org/10.1111/1552-6909.12479

Bergdahl, E., & Bertero, C. M. (2015). The myth of induction in qualitative nursing research. *Nursing Philosophy, 16*(2), 110-120. https://doi.org/10.1111/nup.12073

Bracht, M., O' Leary, L., Lee, S. K., & O' Brien, K. (2013). Implementing family-integrated care in the NICU: A parent education and support program. *Advances in Neonatal Care, 13*(2), 115-126. https://doi.org/10.1097/ANC.0b013e318285fb5b

Bravo, P., Edwards, A., Barr, P. J., Scholl, I., Elwyn, G., & McAllister, M. (2015). Conceptualising patient empowerment: A mixed methods study. *Journal of Biomedical Science Health Service Research, 15*, 252. https://doi.org/10.1186/s12913-015-0907-z.

Brenneman, A., &Price, K.M. (2014). Couplet care: The magic within. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 43* (Supplement 1), S28 https://doi.org/10.1111/1552-6909.12363

Brockman, V. (2015). Implementing the mother-baby model of nursing care using models and quality improvement tools. *Nursing for Womens Health, 19*(6), 490-503. https://doi.org/10.1111/1751-486x.12245

Butt, M. L., McGrath, J. M., Samra, H. A., & Gupta, R., (2013). An integrative review of parent satisfaction with care provided in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 42*(1), 105-120. https://doi.org/10.1111/1552-6909.12002

Cleveland, L. M. (2008). Parenting in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 37*(6), 666-691. https://doi.org/10.1111/j.1552-6909.2008.00288.x

Colorafi, K. J., & Evans, B. (2016). Qualitative descriptive methods in health science research. *Health Environments Research & Design Journal, 9*(4), 16-25. https://org.doi/10.1177/1937586715614171

Craig, J. W., Glick, C., Phillips, R., Hall, S. L., Smith, J., & Browne, J. (2015). Recommendations for involving the family in developmental care of the NICU baby. *Journal of Perinatology, 35 Suppl 1*, S5-S8. https://doi.org/10.1038/jp.2015.142.

Dall'Oglio, I., Mascolo, R., Tiozzo, E., Portanova, A., Fiori, M., Gawronski, O., Dotta, A., Piga, S., Offidani, C., Alvaro, R., Rocco, G., & Latour, J.M. (2019). The current practice of family-centered care in Italian neonatal intensive care units: A multicentre descriptive study. *Intensive Critical Care Nursing, 50*, 36-43. https://doi.org/10.1016/j.iccn.2018.07.005

De Salaberry, J., Hait, V., Thornton, K., Bolton, M., Abrams, M., Shivananda, S., Kiarash, M., & Osiovich, H. (2019). Journey to mother baby care: Implementation of a combined care/couplet model in a level 2 neonatal intensive care unit. *Birth Defects Research*. https://doi.org/10.1002/bdr2.1524

Denham, M. E., Bushehri, Y., & Lim, L. (2018). Through the eyes of the user: Evaluating neonatal intensive care unit design. *Health Environments Research & Design Journal 11*(3), 49-65. https://doi.org/10.1177/1937586718761017

Elliot-Carter, N., & Harper, J. (2012). Keeping mothers and newborns together after cesarean. How one hospital made the change. *Nursing for Women's Health, 16*(4), 290-295. https://doi.org/10.1111/j.1751-486X.2012.01747.x.

Fereday, J., & Muir-Coachrane. E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods, 5 (1),* 80-92. https://doi.org/10.1177/160940690600500107.

Flacking, R., Lehtonen, L., Thomson, G., Axelin, A., Ahlqvist, S., Moran, V.H., Ewald, U., & Dykes, F. (2012). Closeness and separation in neonatal intensive care. *Acta Paediatrica, 101*(10), 1032-1037. https://doi.org/10.1111/j.1651-2227.2012.02787

Flacking, R., Thomson, G., Ekenberg, L., Lowegren, L., & Wallin, L. (2013). Influence of NICU co-care facilities and skin-to-skin contact on maternal stress in mothers of preterm infants. *Sexual & Reproductive Healthcare, 4*(3), 107-112. https://doi.org/10.1016/j.srhc.2013.06.002

Gaboury, J., Capaday, S., Somera, J., & Purden, M. (2017). Effect of the postpartum hospital environment on the attainment of mothers' and fathers' goals. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 46*(1), 40-50. https://doi.org/10.1016/j.jogn.2016.08.008

Griffin, T. (2013). A family-centered "visitation" policy in the neonatal intensive care unit that welcomes parents as partners. *Journal of Perinatal & Neonatal Nursing, 27*(2), 160-165. https://doi.org/10.1097/JPN.0b013e3182907f26

Hall, S. L., Hynan, M. T., Phillips, R., Lassen, S., Craig, J. W., Goyer, E., Hatfield R.F., & Cohen, H. (2017). The neonatal intensive parenting unit: An introduction. *Journal of Perinatology 37*(12), 1259-1264. https://doi.org/10.1038/jp.2017.108

Harris, G. M. (2014). Family-centered rounds in the neonatal intensive care unit. *Nursing for Womens Health, 18*(1), 18-27. https://doi.org/10.1111/1751-486X.12090.

Harris, S. J., Farren, M. D., Janssen, P. A., Klein, M. C., & Lee, S. K. (2004). Single room maternity care: Perinatal outcomes, economic costs, and physician preferences. *Journal of Obstetrics and Gynecology Canada, 26*(7), 633-640. https://doi.org/S1701-2163(16)30610-7

Hildingsson, I., Thomas, J., Olofsson, R. E., & Nystedt, A. (2009). Still behind the glass wall? Swedish fathers' satisfaction with postnatal care. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 38*(3), 280-289. https://doi.org/10.1111/j.1552-6909.2009.01024.x.

Israilov, S., & Cho, H. J. (2017). How co-creation helped address hierarchy, overwhelmed patients, and conflicts of interest in health care quality and safety. *Journal of the American Medical Association, Journal of Ethics, 19*(11), 1139-1145. https://doi.org/10.1001/journalofethics.2017.19.11.mhst1-1711

Janssen, P. A., Keen, L., Soolsma, J., Seymour, L. C., Harris, S. J., Klein, M. C., & Reime, B. (2005). Perinatal nursing education for single-room maternity care: An evaluation of a competency-based model. *Journal of Clinical Nursing, 14*(1), 95-101. https://doi.org/10.1111/j.1365-2702.2004.01014.x

Jones, R., Jones, L., & Feary, A. M. (2016). The effects of single-family rooms on parenting behavior and maternal psychological factors. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 45*(3), 359-370. https://doi.org/10.1016/j.jogn.2015.12.015

Lantz, B., & Ottosson, C. (2014). Neonatal intensive care practices: Perceptions of parents, professionals, and managers. *Advanced Neonatal Care, 14*(3), E1-E12. https://doi.org/10.1097/ANC.0000000000000083

Latour, J. M. (2011). *Empowerment of parents in the intensive care. A journey discovering parents' experiences and satisfaction with care.* (Doctoral thesis) Rotterdam, the Netherlands: Erasmus University. Retrieved from https://repub.eur.nl/pub/22535/110223_Latour-Joseph-Maria.pdf

Macdonell, K., Christie, K., Robson, K., Pytlik, K., Lee, S. K., & O'Brien, K. (2013). Implementing family-integrated care in the NICU: Engaging veteran parents in program design and delivery. *Advances in Neonatal Care, 13*(4), 262-269. https://doi.org/10.1097/ANC.0b013e31829d8319

Makela, H., Axelin, A., Feeley, N., & Niela-Vilen, H. (2018). Clinging to closeness: The parental view on developing a close bond with their infants in a NICU. *Midwifery, 62*, 183-188. https://doi.org/S0266-6138(17)30467-9

Mann, D. (2016). Design, implementation, and early outcome indicators of a new family-integrated neonatal unit. *Nursing for Womens Health, 20*(2), 158-166. https://doi.org/10.1016/j.nwh.2016.01.007

Mianaei, S. J., Karahroudy, F. A., Rassouli, M., & Tafreshi, M. Z. (2014). The effect of creating opportunities for parent empowerment program on maternal stress, anxiety, and participation in NICU wards in Iran. *Iranian Journal of Nursing and Midwifery Research, 19*(1), 94-100. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3917192/

McGrath, J. M. (2013). Family-centered developmental care. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 42*(1), 91. https://doi.org/10.1111/1552-6909.12006

Melnyk, B. M., & Feinstein, N. F. (2009). Reducing hospital expenditures with the COPE (creating opportunities for parent empowerment) program for parents and premature infants: An analysis of direct healthcare neonatal intensive care unit costs and savings. *Nursing Administration Quarterly, 33*(1), 32-37. https://doi.org/10.1097/01.NAQ.0000343346.47795.13

Neale, J. (2016). Iterative categorization (IC): A systematic technique for analysing qualitative data. *Addiction, 111*(6), 1096-1106. https://doi.org/10.1111/add.13314.

O'Brien, K., Bracht, M., Macdonell, K., McBride, T., Robson, K., O'Leary, L., Christie, K., Galarza, M., Dicky, T., Levin, A., & Lee, S. K. (2013). A pilot cohort analytic study of family integrated care in a Canadian neonatal intensive care unit. *Journal of Biomedical Science, Pregnancy Childbirth, 13*(Suppl 1), S12. https://doi.org/10.1186/1471-2393-13-S1-S12

Ortenstrand, A., Westrup, B., Berggren Brostrom, E.B., Sarman, I., Akerström, S., Brune, T., Lindberg, L., Waldenstrom, U. (2010). The Stockholm neonatal family centered care study: Effects on length of stay and infant morbidity. *Pediatrics, 125*(2), e278-e285. https://doi.org/10.1542/peds.2009-1511

Ottosson, C., & Lantz, B. (2017). Parental participation in neonatal care. *Journal of Neonatal Nursing, 23*, 112-118. https://doi.org/10.1016/j.jnn.2016.11.001

Raiskila, S, Lehtonen. L., Tandberg B. S, Normann, E., Ewald, U., Caballero, S., Varendi, H., Toome, L., Nordhøv, M., Hallberg, B., Westrup, B., Montirosso, R., Axelin, A. (2016). Parent and nurse perceptions on the quality of family-centered care in 11 European NICUs. *Australian Critical Care, 29*(4), 201-209. https://do.org/10.1016/j.aucc.2016.09.003

Ramezani, T., Hadian, S. Z., Sabet, S. R., & Moattari, M. (2014). Family-centered care in neonatal intensive care unit: A concept analysis. *International Journal of Community Based Nursing and Midwifery, 2*(4), 268-278. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4201206/

Read, K., & Rattenburg, L. (2018). Parents as partners in care: Lessons from the baby friendly initiative in Exeter. *Journal of Neonatal Nursing, 24, 17-20.* https://doi.org/10.1016/j.jnn.2017.11.006

Stevens, D., Thompson, P., Helseth, C., & Pottala, J. (2015). Mounting evidence favoring single-family room neonatal intensive care. *Journal of Neonatal-Perinatal Medicine, 8*(3), 177-178. https://doi.org/10.3233/NPM-15915035

Stichler, J. F. (2012). The new standard: Single family room design. *Journal of Nursing Administration, 42*(10), 447-450. https://doi.org/10.1097/NNA.0b013e31826a1cd2

Treherne, S. C., Feeley, N., Charbonneau, L., & Axelin, A. (2017). Parents' perspectives of closeness and separation with their preterm infants in the NICU. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 46*(5), 737-747. https://doi.org/10.1016/j.jogn.2017.07.005

Umberger, E., Canvasser, J., & Hall, S. L. (2018). Enhancing NICU parent engagement and empowerment. *Seminars in Pediatric Surgery, 27*(1), 19-24. https://doi.org/10.1053/j.sempedsurg.2017.11.004.

Van Veenendaal, N. R., Heideman, W. H., Limpens, J., van der Lee, J. H., van Goudoever, J. B., van Kempen, A., & van der Schoor, S. R. D. (2019). Hospitalising preterm infants in single family rooms versus open bay units: A systematic review and meta-analysis. *The Lancet. Child & Adolescent Health*. https://doi.org/10.1016/s2352-4642(18)30375-4

VERBI software (2007). MaxQDA 2007 [Software]. Retrieved from https://maxqda.com

White, R. D. (2016). The next big ideas in NICI design. *Journal of Perinatology, 36*(4), 259-262. https://doi.org/10.1038/jp.2016.6

White-Traut, R. C., Rankin, K. M., Yoder, J. C., Liu, L., Vasa, R., Geraldo, V., & Norr, K. F. (2015). Influence of H-HOPE intervention for premature infants on growth, feeding progression and length of stay during initial hospitalization. *Journal of Perinatology, 35*(8), 636-641. https://doi.org//10.1038/jp.2015.11

World Health Organization. (1998). *The WHO health promotion glossary.* Retrieved from https://www.who.int/healthpromotion/about/HPG/en

Zwelling, E., & Phillips, C. R. (2001). Family-centered maternity care in the new millennium: Is it real or is it imagined? *Journal of Perinatal & Neonatal Nursing, 15*(3), 1-12. https://doi.org/10.1097/00005237-200112000-00002.

'Don't raise your voice, improve your argument.'

Desmond Tutu

3

Parents' experiences with a model of integrated maternity and neonatal care designed to empower parents

Mireille Stelwagen
Anne van Kempen
Alvin Westmaas
Erica Vet
Fedde Scheele

Journal of Obstetrics, Gynecologic & Neonatal Nursing, 50 181-192; 2021

Abstract

Objective: To explore the experiences of parents with an integrated maternity and neonatal ward designed to empower parents by providing family-integrated care (FICare) to mother–newborn couplets in single-family rooms.
Design: A qualitative analysis with a contextual constructivist approach.
Setting: An integrated maternity and neonatal level 2 ward designed to empower parents in a teaching hospital in Amsterdam, the Netherlands. Maternity and neonatal care, up to and including highly complex care, are provided to mother–newborn couplets in single-family rooms according to the principles of FICare.
Participants: Twenty-seven mothers and nine fathers of newborns who were hospitalized for at least 7 days.
Methods: We held four focus group discussions and eight semi-structured interviews 1 to 3 months after discharge of the newborn to explore which experiences (mechanisms) facilitated or impeded aspects of parent empowerment (outcomes) under which specific conditions of the integrated infrastructure (contexts). We used the realist evaluation model to analyze the data.
Results: Our analysis revealed five themes of parent empowerment (outcomes): Feeling Respected, Gaining Self-Management Tools, Insights into the Newborn's Condition, Perceived Control, and Self-Efficacy. For each theme, participants reported facilitating and impeding experiences (mechanisms) that were initiated and influenced by the combination of single-family rooms, couplet care, rooming-in, and FICare (contexts). Unrestricted physical proximity to their newborns, 24 hours per day, in a safe private environment, offered parents intensive learning experiences through active participation in care. It helped them to achieve independent parenthood at the time of discharge, but it also generated challenges, such as power conflicts with the staff; prioritizing care for themselves, siblings, or the newborn; feelings of isolation; and lack of sleep.
Conclusion: Providing FICare to mother–newborn couplets in single-family rooms offers parents an intensive learning context for independent parenthood at the time of discharge. Health professionals should be aware of the challenges and facilitators experienced by parents in the context of close physical proximity to their newborns 24 hours per day in single-family rooms. This awareness will allow them to better support parents in their empowerment process toward independent parenthood at the time of discharge.

Introduction

The World Health Organization (WHO, 1998) defines parent empowerment in the context of health as "a process through which people gain greater control over decisions and actions affecting their health." (p.6). In the context of neonatal health care, the persons to be empowered are parents. Parents are important partners who can help health professionals improve the quality of care and the health outcomes of sick newborns (Celenza et al., 2017; Craig et al., 2015; Franck & O'Brien, 2019). Furthermore, empowered parents are better capable of managing their parental roles (Ashcraft et al., 2018). Parents are often not prepared sufficiently for and are insecure about caring for their infants at home after discharge from the hospital (Berman et al., 2019; Van der Pal et al., 2014). Based on the literature reviewed and on a model of patient empowerment (Bravo et al., 2015), we defined parent empowerment for our study as "independent parenthood at the time of discharge."

Two aspects are considered essential for patient empowerment: a patient-centered approach to understand optimally each patient's needs and patient participation in care to enable the patient to adopt a responsible role as soon as possible (Castro et al., 2016; Feely et al., 2016). In neonatal and maternity care, various models focus on parents adopting responsible roles by enabling unrestricted close physical proximity of the family to the hospitalized infant. These models include single-family rooms (Stevens et al., 2015), family-integrated care (FICare; Franck & O'Brien, 2019; Patel et al., 2018), and couplet care (De Salaberry et al., 2019). Individually, these three models positively affected the health outcomes of parents and newborns. For example, single-family rooms were associated with a reduced incidence of neonatal sepsis, improved exclusive breastfeeding rates (Veenendaal et al., 2019), lower stress levels of parents and higher levels of presence, involvement, skin-to-skin care, empowerment, and family centered care (Veenendaal et al., 2020). FICare improved neonatal weight gain, decreased parental stress and anxiety, and increased exclusive breastmilk feeding at discharge (O'Brien et al., 2018). Couplet care significantly reduced mothers' stress levels in relation of feelings of incompetence (Flacking at al., 2013).

However, none of the studies on couplet care included women and newborns who both required highly complex care (Brockman, 2015; De Salaberry et al., 2019). Further, most studies on parents' experiences with family-centered care were conducted in separate neonatal level 3 units (Al Maghaireh et al., 2016; Finlayson et al., 2014; Vetcho et al., 2019), while most sick newborns are admitted to level 2 units immediately after birth or for convalescence after intensive care (American Academy of Pediatrics, 2012). In neonatal level 2 settings, parents can and should develop parental roles to prepare for discharge (Jones et al., 2015).

None of these previous researchers assessed the effects of a combination of single-family rooms, couplet care, and FICare on parent empowerment in neonatal level 2 settings.

In October 2014, we implemented single-family rooms, couplet care, and FICare in a large teaching hospital in the Netherlands. The overall goal of this integrated infrastructure of maternity and neonatal care designed to empower parents (integrated infrastructure) was to keep families close together in an integrated maternity and level 2 neonatal ward by providing standard and highly complex couplet care according to the principles of FICare in single-family rooms. In an earlier article (Stelwagen et al., 2020), we described how the new infrastructure was deployed primarily from the perspectives of the health care system and health professionals and concluded that parent evaluation was needed to learn how to co-create further changes to empower parents.

Exploring parents' experiences in an integrated maternity and level 2 neonatal ward that provides a combination of care models known to promote parent empowerment can help bridge the gap between current professional practice and the needs of parents as they evolve towards independent parenthood at the time of discharge (Nygardh et al., 2012). The purpose of this study was to explore the experiences of parents with an integrated maternity and neonatal ward designed to empower parents by providing FICare to mother-newborn couplets in single-family rooms.

Methods

Design

We used a qualitative research design with a contextual constructivist approach. We used a procedure described as the realist evaluation method (Powson, 2013) to construct context-mechanisms-outcome configurations to explore which experiences (mechanisms) facilitate or impede aspects of parent empowerment (outcomes) under which specific conditions of the integrated infrastructure (context; Linsley et al., 2014). The local medical ethical review board (MEC number WO.14.018) approved the design and ethics of the study.

Setting

We conducted the study in a new mother and child center that was designed to stimulate parent empowerment by integrating the concepts of single-family rooms, couplet care, and FICare (Stelwagen et al., 2020). The center consists of one ward with 53 single-family rooms (see Figure 1) and is located in a teaching hospital in the Netherlands, with approximately 3000 births annually. Approximately 400

newborns require level 2 neonatal care, including approximately 70 newborns who require post-intensive care annually. The integrated nursing team consists of specialized maternity nurses, specialized neonatal nurses, and specialized mother and newborn nurses who are trained to provide different levels of care: from standard to highly complex care for mother-newborn couplets. Because of training the nursing teams, care for most mother and newborn couplets can be provided by a single nurse. Only if the mother and newborn both need highly complex medical care, two nurses are assigned to one single-family room (i.e., a specialized maternity nurse for the mother and a specialized neonatal nurse for the newborn). The goal of keeping parents and newborns together is supported by offering room service and rooming-in facilities for partners. If the mother recovers before the newborn is ready for discharge, parents can take turns to ensure that at least one of them stays with the newborn 24 hours per day. However, parents are not obligated to stay.

Participants

We intended to elicit the views of parents who gained experience in developing independent parenthood at the time of discharge from our hospital by focus group discussions and semi-structured interviews. Therefore, parents were included if they had been hospitalized on our integrated maternity and neonatal care ward with their newborns for at least 7 days, could speak Dutch, and were older than 21 years. Parents whose newborns died and parents under the supervision of social services were excluded.

One to three months after discharge, eligible parents received an invitation letter that included information about the study, privacy regulations, and contact details. One week later, parents were approached by telephone and asked if they wished to participate. If parents were unwilling or unable to participate, the reasons were noted. Parents who were willing to participate received a confirmation letter with details about the topics to be discussed. Before starting the focus group discussions or the interviews, participants signed a consent form and completed a short survey on demographic details, such as age and cultural background. We continued to recruit participants for the focus group discussions and semi-structured interviews using a purposeful sampling approach until we experienced data saturation (i.e., we no longer noticed new insights during the analysis of the focus group discussions and information from the later interviews verified information from the initial interviews; Saunders et al., 2018).

Data sources and procedures

Between December 2015 and January 2017, we conducted different types of interviews that we used for data triangulation (Carter et al., 2014): focus group

Figure 1. A single-family room for highly complex maternity and neonatal level 2 Care. Women and their newborns will remain in this suite for as long as both require specialized care, or at least for 7 days if the newborn requires specialized care. If after 7 days and one of them no longer needs specialized care, the woman and the newborn are transferred to a smaller single-family room, a room for highly complex maternity care and neonatal level 1 care or a room for neonatal level 2 care. All single-family rooms provide rooming-in facilities for one parent/partner. Printed with the permission of the audiovisual department OLVG Hospital, Amsterdam, the Netherlands, June 2020.

discussions with six to eight participants, group interviews with three participants, duo interviews, and individual interviews with fathers or mothers. The first (M.S.), the fourth author (E.V.) and an independent discussion leader who was not involved as an author, all of whom are trained and experienced discussion leaders and interviewers, led the focus group discussions, and M.S. conducted the semi-structured interviews. The aim of the focus group discussions was to generate data on parents' experiences with the integrated infrastructure. We formulated a topic guide based on the principles of FICare and the main research purpose (see Table 1). The aim of alternating focus group discussions with interviews was to explore in more depth the mechanisms leading to the outcome of independent parenthood in the contexts that emerged from the focus group discussions and to verify whether specific aspects were understood correctly. The interviews also enabled us to achieve deeper insight into the similarities and differences between the

views and experiences of parents. We used the last interviews to verify data saturation. We conducted all interviews with the same topic guide as the focus group discussions, supplemented with additional in-depth questions, and held at the participant's home or in the hospital as the participant preferred (Dempsey et al., 2016). All focus group discussions and interviews were audio recorded and transcribed verbatim. We submitted summaries of each focus group discussion and interview to all participants for member checking.

Table 1 Topic guide for the focus group discussions and the interviews

Topics: experiences with
Shared decision-making
Being the primary caregiver of the child
Coaching and counseling
Collaboration and communication with the health professionals
Being in control
Couplet care
Rooming-in
Single-family room
Questions
To what extent have you been able to take care of your child?
To what extent did you feel strengthened, supported by the team?
To what extent did you feel respected and equivalent to the team?
To what extent did you feel in control?
Supplemented with the question: What did or did not contribute to this? Supplemented with the question in case of in-depth interview: Can you tell us more about your experiences with...

Analysis

We used an inductive and deductive coding approach within the context (C), mechanism (M) and outcome (O) method (Linsley et al., 2014). This method emphasizes how causal mechanisms are shaped and constrained within different contexts, leading to certain outcomes. We analyzed the transcripts by searching for all phrases that referred to a specific context element of the integrated infrastructure (couplet care, rooming-in facilities, single-family rooms or FICare) (C) that triggered an experience (mechanism: M) that facilitated or hindered parents in achieving an outcome (O) that fits with independent parenthood. These text

phrases were called CMO strings. Detecting was an inductive process that led to numerous CMO strings with positive or negative experiences of the participants.

The analysis procedure can be divided into three main steps: collecting data, alternating the inductive identification of CMO strings with interim analysis and clustering of mechanisms and outcomes, and final clustering of the results. To collect data, M.S. and E.V. independently used inductive coding to identify key text phrases and classify contexts, mechanisms, and outcomes. Differences in coding were discussed until consensus was reached. If consensus could not be reached, the second (A.K.) or third author (A.W.) were asked for their opinion. M.S. made overviews of all identified text phrases that described mechanisms (M) that were activated in a particular context (C) and that facilitated or hindered the empowerment of parents (O). The overviews of these first CMO strings were crosschecked and discussed with the fifth researcher (F.S.) and an independent researcher who was not involved as an author.

As a second step, we alternated the inductive process of detecting CMO strings with interim analysis and clustering of mechanisms and outcomes. During meetings with all authors except E.V., we further iteratively processed the mechanisms (M) and outcomes (O) detected within the investigated contexts (C). We clustered identified mechanisms and outcomes, iteratively verified them during the next interviews, and supplemented them with additional interview data. When data saturation became evident and no new relevant CMO strings emerged from interviews, we made the final deductive step.

For the final clustering of the results, we used the outcome themes as a format for the description of the results. We used the patient empowerment model of Bravo et al. (2015) to guide the author team in identifying which outcomes would be considered valuable for parent empowerment. Finally, for each outcome, we wrote overviews of the combined identified CMO strings in which the facilitating and hindering experiences (mechanisms) were differentiated.

Findings

We conducted 4 focus group discussions and 8 interviews with a total of 9 fathers and 27 mothers. One out of five parents who received an invitation letter eventually participated. The most common reason for parents not to participate was lack of time. The average age of the mothers was 35 and the average age of the fathers was 39. Almost all participants were employed and highly educated (see Table 2). Hospitalization of participants with their newborns in the single-family rooms ranged from 7 days to 3.5 weeks. Eighteen participants stayed in our hospital with their newborns from birth, and the others stayed in our hospital after their newborns

Table 2 Baseline characteristics participants (*N* = 36)

Participant Characteristic	Median (Range) or Frequency (%)
Age, years mothers (*n* = 27)	35 (29-42)
Age, years fathers (*n* = 9)	37 (34-48)
Nationality (N)	
Dutch	33 (92%)
Hindu	1 (3%)
Belgian	1 (3%)
Spanish	1 (3%)
Education (N)	
University/postgraduate	24 (67%)
College/vocational school	12 (33%)
Labor at hospital (N)	
OLVG	18 (50%)
Academic	16 (44%)
Other	2 (6%)
Birth (N)	
C-section	16 (44%)
Vaginal	17 (47%)
not known	3 (8%)
Siblings < 12 years (N)	
None	23 (64%)
One ()	5 (14%)
Two ()	7 (19%)
Three ()	1 (3%)
Admission mother OLVG (N)	
No	12 (44%)
yes	15 (56%)
in days, *M* (range)	8(2-14)
Admission partner of fathers OLVG (N)	
No	4 (44%)
Yes	5 (56%)
in days, *M* (range)	5 (1-9)
Admission duration newborn (week)	1 (1-8)
Hours present in hospital per day	
Mothers *M* (range)	24 (4-24)
Fathers *M* (range)	6 (4-24)

Note. *M* = median. N = number of mothers and/or fathers

were transferred from other, mainly academic hospitals. Participants indicated they stayed in the single-family room for an average of 17.14 hours per day, with a range of 4 to 24 hours. All newborns of the participants were discharged to home.

We identified five themes related to parent empowerment (outcomes) as well as their underlying mechanisms and contexts: *Feeling Respected, Gaining Self-management Tools, Insight into the Newborn's Condition, Perceived Control,* and *Self-Efficacy.* Most participants started by saying how much they felt respected as a real and complete family by being enabled to stay together during hospitalization. This sense of being respected seems to have created a basis for participants to acquire self-management tools and to gain insight into their newborns' conditions. This contributed positively to the participants' feelings of control and self-efficacy.

Feeling respected

We defined *Feeling Respected* as parents feel respected as the responsible and autonomous parents of the sick newborn and as full and equal members of the care team; they feel that they and their newborns are seen and approached as part of a family. According to the participants, the contexts of single-family room, couplet care, and rooming-in facilities contributed to the feeling of being respected as a complete family. Participants were very pleased with the opportunity to stay together as a family, close to their newborns in their single-family rooms; to have privacy; and to create their own safe, homely atmospheres. A mother said, *"We were placed into a really nice big suite and we were there for almost 2 weeks. In a way we recognized that suite as our own home… it was really my safe environment."* Participants reported that by having their own single-family rooms, they felt more as full and equal members of the health care team, as they were no longer the ones who came to visit their newborns a few times per day. Instead, the staff came to visit them in their single-family rooms.

The amenities of the single-family rooms and rooming-in facilities were helpful, but according to the participants, their experience of being respected was determined by the behavior and attitude of the staff, related to the principles of FICare. They felt most respected by slight gestures of the staff during contact, which made the staff very accessible to them. The sense of being respected as a responsible and autonomous parent was increased if the staff approached participants as primary caregivers, which is one of the key principles of the concept of integrated family care. The major experiences that helped the participants to take care of the newborns themselves were coaching and encouragement by nurses during daily care moments. A mother said: *"It is so nice when they [nurses and doctors] ask you for your opinion and to hold and feel your child yourself, and never to have to give your child away to somebody else to take care of."* By automatically participating in daily medical rounds and by being

encouraged by staff members, participants felt invited to give their views on their newborn's health progress and to be involved in medical decisions.

Certain approaches can directly damage the sense of being respected. In particular, some fathers seem to have struggled with experiences of disrespectful staff behavior: *"Once I felt really left out while I was present. The nurse... was very much speaking to my wife and hardly to me... She should have involved both parents, not just the mother."* Sometimes participants felt disrespected when the staff insisted on imposing their working methods, even though the participants had developed their own methods. A mother who had to defend her work method said, *"Accept that parents take over."* In addition, throughout the day and night, participants experienced many privacy violations when staff members entered the single-family rooms unannounced, which also resulted in sleep deprivation. Feelings of being disrespected seem to affect the other themes negatively.

Gaining self-management tools

We defined *Gaining Self-management Tools* as parents developing knowledge, skills, and attitudes that they need to adapt their behavior to optimize their own health and the health of their newborns. The contexts that helped participants gain self-management tools were couplet care, rooming-in facilities, single-family rooms, and FICare, including shared decision-making. The safe private environment of the single-family rooms seems to be a suitable setting for the daily practical training of parental skills. Couplet care and rooming-in facilities enable both parents to stay close to the newborn 24 hours per day and to understand and participate in all the necessary interventions throughout the newborn's entire care process. The FICare approach helped participants to learn from all staff members how to care for their newborns and how to make health care decisions with comprehensive and intensive staff guidance. A father of a twin said the following:

> *"I think we were well supervised there...Some skills I think we learned very well in the hospital. We skipped maternity care at home [In the Netherlands parents/newborns usually receive home care after discharge from the hospital] because we already knew everything. Good evidence that we learned a lot at the hospital."*

Participants indicated they could learn from the nurses through examples and instructions. They first cared for their newborns with nurses and eventually cared for their newborns themselves under the supervision of nurses. For coaches about their new roles as parents, participants preferred nurses trained in maternal and newborn care rather than nurses who specialized in either area, since the specialized nurses sometimes gave conflicting advice: *"Maternity nurses were*

there for me. Neonatology nurses were there for the newborn with contradictory messages: do it yourself [take care of the newborn] but also get some rest." In the single-family rooms, participants also learned from each other: *"My husband asked, 'What is this alarm for?' I could explain it to him."*

The single-family rooms seemed to prevent the acquisition of certain knowledge that parents could gain on an open bay ward. Some participants who were admitted with previous children to open-bay wards with incubator and crib rooms said they found it helpful to be able to observe parents of other newborns in the open wards, to see to what extent other parents participated in care, and to see when other newborns were ready to be discharged. Some fathers said that they missed being coached in how to take care of themselves, their sick partners, and sometimes-even siblings at home.

Insight into the newborn's condition

We defined *Insight into the Newborn's Condition* as parents have a realistic and consistent understanding of the health status of their newborns. The contexts that contributed to participants gaining insights into the health condition of their newborns were single-family rooms, rooming-in, couplet care, and FICare. During the daily medical rounds, participants felt that the information received and the opportunity to ask questions gave them insight into their newborns' conditions. If the diagnosis was not yet clear, the staff explained the diagnostic process step by step and participants felt involved in the clinical reasoning processes. An in-suite whiteboard was helpful for participants to keep an overview of the development of the newborn's health status and of all the progress of their newborns had to take before being discharged.

Perceived control. We defined *Perceived Control* as parents feeling that they are and can be in control, can decide, have power, can supervise their newborns, are equal to the health professionals in making decisions, and are in charge of health care for their newborns and for themselves. The participants' sense of control was enhanced by the context of couplet care in the single-family rooms, including rooming-in facilities, which allowed parents to stay close to and support each other. Participants had control over the rest and safety of their newborns because the single-family room provided privacy and tranquility. Participants found it very comfortable to watch over the safety of their newborns themselves and to not being disturbed by other families, or by alarms from monitors or distressing situations of other newborns. Mothers experienced the benefits of being close to their partners for support in the care of their newborns and for themselves. *"I liked that he (partner) also slept there because … it was the most intense and anxious time I have experienced in my life… He made me feel like he would watch over both of us and I could go to sleep."* For fathers, the rooming-in

facilities made it possible to take control of supporting their partners and their newborns by staying close to them during hospitalization. This apparently stimulated the perception of control: *"I never left my wife during the delivery and in the maternity period. I was always close to her and to my daughter. To be there and to share every experience with them, that was wonderful."* Participants experienced feelings of control over care during the in-suite medical rounds because they felt well-informed, learned quickly, participated in decision-making, and felt their opinions really mattered. Participants liked it they could give their opinions directly during the medical rounds: *"I could participate directly in discussions and provide input."*

Participants described several situations in which they perceived less control. They did not always feel competent enough to make shared decisions, especially in situations of high complex medical care and shortly after birth. In these circumstances, participants usually left the decisions to the physicians or nurses. Some mothers reported they could feel overwhelmed when confronted with questions such as, "What is your opinion on how your child is doing?" In these situations, participants experienced an enormous responsibility for which they were not ready.

Participants also said that conflicting advice from different staff members upset their perceived control. Mothers mentioned feelings of loss of control when they could not care for their newborns because they needed care for themselves. A mother said she was so involved in the care of her twin that she stood next to the incubators the first night after her caesarean with a catheter in her hands to comfort her twin. She did not know how to ensure her own sleep and rest. Participants also lost control because they were uncertain about the division of tasks and responsibilities between themselves and professionals. The same happened when staff members did not clearly communicate their doubts about the diagnosis or the medical treatments. Under these circumstances, participants appreciated open communication.

Some participants said they found it difficult that in the single-family rooms, they could not literally distance themselves from invasive treatments for their newborns. Participants literally felt isolated from the staff when being left alone in the suite with their newborns for the first time, especially after a transfer from open-bay level 3 units: *"The baby was in his crib, the nurse left the suite, closed the door and then there was silence. At that moment, I thought 'What happened to my daily routine?'...* We did not know what to do any more."

Some participants felt obliged to remain in their single-family rooms because they were unsure whether their newborns would be supervised properly, and thereby they lost control of their lives outside the hospital. Mothers in particular reported feeling guilty and considered themselves bad mothers when they went home while having the privileged opportunity to stay with their newborns.

First, I was thrilled and always stayed for the night, trying to alternate this with my husband. We also had a two-year-old son who could not comprehend the situation. Then the nurse told me, "You are ultimately also a mother of your older son at home, and he needs you too." I really could make that decision by myself at that moment.

Self-efficacy. We defined *Self-Efficacy* as parents' confidence in their own ability to influence successfully the health of their newborns and their self-estimated ability to perform independently as parents at the time of discharge. According to the participants, all key contexts contributed to their experiences of self-efficacy: single-family rooms, couplet care, rooming-in facilities and FICare, including the medical rounds with active participation of the participants. Being able to eat, sleep, and relax together and having a private bathroom in their own single-family rooms gave participants the opportunity to learn 24 hours per day to care for each other and their sick newborns and to prepare for discharge. A father of a twin said, *"I was ready to take care of the children by myself. If I could have visited only during visiting hours, I probably might only have been able to change a diaper."* The FICare approach, in which nurses coach, support, and encourage parents and offer them the choice to take care of their newborns by themselves, gave participants the confidence to act. *"I felt encouraged positively... I needed just that bit of support and encouragement ... It really helped me feel confident ... After a week, I thought 'Now I'm ready to go home'."*

Participants described how problems arose after they achieved self-efficacy. They experienced power struggles when they wanted to take initiatives to manage their newborns' health care themselves and thought that they could do better than the health professionals could. In these situations, they were afraid of being labeled a "difficult parent."

Discussion

The participants in our study indicated that the integrated infrastructure of maternity and neonatal care in single-family rooms enhanced their empowerment processes through FICare offered to mother-newborn couplets in their single-family rooms. Being able to be close to their newborns, being able to follow the clinical condition of their newborns, and being involved in care and medical decision-making for 24 hours per day contributed to a very intense learning process. This process led to a sense of competence in independent parenthood and feelings of being full and respected members of the health care team. Participants also faced challenges with couplet care and FICare in their own single-family rooms, such as

sleep deprivation, power conflicts with the staff, uncertainties about which priorities should be set when caring for themselves or their newborns, and feelings of isolation from staff and from parents of other newborns in the ward.

Feeley et al. (2016) found that close physical proximity between parents and newborns is necessary to enable parents to adopt their roles as parents from birth and to develop this role thereafter. The infrastructure that participants experienced in our study facilitated close physical proximity of participants and their newborns 24 hours per day from birth on, even if the mother and the newborn needed highly complex specialized care. This is one aspect that our participants appreciated the most. Previous recommendations for supporting parents in NICUs include the provision of single-family rooms in which parents can practice caring for their newborns a few days before discharge, but not specifically from birth onwards (Craig et al., 2015). We believe couplet care in single-family rooms could be considered the ideal setting; above all, these rooms are a catalyst for providing FICare and the achievement of parent empowerment. We are aware that not all wards can offer single-family rooms in the short term, but implementing the FICare model cannot and does not have to wait until wards are remodeled or built with this patient care configuration. Indeed, the FICare model has already been successful in open-bay units (Hall et al., 2017, O'Brien et al., 2018, Bradford-Duarte & Gbinigie, 2020).

Learning processes of participants in their single-family rooms shows similarities with competency-based learning processes of health care students (Gervais, 2016). Competency-based learning is learner-focused and entails practical experiences and self-determination with instructors taking the role of facilitator and coach. This learning method allows students to acquire individual skills, including the ones they find challenging, at their own pace, practicing and refining them as much as they like. Similarly, our participants seemed to learn from health professionals (as instructors and role models) and their partners in the safe and private context of their own single-family rooms (learning context), and they occasionally were challenged to try out new skills under the guidance of professionals (coaches). Participants seem to go through a learning process towards independent parenthood to become finally consciously competent (self-efficacy). In this learning process, the health professionals act as teachers in the beginning and reduces their influences during the process. For an optimal learning process, continuous attention needs to be paid to aligning the expectations of parents and health professionals. Another challenge for the health professionals to ensure optimal learning experiences for parents is to avoid conflicting advice. Integrating the nursing team of nurses who are focused on and trained in maternal and neonatal care (Stelwagen et al., 2020) can help reduce conflicting advice.

Harris (2014) found that shared decision-making was an important intervention for parent empowerment. In our study, participants reported contrasting effects of the daily medical rounds and shared decision-making on their empowerment processes. Most experienced the daily medical rounds as helpful for gaining insight into their newborns' conditions, treatment policies, and as a basis on which to make shared decisions. On the other hand, some participants had negative experiences if different staff members gave conflicting advice and if they were asked certain questions that they could not answer. These conflicting experiences may explain the findings of previous researchers who reported no reduction in stress in parents who attended medical rounds in the NICUs (Abdel-Latif et al., 2015; Gustafson et al., 2016).

It appears that participants in our study experienced power struggles once they considered themselves more skilled to care for their newborns than the staff. Jones (2015) described power struggles between nurses and parents in infrastructures that were not designed specifically for the empowerment of parents. In our study, participants experienced similar problems, despite or perhaps because of their empowerment processes. Well-skilled parents who experience self- efficacy fear being labeled as "difficult parents" when they speak up. Health professionals should recognize and manage these changes in relationships with parents to prevent power struggles (Finlayson et al., 2014) and recognize and deal with parents' worries about discharge to home (Van der Pal et al., 2014). This requires adjustments and changes in the roles of the medical teams and improvement of staff-parent interactions (Provenzi & Santoro, 2015; Sisson et al., 2015), despite the challenge of accepting parents as equal members of the team and as respected experts and constant factors in their newborn's life (Butt et al., 2013).

Marthinsen et al. (2018) identified sleep deprivation among parents of premature infants and its relationship to negative health outcomes for parents. They reported sleep deprivation due to stress and extra alert behavior of parents towards their newborns after discharge. Participants in our study mainly reported sleeping problems during hospital stay. Participants did not mention sleep problems after discharge, perhaps because we did not focus on the post-discharge period or because they learned skills to get enough sleep during hospitalization and were less stressed by being close to their newborns from birth.

To enhance the learning and empowerment process even further, it may be helpful to provide parent education sessions and meetings with other parents as potential role models (Bravo, 2015). Experiences of participants suggest it might be advisable to organize a ward as if it were a school for parents, adding formal teaching and coaching moments and meetings with other parents and maybe even assessments of essential skills for newborn care and parental self-care (Mosher, 2017).

Limitations and directions for further research

Our study focused on the views of highly educated Dutch participants, so the participants probably had sufficient general health literacy. This may explain why, on analyzing the data, we could not identify evident experiences concerning increased health literacy, which is an important empowerment outcome in the model of Bravo et al. (2015). For better insight into this aspect, future research should include parents with different education levels and/or different social-economic status or from urban as well as rural areas.

The single setting of our study is a limitation, as the participants were all hospitalized on one level 2 neonatal ward; therefore, our findings are not generalizable to all settings. We recommend exploring how parents experience infrastructures designed for parent empowerment in more diverse samples. However, some results may be generalizable because parents who undergo an empowerment process will probably experience issues of sleep deprivation and power issues with health professionals worldwide.

We did not investigate the perspectives of health professionals. Future research may reveal their opinions about improving parent empowerment. An integrative review on family-centered care in NICUs (Vetcho et al., 2019) highlighted recently large gaps in the literature when considering a focus on dignity and respect in partnerships with parents, which we identified as an outcome theme for parent empowerment. In addition, the perspectives of health professionals are needed to fine-tune efforts to create a school for enhancing parent empowerment in a complex health care context.

Conclusion

Providing FICare to mother-newborn couplets in single-family rooms offers parents an intensive learning context for independent parenthood at the time of discharge. Health professionals should be aware of the challenges and facilitators experienced by parents in the context of close physical proximity to their newborns 24 hours per day in single-family rooms. This awareness will allow them to better support parents in their empowerment processes towards independent parenthood at the time of discharge. The findings of the present study have important implications for the design of infrastructures to empower parents of newborns in maternity and neonatal care. We recommend that health professionals accept parents as primary caregivers; embrace the principles of respect and open communication with parents; arrange formal teaching opportunities and meetings with other parents who may act as role models; respect the pace of parents' progress and focus on care for mothers, partners, and newborns; mentor and support parents who

witness their newborns undergoing invasive medical procedures; and respect the parents' needs for privacy and sleep. The next step in determining how to organize a ward as a school for empowering parents of newborns to independent parenthood at the time of discharge is to investigate the perspectives of health professionals.

References

Abdel-Latif, M.E., Boswell, D., Broom, M., Smith, J., & Davis, D. (2015). Parental presence on neonatal intensive care unit clinical bedside rounds: Randomised trial and focus group discussion. *Archives of Disease in Childhood. Fetal and Neonatal Edition, 100*(3):F203-9. https://doi.org/10.1136/archdischild-2014-306724

Al Maghaireh, D. F. Abdullah, K. L., Chan, C. M., Piaw, C. Y., & Al Kawafwa, M. M. (2016). Systematic review of qualitative studies exploring parental experiences in the neonatal intensive care unit. *Journal of Clinical Nursing, 25*(19-20), 2745-2756. https://doi.org/10.1111/jocn.13259

American Academy of Pediatrics. Committee on Fetus and Newborn. (2012). Levels of neonatal care. *Pediatrics, 130*(3), 587-597. https://pediatrics.aappublications.org/content/130/3/587

Ashcraft, L. E., Asato, M., Houtrow, A. J., Kavalieratos, D., Miller, E., & Ray, K. N. (2018). Parent empowerment in pediatric healthcare settings: A systematic review of observational studies. *Patient, 12*(2), 199-212. https://doi.org/10.1007/s40271-018-0336-2

Berman, L., Raval, M.V., Ottoson, M., Mackow, A.K., Cho,M., & Goldin, A.B. (2019). Parent perspectives on readiness for discharge home after neonatal intensive care unit admission. *Journal of Pediatrics (205)* 89-104.e4 https://doi.org/10.1016/j.jpeds.2018.08.086

Bradford-Duarte, R., & Gbinigie, H. (2020). Neonatal family integrated care: Ensuring a positive parental experience. *Journal of Neonatal Nursing, 26*(5), 284-290. https://doi.org/10.1016/j.jnn.2020.03.003

Bravo, P., Edwards, A., Barr, P. J., Scholl, I., Elwyn, G., & McAllister, M. (2015). Conceptualising patient empowerment: A mixed methods study. *Journal of Biomedical Science Health Service Research, 15*, 252. https://doi.org/10.1186/s12913-015-0907-z.

Brockman, V. (2015). Implementing the mother-baby model of nursing care using models and quality improvement tools. *Nursing for Women's Health, 19*(6), 490-503. https://doi.org/10.1111/1751-486X.12245.

Butt, M. L., McGrath, J. M., Samra, H. A., & Gupta, R. (2013). An integrative review of parent satisfaction with care provided in the neonatal intensive care unit. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 42*(1), 105-120. https//doi.org/10.1111/1552-6909.12002

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe. J., & Neville, A.J. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum, 41*(5):545-7. https://doi.org/10.1188/14.ONF.545-547

Castro, E. M., Van, R. T., Vanhaecht, K., Sermeus, W., & Van, H. A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education and Counseling, 99*(12), 1923-1939. https://doi.org/10.1016/j.pec.2016.07.026

Celenza, J. F., Zayack, D., Buus-Frank, M. E., & Horbar, J. D. (2017). Family involvement in quality improvement: From bedside advocate to system advisor. *Clinical Perinatology, 44*(3), 553-566. https://doi.org/10.1016/j.clp.2017.05.008

Craig, J. W., Glick, C., Phillips, R., Hall, S. L., Smith, J., & Browne, J. (2015). Recommendations for involving the family in developmental care of the NICU baby. *Journal of Perinatology, 35(Suppl 1)*, S5-S8. https://doi.org/10.1038/jp.2015.142.

De Salaberry, J., Hait, V., Thornton, K., Bolton, M., Abrams, M., Shivananda, S., Kiarash, M., Osiovich, H. (2019). Journey to mother baby care: Implementation of a combined care/couplet model in a Level 2 neonatal intensive care unit. *Birth Defects Research, 111*(15), 1060-1072. https//doi.org/10.1002/bdr2.1524.

Dempsey, L., Dowling, M., Larkin, P., & Murphy, K. (2016). Sensitive interviewing in qualitative research. *Research in Nursing & Health*, *39,* 480-490. https://doi.org/10.1002/nur.21743

Feeley, N., Genest, C., Niela-Vilen, H., Charbonneau, L., & Axelin, A. (2016). Parents and nurses balancing parent-infant closeness and separation: A qualitative study of NICU nurses' perceptions. *BMC. Pediatrics, 16*, (134). https://doi.org/10.1186/s12887-016-0663-1

Flacking, R., Thomson. G., Ekenberg, L., & Wallin, L. (2013). Influence of NICU co-care facilities and skin-to-skin contact on maternal stress in mothers of preterm infants. *Sexual & Reproductive Healthcare, 3* (3), 107-112 http://www.ncbi.nlm.nih.gov/pubmed/24041731

Finlayson, K., Dixon, A., Smith, C., Dykes, F., & Flacking, R. (2014). Mothers' perceptions of family centered care in neonatal intensive care units. *Sexual & Reproductive HealthCare, 5*(3), 119-124. https://doi.org/10.1016/j.srhc.2014.06.003

Franck, L. S., & O'Brien, K. (2019). The evolution of family-centered care: From supporting parent-delivered interventions to a model of family-integrated care. *Birth Defects Research, 111*(15), 1044-1059. https://doi.org/10.1002/bdr2.1521

Gervais, J. (2016). The operational definition of competency-based education. *The Journal of Competency-Based Education, 1*(2), 9. https://doi.org/10.1002/cbe.1011

Gustafson, K.W., LaBrecque, M.A., Graham, D.A., Tella, N.M., & Curley, M.A. (2016). Effect of parent presence during multidisciplinary rounds on NICU-related parental stress. *Journal of Obstetric, Gynecologic and Neonatal Nursing, 45*(5), 661-70. https://doi.org/10.1016/j.jogn.2016.04.012

Hall, S.L., Hynan, M.T., Phillips, R., Lassen, S., Craig, J.W., Goyer, E., Hatfield, R.F., & Cohen, H. (2017). The neonatal intensive parenting unit: An introduction. *Journal of Perinatology, 37*, 1259-1264. https://doi.org/10.1038/jp.2017.108.

Harris, G. M. (2014). Family-centered rounds in the neonatal intensive care unit. *Nursing for Women's Health, 18*(1), 18-27. https://doi.org/10.1111/1751-486X.12090.

Jones, L., Taylor, T., Watson, B., Fenwick, J., & Dordic, T. (2015). Negotiating care in the special care nursery: Parents' and nurses' perceptions of nurse–parent communication. *Journal of Pediatric Nursing, 30*(6), p e71-e80. https//doi.org/10.1016/j.pedn.2015.03.006

Linsley, P., Howard, D., & Owen, S. (2014). The construction of context-mechanisms-outcomes in realistic evaluation. *Nurse Researcher, 22*(3), 7. https://doi.org/10.7748/nr.22.3.28.e1306

Marthinsen, G. N., Helseth, S., & Fegran, L. (2018). Sleep and its relationship to health in parents of preterm infants: A scoping review. *BMC Pediatrics, 18*(1), 352. https://doi.org/10.1186/s12887-018-1320-7

Mosher, S. L. (2017). Comprehensive NICU parental education: Beyond baby basics. *Neonatal Network, 36* (1), 18-25. https://doi.org/10.1891/0730-0832.36.1.18

Nygardh, A., Malm, D., Wikby, K., & Ahlstrom, G. (2012). The experience of empowerment in the patient-staff encounter: The patient's perspective. *Journal of Clinical Nursing, 21*(5-6), 897-904. https://doi.org/10.1111/j.1365-2702.2011.03901.x

O'Brien, K., Robson, K., Bracht, M., Cruz, M., Lui, K., Alvaro, R., Da Silva, O., Monterrosa, L., Narvey, M., Ng, E., Soraisham, A., Y Ye, X., Mirea, L., Tarnow-Mordi, W., & Lee, S. K. (2018). Effectiveness of family-integrated Care in neonatal intensive care units on infant and parent outcomes: A multicenter, multinational, cluster-randomised controlled trial. *The Lancet Child & Adolescent Health, 2*(4), 245-254. https://doi.org/10.1016/s2352-4642(18)30039-7

Patel, N., Ballantyne, A. & Bowker, G. (2018). Family Integrated Care: Changing the culture in the neonatal unit. *Archives of Disease in Childhood* 103:415-419.

Powson, R. (2013). *The science of evaluation: A realistic manifesto*. Sage Publications.

Provenzi, L., & Santoro, E. (2015). The lived experience of fathers of preterm infants in the neonatal intensive care unit: A systematic review of qualitative studies. *Journal of Clinical Nursing, 24*(13-14), 1784-1794. https://doi.org/10.1111/jocn.12828.

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity, 52*(4): 1893–1907. https://doi.org/ 10.1007/s11135-017-0574-8

Sisson, H., Jones, C., Williams, R., & Lachanudis, L. (2015). Meta-ethnographic synthesis of fathers' experiences of the neonatal intensive care unit environment during hospitalization of their premature infants. *Journal of Obstetric, Gynecologic & Neonatal Nursing, 44*(4), 471-480. https://doi.org/10.1111/1552-6909.12662

Stelwagen, M. A., Kempen Van, A., Westmaas, A., Blees, Y. J., & Scheele, F. (2020). Integration of maternity and neonatal care to empower parents. *Journal of Obstetrics, Gynecologic & Neonatal Nursing, 49*(1), 12. https://doi.org10.1016/j.jogn.2019.11.003

Stevens, D., Thompson, P., Helseth, C., & Pottala, J. (2015). Mounting evidence favoring single-family room neonatal intensive care. *Journal of Neonatal-Perinatal Medicine, 8*(3), 177-178. https://doi.org/10.3233/NPM-15915035

Van der Pal, S. M., Alpay, L. L., Van Steenbrugge, G. J., & Detar, B. D. (2014). An exploration of parents' experiences and empowerment in the care for preterm born children. *Journal of Child and Family Studies, 23*(6), 1081-1089. https://doi.org/10.1007/s10826-013-9765-7

Van Veenendaal, N.R., Heideman, W.H., Limpens, J., Van der Lee, J.H., van Goudoever, J.B., van Kempen, A.A.M.W., & van der Schoor, S.R.D. (2019). Hospitalising preterm infants in single family rooms versus open bay units: A systematic review and meta-analysis. *The Lancet Child & Adolescent Health, 3*(3), 147-157.

Van Veenendaal, N.R., van Kempen, A.A.M.W., Franck, S. L., O'Brien, K., Limpens, J., Van der Lee, J.H., van Goudoever, J.B., & van der Schoor, S.R.D. (2020). Hospitalising preterm infants in single family rooms versus open bay units: A systematic review and meta-analysis of impact on parents. *The Lancet, 23* https://doi.org/10.1016/j.eclinm.2020.100388

Vetcho, S., Cooke, M., & Ullman, A.J. (2020). Family-centered care in dedicated neonatal units: An integrative review of international perspectives. *Journal of Neonatal Nursing, 26* (2), p.73-92. https://doi.org/10.1016/j.jnn.2019.09.004

World Health Organization. (1998). *The WHO promotion glossary.* Retrieved from https://www.who.int/healthpromotion/about/HPG/en

'Education is the most powerful weapon which you can use to change the world.'

Nelson Mandela

4

In-hospital education of parents of newborns may benefit from competency-based education: A focus group and interview study among health professionals

Mireille Stelwagen
Alvin Westmaas
Anne van Kempen
Fedde Scheele

Journal of Clinical Nursing, 22 April 2022: 1-13.

Abstract

Aims/Objectives*:* The aim of this study was to appraise health professionals' self-reported practices in educating parents of hospitalized newborns from the perspective of competency-based education and to identify areas for improvement of parental learning.

Background: Patient education is essential to achieve autonomy in parents of hospitalized newborns. The literature provides descriptions of the use of various components of competency-based education in patient education. This suggests that competency-based education is a valuable concept for patient education.

Design*:* A case-based qualitative study

Methods: Three focus group discussions were conducted and 28 semi-structured interviews with 45 health professionals who practice in a hospital setting that is designed to empower parents. The data were analyzed with a framework analysis approach, using a framework of competency-based education themes for a combined inductive and deductive content data analysis. The recommendations of the Standards for Reporting Qualitative Research checklist were followed.

Findings: Two themes of competency-based education emerged as evidently operationalized: (1) "Learning climate" and (2) "Role modeling". Five themes emerged as incompletely operationalized: (1) "Parent curriculum based on inter-professional consensus"; (2) "Transparency about the competencies needed"; (3) "Access to teaching"; (4) "Assessing and reporting results", and (5) "Proficiency statements based on autonomy expectations". Two themes did not emerge: (1) "Empowering parents to be active learners" and (2) "Evaluation and improvement of the education program".

Conclusions: Parent education is at risk of being merely on a master-apprentice model and may be more effective if it is designed on competency-based education principles. Identified areas for improvement are empowering parents to be 'active learners' and by involving them in the evaluation and improvement of the educational program. Parent education programs in neonatal healthcare may benefit from an appraisal based on competency-based education themes.

Relevance to clinical practice*:* Appraising parent education based on competency-based education principles is feasible for improving the learning process toward parent autonomy.

Introduction

Leaving behind the era of paternalism (Kilbride & Joffe, 2018) and maternalism (Lindberg et al., 2018), the next step in achieving high-quality health care requires a balanced transition to patient autonomy. Ubel et al. (Ubel et al., 2018) defined patient autonomy as the patients' right to decide about their medical care without undue influence from health professionals. Lindberg et al. (2018) described guiding

principles for patient autonomy: recognizing the patient as a person, showing respect, providing information, and making the patient a member of the health care team. These principles must be in balance with caring and taking responsibility for the patient. In the context of neonatal health care, the 'patient' is a trinity consisting of the newborn and its parents, and it is the parents who should be able to assume parenthood autonomously. The move towards greater 'parent' autonomy is reflected in the ongoing evolution from family-centered care (FCC) models to more specific models of care that focus on 'parent' autonomy and empowerment, such as family-integrated care (FICare) (Franck & O'Brien, 2019). A key principle of FICare is to integrate the parents in the care team of their newborns as primary caregivers and equal team members. Although patients and, in the case of neonatal care, parents do not have full autonomy in decision-making processes (Ubel et al., 2018), health professionals are taking steps in the direction of greater autonomy for parents, which is at least partly due to parents' ability to obtain information from online sources and to order diagnostic tests from commercial providers (Kilbride & Joffe, 2018). It is a common theme in discussing 'patient' autonomy and shared decision-making that 'patients' can gain knowledge, skills, and attitudes that support an autonomous role in medical decision-making and self-care (Castro et al., 2016). Recently, the European Foundation for the Care of Newborn Infants **(**EFCNI**)** published Neonatal Care Standards advocating the importance of increasing parent autonomy by supporting parents in their role as primary caregivers and by involving them in shared decision-making (European Foundation for the Care of Infants (EFCI), 2018).

Background

Parent education is a beneficial factor for an effective learning process toward parent autonomy. In addition to viewing the achievement of 'patient' autonomy from the usual perspectives of nursing (Lindberg et al., 2018), medical care (Kilbride & Joffe, 2018), and ethics (Ubel et al., 2018), the question arises how parents can benefit from current insights into the adult learning processes of health professionals, as reflected in competency-based education (CBE) (Gervais, 2016). CBE may be appropriate for parents because it is based on flexible, self-directed learning, focuses on learning outcomes rather than on time investment, is attuned to busy lives and different learning styles, and can consider previous experiences in life, work, and education (Gervais, 2016; Wascavage Gravina, 2017). For the clinical context, Carraccio et al. (2016) described a framework for competency-based medical education (CBME). Translating the fundamental principles of CBME (Carraccio et al., 2016) to competency-based parent education (CBPE) results in

three leading principles: (1) Parent education is based on the health needs of newborns and parents; (2) education and training should focus on parents' desired health literacy outcomes and not on the structures and processes of the clinical environment; and (3) health education for parents starts during their own childhood, builds on life events and is a lifelong process.

To the best of our knowledge, the literature does not describe a complete example of an operationalization of CBE in parent education, but the literature that exists provides descriptions of the use of some components, both for adult patients and for parents in neonatal care. Su et al. (2011) reported steps for developing a curriculum for patients with heart failure that included establishing essential competencies, advice on teaching methods as well as criteria for evaluating patients' learning achievements and a method for documenting learning outcomes. Other studies focused on the effects of the use of components of CBE. Johnston et al. (2000) evaluated a competency-based approach for patient education in maternity care and showed that it was cost saving due to shortening hospital stay while maintaining high patient satisfaction. In their study, Johnston et al. (2000) used a tool that allowed women to self-assess and track their educational needs. They based this self-assessment tool on pre-defined core competencies for self-care and newborn care and validated it prior to discharge through both individual instruction and daily information group sessions for parents, led by nurses. Byrne et al. (2019) used an assessment tool influenced by Miller's pyramid of competency to measure the effects of instruction on parent competencies during infant handling in a NICU.

Within CBE, communication between health professionals as coaches and parents as adult learners is important for building relationships for safe learning climates, as well as for identifying individual learning needs and assessing learning processes. The importance of communication has already been demonstrated by Benzies et al. (2020), who found a reduction in hospital length of stay for newborns in a level 2 NICU using a dynamic psychoeducational intervention, called Alberta FICare™, that empowers parents to build their knowledge, skills and confidence to care for their infant, with support and education from health professionals. The intervention consists of three components, namely (1) 'relational communication', based on family systems theory, (2) 'parent education', based on adult learning and self-efficacy theory and (3) 'parents support', based on stress and coping theory. They used the 'relational communication' component to encourage parents, when they were ready and willing to participate, to introduce and share information about their newborns during bedside rounds, and to participate in decision-making and care planning. Commendations were used as positive feedback to negotiate mutually equivalent roles between parents and health professionals to align them during the newborn's stay in the NICU, giving parents

confidence in providing care. Relational communication was also recommended to inventory the family's situation and their readiness and willingness to provide care. For parent education, parents received the use of an app, individual bedside teaching, group education sessions and a printed 'Parent Education Pathway', which was signed off by health professionals as parents acquired competencies and confidence. Parent support consisted of psychosocial support, peer-to-peer support, and a parking pass. Effect research showed that especially the individual parent intervention programs increased parental confidence, competence, satisfaction (Puthussery et al., 2018), and mental health (Zhang et al., 2021).

While the remaining available literature focused primarily on the development and efficacy of CBPE, to our knowledge, no study has explored the use of CBPE. The aim of this study was to appraise health professionals' self-reported practices in educating parents of hospitalized newborns from the perspective of CBE and to identify areas for improvement of parental learning themes to appraise and improve current practices of educating patients towards patient autonomy.

Methods

Design

A case study was performed based on a qualitative research design (Cresswell, 2017; Yin, 2017). Health professionals were invited for focus group discussions and semi-structured in-depth interviews, which were triangulated in an iterative manner (Moon, 2019). An open discussion was chosen to elicit health professionals' self-reports about their teaching practices in parent education. During these discussions, themes of the competency-based learning philosophy were not explicitly discussed in order to avoid socially desirable answers. To develop the interview questions, principles of FICare (Franck & O'Brien, 2019; Franck et al., 2020) were used known to the health professionals in this setting. The key question was: 'What experiences concerning parent learning did you have within the integrated infrastructure for Couplet Care, Rooming-in, Single Family Rooms, and FICare to empower parents?' After a trial interview with one physician and one nurse, the data collection was started.

The research team consisted of members with different types of expertise: nursing science (authors 1 and 2), qualitative research (authors 1, 2, and 4), CBME (authors 2 and 4), obstetrics (author 4), neonatology (author 3) and FICare (authors 1 and 3). The first author was previously associated with the maternity and neonatal care nursing team as a nurse educator, but had been out of the team for two years at the start of the study. The third author worked as a neonatologist within the pediatric team. The second and fourth author were not part of the team, and one of their roles was to detect bias in the selection of the themes.

The Standards for Reporting Qualitative Research (SRQR; File 1) were followed to evaluate the quality of qualitative methods and reporting (O'Brien et al., 2014).

Setting

The study was conducted in an integrated ward of the previously separate maternity ward, neonatal ward and delivery rooms for complex maternity and neonatal level 2 care. This integrated ward was designed to empower parents as primary caregivers from admission onwards by implementing and integrating the concepts of single-family rooms, couplet care, rooming-in, and FICare (Stelwagen et al., 2020). The 'integrated care setting' consisted of 53 single-family rooms and was located in a public teaching hospital in Amsterdam with approximately 3000 births annually. Each year, level 2 neonatal care was required by approximately 400 newborns born at 32 0/7 weeks' gestation or more and by approximately 70 newborns with a post-conceptional age of 30 weeks or more who were convalescing from intensive care.

During the study, on average, the multidisciplinary team consisted of the integrated nursing team (N= 111), including 3 male nurses and the physician team (N=68), including 10 male physicians. The integrated nursing team consisted of 71 specialized maternity nurses, 25 specialized neonatology nurses, and 15 specialized mother and newborn nurses, who were trained to provide different levels of care: from standard to highly complex care for mothers and newborns (Stelwagen et al., 2020). In the previous setting with separate maternity and neonatal wards, the nurses had already been accustomed to providing coaching for parents as primary caregivers of their newborns. After the transition to the integrated ward, the nurses received advanced training, based on their own experiences and on those of the parents (Stelwagen et al., 2021). The physician team consisted of 25 gynecologists, including their residents, 2 neonatologists, 18 pediatricians, including their residents, 20 midwives, 2 physiotherapists, and 1 speech therapist.

The new setting supported the goal of keeping parents and newborns together 24/7 during admission by providing rooming-in facilities for partners during the hospital stay of the mother. If the newborn needed to remain in hospital after discharge of the mother, sleeping facilities were available for one parent. Both parents were welcome to visit their newborn 24/7 and were encouraged to stay as often and as long as their personal situation allows, but they were never obligated to stay or sleep in the hospital. Mothers were present for a mean of 20 (IQR 9-24) hours per day, and partners/fathers were present for a mean of 9 (IQR 2-15 per) hours per day (Van Veenendaal et al., 2022 a). In the Netherlands, women were entitled to take at least 10 weeks of maternity leave, which could be expanded if the newborn was hospitalized, and fathers were entitled to take one week of paid leave. In addition, parents could legally take 26 working weeks of parental leave,

divided between both parents, before their child's 8th birthday. Research on this setting had shown that fathers in particular found it easier to stay with their child in a relaxed manner outside of work hours. In addition, in our previous study, both parents regarded this integrated infrastructure as a school for autonomous, independent parenting (Stelwagen et al., 2021). In this setting, health professionals used electronic medical records without special parent education modules. Parents and health professionals could visualize the newborn's progress and the progress of the parents' participation in care for their newborn on a specially developed whiteboard in the single-family room.

Participants and recruitment

In this case study, health professionals involved in maternity and neonatal care were eligible to participate if they had at least three months of work experience in the study setting. The first and third authors (initials of author 1 and 3) invited participants for voluntary participation in the newsletter of the integrated ward and by e-mail. Information was also provided about the focus group discussions and interviews. Team leaders assisted in making health professionals aware of the invitation. Of the health professionals who signed up, participants were purposefully selected, aiming both for a valid reflection of the specific health professionals in the multidisciplinary care team, and for an opportunity to explore different perspectives. The selected participants were approached by the researchers who organized the focus meeting and/or conducted the interviews (Table 1) to answer questions and provide further information.

Data collection

The focus group discussions and interviews with various health professionals were alternated and recorded between May 2018 and in January 2020. The first author, an experienced moderator, led the focus group discussions and interviews with the assistance of independent students mastering in Health Sciences (Table 1). These students transcribed the recordings of the focus group discussions into anonymized reports. At the start of the focus group discussions and interviews, demographic data on gender, age, years of experience as a health professional in maternal and/or newborn care, and role within the multidisciplinary team were collected. All focus group discussions and interviews were held in Dutch and lasted between 35 and 60 minutes. Interview summaries were sent to the participants for a member check to cover participants' bias and for validation of the data (Noble & Smith, 2015). Data collection took place until no new relevant data emerged from the focus group discussions and interviews and the research team considered that data saturation was reached.

Table 1 Conducted focus group discussions and interviews, participants, interviewers, and analyzers

Focus group discussion/interview	Participants (*n = 45*)	Interviewers	Analyzers
Focus Group Discussion 1	Pediatricians (*n* = 5)	M.S. and W.G.	W.G, A.G and M.S
Focus Group Discussion 2	Pediatricians (*n* = 5)	M.S. and W.G.	W.G, A.G and M.S
Interview	Pediatricians (*n* = 3)	W.G.	W.G, A.G and M.S
Interview	Specialized Neonatology Nurses (*n* = 10)	A.G.	W.G, A.G and M.S
Interview	Specialized Mother and Newborn Nurses (*n* = 2)	A.G.	W.G, A.G and M.S
Interview	Physio-/speech therapists (*n = 2/1*)	W.G. and A.G.	W.G, A.G and M.S
Interview	Specialized Maternity Nurses (*n* = 5)	A.K.	A.G and M.S
Focus Group Discussion 3	Gynecologists/Midwives (*n = 4/3*)	M.S. and L.H.	A.G and M.S
Interview	Specialized Mother and Newborn Nurses (*n* = 5)	A.K.	A.G and M.S

Data analysis

A framework approach was used to analyze the data (Gale et al., 2013; Ritchie, 2003). In the first phase, an inductive content analysis was conducted of the data to explore participants' self-reported practices and experiences with educating the parents. Two researchers (see Table 1) independently unrestrictedly open coded the transcripts of the focus group discussions and interviews and sorted the codes that emerged into categories in MaxQDA 2007 (VERBI Software, 2007). The same two researchers discussed the emerged codes and categories with the first author to reach consensus and establish unequivocal definitions. In the second, deductive phase, our framework of *a priori* themes of competency-based parent education (CBPE) (Table 2) was used, that had been constructed and operationalized using previous literature (Carraccio et al., 2016; Su et al., 2011; Wascavage Gravina, 2017). The first author assigned the emerged codes and categories to the *a priori* themes of the framework, a step called 'indexing'. In the final step, called 'mapping', the first author rearranged the data into matrices, participant versus a code or by theme, to analyze where they occur and where they do not, and to consider the relationships between the participants, codes and the themes. The entire research team regularly met in organized meetings to discuss the findings and to identify additional themes.

Ethical considerations

The study design was approved by the local ethics committee (WO 14.018). The anonymized data were stored in a secure environment of the research setting and will be kept there for 15 years, accessible only to members of the research team. Only the first author can access the key that links the data to the participants.

Each participant received information about the procedure, including details about the focus group discussions and interviews being recorded, the verbatim transcriptions being anonymized, and the data being analyzed. All personal identifiers were removed from the transcriptions or disguised to ensure that participants and patients described cannot be identified through the details of the stories. All the participants provided written informed consent.

Table 2 Framework for competency-based parent education

Themes:	Definition/operationalization
1. Parent curriculum based on inter-professional consensus	The specific skills a parent needs to practice independent parenthood are outlined in a step-by-step process for learning. The curriculum is co-created by parents and health professionals of different disciplines.
2. Transparency about the competencies needed	It is transparent for all stakeholders which competencies or activities must be mastered.
3. Learning climate	Safe: Coaching of parents is based on learning experiences rather than on time investment, parents are equal partners of the care-team, and caretakers guard the balance between patient safety and the development of parental autonomy.
	Personalized: Coaching of parents is aligned to each parent's level of competence and learning needs and acknowledges differences in learning styles.
	Efficient: Parents have continuous access to the clinical setting and are equal members of the care team
4. Access to teaching	Parents have access at all times and to practice and formal teaching, such as webinars, interactive exercises, simulations, videos, audiotapes, group education sessions, etc.
	The learning material is based on the learning needs and development of the parents
5. Role modeling	Professionals: Nurses, physicians and therapists are aware of being role models, demonstrate clinical competence, preserve time for teaching, facilitate reflection on experiences and on what has been modeled, and encourage dialogue. They show behavior based on the principles of the chosen care concept and model self-directed learning, lifelong learning and the implementation of quality improvement.
	Peers: Other parents or grandparents
6. Assessing and reporting results	Assessment (before, during and after the curriculum) is based on focused feedback from multiple assessors using multiple methods.
7. Proficiency statements based on autonomy expectations	Proficiency statements are based on the assessment of the parents' autonomy and expressed in levels of competence.
8. Empowering parents to be active learners	Focus on parents to be active participants in their learning and assessment processes, to become self-directed learners.
9. Evaluating and improving the education program	Regularly evaluate and improve the education program with all stakeholders, professionals and parents' advisory councils.

Note. Based on Carraccio et al. (2016) and Gervais (2016)

Findings

Forty-five health professionals were included, with whom 28 interviews and 3 focus group discussions were held. Of the participants, 22 were nurses, 20 were physicians, 2 were physiotherapists, and 1 was a speech therapist. For each discipline, the participants' average period of professional experience was longer than ten years. The mean age of the nurses was slightly lower than the mean age of the other participants (Table 3).

Table 3 Demographic characteristics (n = 45)

Item	Mean (range) or N
Nurses	22
Gender	
Female	22
Neonatal Nurses	10
Maternity Nurses	5
Mother & Newborn Nurses	7
Age (range), years	35 (28-61)
Experience (range), years	10 (2- >10)
Physicians	20
Gender	
Male	2
Female	18
Pediatrics (residents)	13
Gynaecologists (residents)	4
Midwives	3
Age (range), years	39 (26-60)
Experience (range), years	10 (0.5- >10)
Physio-/speech therapists	2/1
Age (range), years	45 (40-51)
Experience, years	>10

During the analysis of the participating health professionals' self-reported practices for adults, two themes of the framework of CBPE (see Table 2) emerged as evidently operationalized: (1) "Learning climate" and (2) "Role modeling". Five themes emerged as incompletely operationalized: (1) "Parent curriculum based on inter-professional consensus"; (2) "Transparency about the competencies needed"; (3) "Access to teaching"; (4) "Assessing and reporting results", and (5)

"Proficiency statements based on autonomy expectations". Two themes did not emerge from the data: (1) "Empowering parents to be active learners" and (2) "Evaluation and improvement of the education program". The analysis revealed no additional themes outside the used CBPE framework.

Operationalized themes of practices of parent education

Learning climate

Participants generally described a form of master-apprentice learning in an adequate climate. Almost all the participants started the interview with stories that fitted into the theme 'learning climate' by describing how the integrated care setting facilitated the parents in having their own 'private' learning environment, with day and night access to the newborn enabling them to practice their parenting skills. We distinguished three sub-themes within this theme: safe, personalized, and efficient.

Safe. According to the participants, the context of the single-family room with rooming-in facilities, couplet care, and FICare provided parents with a safe and privately experienced environment that encouraged learning by doing. *'Parents seem more comfortable trying out actions and skills without being seen and judged by other parents or other staff members'* (R1, Gynecologists [G]).

Personalized. Participants mentioned recognizing the individual learning needs based on variations in educational levels and previous experience as a parent, cultural background, and personal characteristics, such as age, to which they adapted their coaching style. The coaching styles varied depending on what parents needed. For example, insecure parents were encouraged to take small steps: '*Some parents do nothing at all or perhaps do not dare.'* (R6, Mother and Newborn Nurse [M&NN]). *'I try to encourage them in small steps to take over more and more.'* (R7, Neonatal Nurse [NN]). An example of another coaching style was to create awareness in unconsciously incompetent parents by teaching: '*Some parents want to do everything themselves without being able to do it well yet, so then we have to train them.'* (R6, M&NN). Some participants reported they found it difficult to guide parents with a low level of education or limited health literacy.

Efficient. Participants noticed that because the parents could be close to their newborn 24 hours per day, they became the most constant members of the care team. "*In the past, they came to visit, but now they are constantly with their child.*" (R12, NN). This constant presence had a synergistic effect on the parents and health professionals: it supported the parents to grow into their role as the primary caregiver for their newborn and facilitated the health professionals in accepting the parents as equal partners in the care team. "*Integrating the parents into the care, that's the core aspect in empowering parents.'* (R1, NN). In addition, participants mentioned as an important benefit of the integrated care setting that the commute between different hospital wards, or between the hospital and

home, was no longer necessary or less time-consuming, allowing parents to get to know their newborn more efficiently and to have more time to learn how to provide care. Furthermore, because participants could observe and guide both the mother and the father, as parents care for their newborns jointly in the single-family room, the participants could teach them simultaneously how to parent. '*I also think we observe more of family systems, of parents together. I encourage parents more maybe, because I sense more … involve the father in the care … they are here and we have the facilities … a large room, rather than in a shared room with other newborns'* (R2, G, FGD 3).

Role modeling

The theme 'role modeling' emerged as participants mentioned that the single-family rooms allowed and supported professional staff members to serve as role models for both of the parents, whereas the setting precluded other parents from also serving as role models for the parents.

Professionals. Participants noticed that the first step in parental learning was observing and copying the skills of the staff members: '*The mother is present and can see how we handle the child.'* (R3, NN), *'In the past, they were not even present*' (R2, NN). Over time, the parents naturally participated more and more, and eventually, they could provide the care for their newborn independently. '*They (parents) automatically take over the care of their newborn… and do more and more, while we do less'* (R2, M&NN]).

Peers. According to the participants, the single-family rooms were a limitation for role modeling by the parents' peers, as parents had fewer opportunities to be in contact with other parents and to share knowledge and experiences. On the open-bay ward, '*parents used to teach and coach each other'* (R3, NN). Participants reported that to promote contact with other parents, staff members organized weekly group sessions for the parents. However, according to the participants, these sessions might not have emulated the situation on an open bay ward, where parents interacted more and learned from each other by watching and listening to their peers.

Incompletely operationalized themes of practices of parent education

Parent curriculum and transparency of competences

Participant interviews revealed an implicit and incomplete fit with the themes 'parent curriculum based on inter-professional consensus' and 'transparency of competences', which determined which expected roles and skills parents should learn before discharge and in what order these skills should be learned. Participants did mention roles and skills for parents related to newborn care, such as interacting with their child, understanding their child's specific needs, and

advocating for themselves and their child, but they did not use a formal checklist or blueprint to define these competencies. One neonatal nurse said, '*Parents are often not well aware of what they may do and learn'* (R1,P). Participants reported that parents who were transferred from NICU level 3 units in particular might have benefited from insight into the availability of education programs to take a more participatory role in caring for their newborn on the neonatal level 2 ward, focusing on preparation for home instead of on the newborn's survival, which was appropriate at the NICU level 3.

Access to teaching

The theme 'access to teaching' was mentioned by the participants, expressing that the integrated care setting excelled at providing parents with "just in time" opportunities to learn and practice parenting skills. According to the participants, the medical rounds in which the parents were actively involved in medical decision making, were particularly important informal learning moments for parents. The participants stated that parental knowledge automatically increased as professionals explained the medical situation, answered questions and encouraged parents to take on the parent role. They also noticed that parents were more involved in medical decision-making, for example, by coming up with ideas and suggestions. Participants also reported that they facilitated reflection by the parents: '*I teach parents by asking questions about what they observe'* (R4, P). The participants also mentioned that parent group sessions were organized for education and peer-to-peer contact, but they felt these meetings did not always meet the parents' individual development and learning needs. "*Neonatologists provide clinical lessons for parents on the ward, but other disciplines [physiotherapists, speech therapists or veteran parents] also provide classes or information sessions, for example, on topics for parents of preterm infants, as a kind of information provision"* (R3, P). Besides, in every room, an extensive information book compiled by the nurses and neonatologists was available for the parents. Other forms of formal education that could be found in the CBPE, such as e-learning programs, did not emerge from the data.

Assessing and reporting results

About the theme 'assessing and reporting results', participants said that they paid much attention to giving parents feedback '*without judging'* (R4, NN). Participants stated that, in the integrated infrastructure, they were better able to assess whether the parents were confident and competent enough, and that they therefore were better able to determine an appropriate time of discharge of the newborn. '*They go home safer, safe for the child, but also in a way that parents feel comfortable enough*' (R8, NN). They reported medical rounds as important

moments for nurses and physicians to assess how well the parents understood their newborn's situation: '*Then, in fact, for me, it is clear what they think. Whether they understand it well'* (R4, NN). Some participants said that they found it difficult to assess the learning level of the individual parent or to assess what parents could or could not do independently: '*We do not have a system that shows what parents can do with their child and what their questions are'* (R1, NN). To address this issue, according to the participants, the nursing team developed a whiteboard that was placed in each single-family room, so parents and nurses could use it to visualize the level of parent participation in specific skills, such as bathing, feeding or tube feeding.

Proficiency based on autonomy expectations

Participants mentioned the theme 'proficiency based on autonomy' only as allowing parents to care for their newborns independently during hospitalization once the participants and the parents were confident about the parents' skills. *'Especially when we see parents for several days in a row, we notice that sometimes the next day they say: "Well, I did this myself". It is a form of self-assessment' (R10, Maternity Nurse [MN]).* In addition, participants reported that they regularly consulted with parents to assess their readiness for discharge as independent parents and discussed this readiness within the care team. However, no systematic assessment of readiness for discharge was present.

Themes of the framework that did not emerge

Participants did not speak about strategies fitting the theme 'empowering parents to be active learners', nor did they mention aspects of the theme 'evaluation and improvement of the education program' with parents.

Discussion

In this case-based qualitative study, the current practice of educating patients as adult learners in an integrated maternity and neonatal ward was appraised to detect areas of improvement. CBE can be used to appraise and improve the education of parents of newborns in hospitals.

We noticed that the participants' stories reflected a classic master-apprentice approach, in which role modeling and coaching were important pillars. Besides, learning took place in a learning climate in which parents felt safe and respected, parents were encouraged to be equal members of the health care team, and they had a lot of exposure to professional role models. These findings were consistent with the findings of our previous study, which explored parents' experiences

(Stelwagen et al., 2021). In the clinical setting of the present study, parents were in close proximity to their newborn 24 hours per day, which is still not a common situation for parents and newborns (Head Zauche et al., 2020; McNair et al., 2020; Oude Maatman et al., 2020). Within CBE, role modeling is an important component for training, but according to Horsburgh et al. (Horsburgh & Ippolito, 2018), it must be done systematically when used within a curriculum for learning specific competencies. If role modeling is not intentionally applied or applied unilaterally, education may be less focused on self-directed and independent learning (Sternszus et al., 2020). Moreover, if parent education is only based on role modeling, parents risk of copying professionals trained in more 'conservative' health care paradigms instead of being well prepared for parental autonomy (Benbassat, 2014; Frenk et al., 2010).

The literature describes various programs to educate parents in a clinical setting (Banerjee *et al.,* 2020; Kadivar *et al.,* 2017; Lebel *et al.,* 2020; Platonos *et al.,* 2018; Puthussery *et al.,* 2018). What stands out is that, in contrast to CBE, these programs and the role-modeling professionals in our study focus on teaching content-based parenting skills, such as caring for the newborn, rather than on teaching learning skills aimed at lifelong empowerment. Van Houten-Schat et al. (2018) found similar results in a study on supervising medical students in practice; supervisors focused on interventions for goal setting and monitoring and not on supporting self-evaluation. Our findings are in line with those of a review of parent education in primary care by Gilmer et al. (2016), who found that adult education methods are overlooked. To succeed as autonomous parents in an ever-changing environment, parents in maternity and neonatal care should be empowered to be active participants in their learning and assessment processes (Bajis et al., 2020) so that they can continue a lifelong learning process for parenting after hospital discharge. For this empowerment, it may be helpful to use 'just in time' learning systems, such as reflective learning portfolios for parents (Cheng et al., 2018) and a 'Patient-Activated Learning System', which has been evaluated as a promising approach to eHealth patient education (Carmel et al., 2019).

Our study showed that group parent education did not meet parents' learning needs. This finding is consistent with recent evidence on parents' expectations of learning. Parents have a higher priority for education that is provided "just in time" and is "tailored" to their individual needs than for group education sessions (Monaghan et al., 2020). In the group parenting sessions organized in the research setting of our study, we also noticed a shift from substantive topics to peer support and social contact moments for parents. To expand the opportunities for acquiring competencies, it may be useful to consider other approaches that are already being used in prenatal care, such as social learning through shared medical appointments (Nisbeth Jensen & Fage-Butler, 2016; Tsiamparlis-Wildeboer et al., 2020).

The findings in our study confirmed the outcomes of Axelin et al. (2018), who stated that supporting parent involvement in medical rounds, the so-called Family Centered Rounds (FCRs) in FICare, seems crucial to for parents' participation in decision making. We found FCRs can provide opportunities to educate parents as individuals, as well as opportunities for health professionals to assess the parents' knowledge. In addition, we found FCRs can serve as social learning moments for parents to establish themselves as valued team members, which is consistent with the previously reported experiences of the parents who participated in these rounds (Stelwagen et al., 2021).

In our present case study, other forms of formal education, such as e-learning, did not emerge, which is consistent with the findings of previous studies on digital approaches to educating parents. Apps for NICU parents are either lacking or of concern in terms of quality and credibility (Richardson et al., 2019). More recent literature showed that the use of digital approaches in parent education is considered relevant, effective and safe, but is still being explored and promoted (Lebel et al., 2020; Rau et al., 2020, Waddington et al., 2021).

In the present study, no curriculum for parents was found that described what competencies they need to master, and that outlined these competencies in a step-by-step learning process. According to Gehl et al. (2020), prioritizing core areas for a curriculum can help implement standardized curricula in existing parental education in a NICU (Gehl et al., 2020). Our author team underscores the importance of including a core topic of 'family care' in the curriculum, besides a core topic of 'newborn care'. In our earlier study, fathers in particular expressed a need to learn how to care for their entire family and how to maintain a balance in the family between caring for each other and for themselves (Stelwagen et al., 2021). Participants in our study identified new learning objectives in family care due to being more directly involved in and able to observe the dynamics of the whole family with all the specific interrelationships and roles, as the single-family room enabled both parents to be present and participate more frequently in caring for their newborn. Our author team believes that further staff development on the topic of family care is necessary to prevent staff from feeling inadequately trained to teach parents (Puddester et al., 2015).

In clinical training, entrustable professional activities are used to bridge the gap between educational science and practice (Henry & West, 2019; Hodges et al., 2019). Similarly, in a parent curriculum, prioritized competencies may be translated into measurable entrustable parental activities that parents can be expected to perform at varying levels of competence. A good example of the demonstrated effectiveness of such a parent curriculum is the use of a "parent education pathway" as part of a multiple intervention approach (Benzies et al., 2020). To help health professionals decide on patients' competencies in managing

their affairs and in self-management, Tremblay et al. (2020) designed a web-based tool, the Competency Assessment Tool, and studied its usability among health professionals. The researchers advocated including the user experience at the beginning of such a design process, but did not mention the patients as users. Our author team recommends including patients as users of assessment tools to address our finding that parental empowerment was lacking in the evaluation and improvement of parent education programs.

Parent involvement in the design, content, and delivery of parent education requires equal relationships between healthcare professionals and parents, i.e., it requires empowered parents. Recent research has once again highlighted the need for improvement of the communication between health professionals and parents in the NICU with the aim of parent empowerment and the development of self-management (Labrie et al., 2021, Lorie et al., 2021; Wreesman et al., 2021). Our author team recommends creating an equal partnership by incorporating 'relational communication' to help health professionals to understand and respond to parents' needs, as Benzies (2016) described. Relational communication can help and motivate parents to give real input in the development of parent education programs. Real input of parents may help to create a program that meets the interests and needs of both parties, addressing both the minimum requirements of professionals to educate parents and the learning needs of parents. Participants in our study mentioned that assessing parents' knowledge and skills must be done without 'judging' the parents. Using of commendations and positive feedback, which is a part of relational communication as described by Benzies (2016), can also help health professionals to make a difference in assessing parental skills without judging parents.

Limitations

The findings of the present study should be interpreted within certain limitations. First, the CBE approach reflects ideas about adult learning, but more validation is needed for its use with patients. Future research should evaluate the effects that will result from curriculum improvements. Second, although a plea is made to regard parents as students, parents must develop their skills in a context that is often perceived as stressful and emotionally charged differently than that of students in health professions. Further research may shed light on the implications of this difference. Third, this study was based on only one case, albeit a special case in a setting that contributed greatly to autonomous parenthood. The transferability lies in the idea that such CBE-inspired appraisal may be feasible in many other contexts, but the outcomes and recommendations may differ significantly. Fourth, this study relied on the stories of a large number of health professionals; relevant information might be added by observations made in the work situation

by researchers with an educational perspective. Fifth, the importance of curriculum recommendations might be mitigated by the need for an individual approach with parents of different backgrounds and different levels of health literacy (Blom et al., 2018; Van der Gaag et al., 2017).

Further research

A subject for further research is health professionals' perceptions of their professional role when they use CBE for parent education. The change from a health professional who "knows best" to one that is "a coach for parents in their learning process" may be experienced as a loss of status. Such a change in professional identity may have negative side effects, such as a loss of invaluable staff. Parents have already been reported to experience power problems with health professionals in clinical settings geared towards parent empowerment (Gervais, 2016).

Conclusion

Current parent education programs in neonatal care may benefit from appraisal based on CBE themes to detect areas for improvement. In our case, the education of parents depended mainly on role modeling and coaching in an adequate learning climate, mimicking the classic master-apprentice model. A structured curriculum that employed all the CBPE themes was missing, and the appraisal revealed several opportunities to improve in-hospital parent education. In appraising in-hospital education of parents of newborns with the CBE principles, it became evident that the greatest improvement for parental autonomy could be achieved by empowering parents to be "active learners" and by involving them in the evaluation and improvement of the educational program. Our author team advocates using our method of appraisal in several other contexts, especially since the team believes that parent education is essential for effective empowerment towards parent autonomy.

Relevance to clinical practice

Appraisal of in-hospital parent education based on CBPE themes is a feasible approach for the improvement of adult learning processes towards parent autonomy. Parent education is at risk of being merely based on a master-apprentice model and may be more effective if it is designed as an adult learning program based on CBE principles. To achieve parental autonomy, health professionals may

benefit from developing a structured formal training program, including a transparent curriculum for learning entrustable parental activities and systems for assessment and feedback of parental learning supported by parental learning portfolios. Relational communication can be used to guide parents in their parental role within the care team and in their individual learning processes. Health professionals can use 'role modeling' as an education tool but must be aware of the extent to which their professional behaviour actually is a good example of the parental role. In addition, health professionals can use interventions to empower parents to actively participate in their learning and assessment processes. Our author team advocates the inclusion of parents as important stakeholders in the evaluation and improvement of the educational program, as well as their inclusion in interdisciplinary learning teams to take further steps in guiding them towards autonomous parenting.

References

Axelin, A., Outinen, J., Lainema, K., Lehtonen, L. & Franck, L.S. (2018). Neonatologists can impede or support parents' participation in decision-making during medical rounds in neonatal intensive care units. *Acta Paediatrica* 107 (12), 2100-2108. https://doi.org/*10.1111/apa.14386*.

Bajis, D., Chaar, B. & Moles R., (2020). Rethinking competence: A nexus of educational models in the context of lifelong learning. *Pharmacy (Basel)* 8, 283-288. https://doi.org/10.3390/pharmacy8020081.

Banerjee, J., Aloysius, A., Mitchell, K., Silva, I., Rallis, D., Godambe, S.V. & Deierl, A. (2020). Improving infant outcomes through implementation of a family integrated care bundle including a parent supporting mobile application. *Archives of Diseases in Childhood-Fetal & Neonatal Education* 105, 172-177. https://dx.doi.org/10.1136/archdischild-2018-316435.

Benbassat, J. (2014). Role modeling in medical education: The importance of a reflective imitation. *Academic Medicine*. 89, 550-554. https://doi.org/10.1097/ ACM.0000000000000189

Benzies, K.M. (2016). Relational Communications Strategies to support family-centered neonatal intensive care. The Journal of Perinatal & Neonatal Nursing 30, 233-236. https://doi.org/10.1097/JPN.0000000000000195

Benzies, K.M., Aziz, K., Shah, V., Faris, P., Isaranuwatchai, W., Scotland, J., Larocque, J., Mrklas, J.,Naugler, C., Stelfox, H.T., Chari, R., Soraishan, A.S., Akierman, A.R., Phillipos, E., Amin, H., Hoch, J.S., Zanoni, P., Kurilova, J., & Lodha, R. (2020). Effectiveness of Alberta Family Integrated Care on infant length of stay in level II neonatal intensive care units: a cluster randomized controlled trial. *BMC Pediatrics*. 20: 535. https://doi.org/10.1186/s12887-020-02438-6

Blom, I.M., Cohen, E.S., Eshuis, L.V., Woudstra, A.J., Snijder, M.B., Kunst, A.E., Fransen, M.P., Van der Gaag, M., Van der Heide, I., Spreeuwenberg, P.M.M., Brabers, A.E.M. & Rademakers, J. (2018). Ethnic differences in health literacy among young adults in Amsterdam. *Health Literacy Research and Practice* 2, 192-204. https://doi.org/10.3928/24748307-20180926-01

Byrne, E.M., Sweeney, J.K., Schwartz, N., Umphred, D. & Constantinou, J. (2019). Effects of instruction on parent competency during infant handling in a neonatal intensive care unit. *Pediatric Physical Therapy* 31, 43-49. https://doi.org/10.1097/PEP.0000000000000557.

Carmel, A.S., Cornelius-Schecter, A., Frankel, B., Jannat-Khah, D., Sinha, S., Pelzman, F. & Safford, M.M. (2019). Evaluation of the Patient Activated Learning System (PALS) to improve knowledge acquisition, retention, and medication decision making among hypertensive adults: Results of a pilot randomized controlled trial. *Patient Education & Counseling* 102, 1467-1474. https://doi.org/10.1016/J.PEC.2019.03.001

Carraccio, C., Englander, R., Van Melle, E., Ten Cate, O., Lockyer, J., Chan, M.K., Frank, J.R. & Snell, L.S. (2016). Advancing competency-based medical education: A charter for clinician-educators. *Academic Medicine* 91 (5), 645-649.https://doi.org/10.1097/ACM.0000000000001048.

Castro, E.M., Van, R.T., Vanhaecht, K., Sermeus, W. & Van, H.A. (2016). Patient empowerment, patient participation and patient-centeredness in hospital care: A concept analysis based on a literature review. *Patient Education & Counseling* 99, 1923-1939. https://doi.org/10.1016/j.pec.2016.07.026.

Cheng, Y.C., Chen, L.L., Chang, Y.S., Li, T.C., Chen, C.J. & Huang, L.C. (2018). The effectiveness of learning portfolios in learning participation and learners' perceptions of skills and confidence in the mother of preterm infant. *Midwifery* **62**, 86-91. https://doi.org/10.1016/j.midw.2018.03.010.

Cresswell, J. (2017). *Qualitative inquiry and research design: Choosing among five approaches*. Sage.

European Foundation for the Care of Infants (EFCI) (2018). *European standards of care for newborn health*. Retrieved from https://www.efcni.org/wp-content/uploads/ 2018/11/2018_11_16_ESCNH_Report_final.pdf.

Franck, L.S. & O'Brien, K. (2019). The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care. *Birth Defects Research* 111, 1044-1059. https://doi.org/ 10.1002/bdr2.1521.

Franck, L.S., Waddington, C. & O'Brien, K. (2020). Family integrated care for preterm infants. *Critical Care Nursing Clinics of North America* 32, 149-165. https://doi.org/10.1016/j.cnc.2020.01.001

Frenk, J., Chen, L., Bhutta, Z.A., Cohen, J., Crisp, N., Evans, T., Fineberg, H., Garcia, P., Ke, Y., Kelley, P., Kistnasamy, B., Meleis, A., Naylor, D., Pablos-Mendez, A., Reddy, S., Scrimshaw, S., Sepulveda, J.,

Serwadda, D. & Zurayk, H. (2010). Health professionals for a new century: Transforming education to strengthen health systems in an interdependent world. *Lancet* 376, 1923-1958. https://doi.org/10.1016/S0140-6736(10)61854-5

Gale, N.K., Heath, G., Cameron, E., Rashid, S. & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology* 13, 117. https://doi.org/10.1186/1471-2288-13-117

Gehl, M.B., Alter, C.C., Rider, N., Gunther, L.G. & Russell, R.B. (2020). Improving the efficiency and effectiveness of parent education in the neonatal intensive care unit. *Advances in Neonatal Care* 20, 59-67. https://doi.org/10.1097/ANC.0000000000000644

Gervais, J. (2016). The operational definition of competency-based education. *The Journal of Competency-Based Education* 1, 98-106. https://doi.org/10.1002/cbe2.1011

Gilmer, C., Buchan, J.L., Letourneau, N., Bennett, C.T., Shanker, S.G., Fenwick, A. & Smith-Chant, B. (2016). Parent education interventions designed to support the transition to parenthood: A realist review. *Int J Nurs Stud* **59**, 118-133. https://doi.org/10.1016/j.ijnurstu.2016.03.015

Head Zauche ,L., Zauche, M.S., Dunlop, A.L. & Williams, B.L. (2020). Predictors of parental presence in the neonatal intensive care unit. *Advances in Neonatal Care* 20, 251-259. https://doi.org/10.1097/ANC.0000000000000687

Henry, D. & West, D.C. (2019). The clinical learning environment and workplace-based assessment: Frameworks, strategies, and implementation. *Pediatric Clinics of North America* 66, 839-854. https://doi.org/10.1016/j.pcl.2019.03.010

Hodges, A.L., Konicki, A.J., Talley, M.H., Bordelon, C.J., Holland, A.C. & Galin, F.S. (2019). Competency-based education in transitioning nurse practitioner students from education into practice. *Journal of the American Assoc Nurse Practitioners* 30, 675-682. https://doi.org/10.1097/JXX.0000000000000327

Horsburgh, J. & Ippolito, K. (2018). A skill to be worked at: Using social learning theory to explore the process of learning from role models in clinical settings. *BMC Medical Education* 18, 156. https://doi.org/10.1186/1471-2288-13-117

Johnson, T.R., Zettelmaier, M.A., Warner, P.A., Hayashi, R.H., Avni, M. & Luke, B. (2000). A competency based approach to comprehensive pregnancy care. *Women's Health Issues* 10, 240-247. https://doi.org/10.1016/s1049-3867(00)00058-x

Kadivar, M., Seyedfatemi, N., Mokhlesabadi Farahani, T., Mehran, A. & Pridham, K.F. (2017). Effectiveness of an internet-based education on maternal satisfaction in NICUs. *Patient Education & Counseling* 100, 943-949. https://doi.org/10.1016/j.pec.2016.11.005

Kilbride, M.K. & Joffe, S. (2018). The new age of patient autonomy: Implications for the patient-physician relationship. *Journal of American Medical Association* 320, 1973-1974. https://doi.org/10.1001/jama.2018.1438

Labrie, N. H. M., van Veenendaal, N.R., Ludolph, R.A., Ket, J. C. F., van der Schoor, S.R.D. & van Kempen & A.A.M.W. (2021). Effects of parent-provider communication during infant hospitalization in the NICU on parents: A systematic review with meta-synthesis and narrative. *Patient Education & Counseling*. 104 (7), 1526-1552. https://doi.org/10.1016/j.pec.2021.04.023

Lebel, V., Heon, M., Juneau, A.L., Colette, K. & Feely, N. (2020). The development of a digital educational program with parents of preterm infants and neonatal nurses to meet parents' educational needs. *Journal of Neonatal Nursing* 27, 52-57. https://doi.org/10.1016/j.jnn.2020.06.004

Lindberg, C., Fagerström, C. & Willman, A. (2018). Patient autonomy in a high-tech care context: A theoretical framework. Journal of Clinical Nursing 27, 4128-4140. https://doi.org/10.1111/jocn.14562

Lorié, E.S., Wreesmann, W.W., van Veenendaal, N.R., van Kempen, A.A.M.W. & Labrie, N.H.M. (2021). Parents' needs and perceived gaps in communication with healthcare professionals in the neonatal (intensive) care unit: A qualitative interview study. *Patient Education & Counseling*. 104 (7), 1518-1525. https://doi.org/10.1016/j.pec.2020.12.007.

McNair, C., Chinian, N., Shah, V., McAllister, M., Franck, L.S., Stevens, B., Burry, L. & Taddio, A. (2020). Meta-synthesis of factors that influence parents' participation in pain management for their infants in the NICU. *Journal of Obstetric, Gynecologic & Neonatal Nursing* 49, 263-271. https://doi.org/10.1016/j.jogn.2020.02.007

Monaghan J., Kim, T., Dol, J., Orovec, A., Campbell-Yeo, M. (2020). Parents' learning needs and preferences in a neonatal intensive care unit: A desire for enhanced communication and eHealth technology. *Journal of Neonatal Nursing*.26 (2), 101-105. https://doi.org/10.1016/j.jnn.2019.09.001

Moon, M.D. (2019). Triangulation: A method to increase validity, reliability, and legitimation in clinical research. *Journal of Emergency Nursing* 45, 103-105. https://doi.org/10.1016/j.jen.2018.11.004

Nisbeth Jensen, M. & Fage-Butler, A.M. (2016). Antenatal group consultations: Facilitating patient-patient education. *Patient Education & Counseling* 99, 1999-2004. https://doi.org/ 10.1016/j.pec.2016.07.032.

Noble, H. & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence Based Nursing*. 18, 34-35. https://doi.org/ 10.1136/eb-2015-102054.

O'Brien B.C., Harris, I.B., Beckman, T.J., Reed, D.A. & Cook, D.A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine*. 89, 1245-1251. https://doi.org/10.1097/ACM.0000000000000388. PMID: 24979285.

Oude Maatman, S.M., Bohlin, K., Lillieskӧld, S., Garberg, H.T., Uitewaal-Poslawky, I., Kars, M.C. & Van den Hoogen, A. (2020). Factors influencing implementation of family-centered care in a neonatal intensive care unit. *Frontiers in Pediatrics* 8, 222. https://doi.org/10.3389/fped.2020.00222

Platonos, K., Aloysius, A., Banerjee, J. & Deierl, A. (2018). Integrated family delivered care project: Parent education programme. *Journal of Neonatal Nursing* 24, 29-34. https://doi.org/10.1016/j.jnn.2017.11.008.

Puddester, D., MacDonald, C.J., Clements, D., Gaffney, J. & Wiesenfeld, L. (2015). Designing faculty development to support the evaluation of resident competency in the intrinsic CanMEDS roles: Practical outcomes of an assessment of program director needs. *BMC Medical Education* 15, 100. https://doi.org/10.1186/s12909-015-0375-5

Puthussery, S., Chutiyami, M., Tseng, P.C., Kilby, L. & Kapadia, J. (2018). Effectiveness of early intervention programs for parents of preterm infants: A meta-review of systematic reviews. *BMC Pediatrics* 18, 223. https://doi.org/10.1186/s12887-018-1205-9

Rau, N. M., Hasan, K., Ahamed, S. I., Asan, O., Flynn, K. E., & Basir, M. A. (2020). Designing a tablet-based prematurity education app for parents hospitalized for preterm birth. *International Journal of Medical Informatics*, 141, 104200. https://doi.org/10.1016/j.ijmedinf.2020.104200

Richardson, B., Dol, J., Rutledge, K., Monaghan, J., Orovec, A., Howie, K., Boates, T., Smit, M. & Campbell-Yeo, M. (2019). Evaluation of Mobile Apps Targeted to Parents of Infants in the Neonatal Intensive Care Unit: Systematic App Review. *JMIR Mhealth Uhealth*, 7(4), e11620. https://doi.org/10.2196/11620

Ritchie, J. (2003). *Qualitative research practice: A guide for social science students and researchers*. Sage, London. https://mthoyibi.files.wordpress.com/2011/10/qualitative-research-practice_a-guide-for-social-science-students-and-researchers_jane-ritchie-and-jane-lewis-eds_20031.pdf

Sternszus, R., Boudreau, J.D., Cruess, R.L., Cruess, S.R., Macdonald, M.E. & Steinert, Y. (2020). Clinical teachers' perceptions of their role in professional identity formation. *Academic Medicine* 95, 1594-1599. https://doi.org/10.1097/ACM.0000000000003369.

Stelwagen, M.A., van Kempen, A.A.M.W., Westmaas, A.H., Blees, Y.J. & Scheele, F. (2020). Integration of maternity and neonatal care to empower parents. *Journal of Obstetric, Gynecologic & Neonatal Nursing* 49, 65-77. https://doi.org/10.1016/j.jogn.2019.11.003.

Stelwagen, M.A., van Kempen, A.A.M.W., Westmaas, A.H., Scheele, F. (2021). Parents' experiences with a model of integrated maternity and neonatal care designed to empower parents. *Journal of Obstetric, Gynecologic, & Neonatal Nursing* 50, 181-192. https://doi.org/10.1016/j.jogn.2020.11.001

Su, W.M., Herron, B. & Osisek, P.J. (2011). Using a competency-based approach to patient education: achieving congruence among learning, teaching and evaluation. *The Nursing Clinics of North America* 46, 291-298. https://doi.org/10.1016/j.cnur.2011.05.003

Tremblay, M., Vallee, C., Carignan, M., Provencher, V., Delli-Colli, N., Poulin, V., Giguere, A., Careau, E. & Giroux. D. (2020). Design and implementation of the Competency Assessment Tool (CAT): User experience usability study. *Informatics for Health & Social Care 45,* 57-76. https://doi.org/10.1080/17538157.2018.1550414

Tsiamparlis-Wildeboer, A.H.C., Feijen-De Jong, E.I. & Scheele, F. (2020). Factors influencing patient education in shared medical appointments: Integrative literature review. *Patient Education & Counseling* 103, 1667-1676. https://doi.org/10.1016/j.pec.2020.03.006

Ubel, P.A., Scherr, K.A. & Fagerlin, A. (2018). Autonomy: What's shared decision making have to do with it? *The American Journal of Bioethics* 8, 11-12. https://doi.org/10.1080/15265161.2017.1409844

Van der Gaag, M., Van der Heide, I., Spreeuwenberg, P.M.M., Brabers, A.E.M. & Rademakers, J. (2017). Health literacy and primary health care use of ethnic minorities in the Netherlands. *BMC Health Service Research* 17, 350. https://doi.org/10.1186/s12913-017-2276-2

Van Houten-Schat, M.A., Berkhout, J.J., Van Dijk, N., Endedijk, M.D., Jaarsma, A.D.C. & Diemers, A.D. (2018). Self-regulated learning in the clinical context: A systematic review. *Medical Education* 52, 1008-1015. https://doi.org/10.1111/medu.13615

Van Veenendaal, N.R., van der Schoor, S.R.D., Birit, F., Broekman, B.F.P., de Goof, F., van Laerhoven, H., van den Heuvel, M., Rijnhart, J.J.M., van Goudoever, H.B., van Kempen, A.A.M.W. (2022). Association of a family integrated care model with paternal mental health outcomes during neonatal hospitalization. *JAMA Network Open.* 5(1): e2144720. htttp://doi.org/10.1001/jamanetworkopen.2021.44720

VERBI Software (2007). *MaxQDA 2007 [software]*. Retrieved from https://maxqda.com

Waddington, C., van Veenendaal, N.R., O'Brien, K. & Patel, N. (2021). Family integrated care: Supporting parents as primary caregivers in the neonatal intensive care unit. *Pediatric Investigation* 5, 4. https://doi.org/10.1002/ped4.12277

Wascavage Gravina, E. (2017). Competency-based education and its effect on nursing education: A literature review. *Teaching and Learning in Nursing* 12, 4. https://doi.org/10.1016/j.teln.2016.11.004

Wreesmann, W.W., Lorié, E.S., van Veenendaal, N.R., van Kempen, A.A.M.W., Ket, J.C.F. & Labrie, N.H. (2021). The functions of adequate communication in the neonatal care unit: A systematic review and meta-synthesis of qualitative research. *Patient Education & Counseling.* 104 (7), 1505-1517. https://doi.org/10.1016/j.pec.2020.11.029

Yin R. (2017). Case study research and applications: design and methods. Sage.

Zhang, Q., Wu, J., Sheng, X. & Ni, Z. (2021). Empowerment programs for parental mental health of preterm infants: A meta-analysis. *Patient Education & Counseling* 104, 1636-16-43. https://doi.org/10.1016/j.pec.2021.01.021

'A person is a person through other persons; you can't be human in isolation; you are human only in relationships.'

Desmond Tutu

5

Changes in professional identity related to parent autonomy in maternity and neonatal care: Rebalancing of roles

Mireille A. Stelwagen
Alvin H. Westmaas
Anne A.M.W. van Kempen
Fedde Scheele

Out for review Journal of Interprofessional Care, 5 September 2022

'For the sick it is important to have the best.'

Florence Nightingale

6

General discussion

As outlined in the introductory chapter of this thesis, the importance of empowering parents in neonatal care has been substantiated scientifically since the last decades, but it has been hampered by the physical, social or emotional separation of parents and newborns, which is caused by the cultural and the traditional organization of the hospitals. To prevent separation and to increase parental involvement in the care of their newborns, several interventions have been developed and evaluated independently, particularly in NICU level 3 settings. The aim of this thesis was to answer the following questions:

1. What can we learn from empowering parents in a neonatal level 2 setting after implementing family-integrated (FI) Care in combination with couplet care, single-family rooms, and rooming-in options?
2. What does this combination of care interventions mean for parents and health professionals?

To answer these questions, we studied the infrastructural changes that took place in our study setting, the Anna Pavilion in the OLVG hospital, which combines FICare, couplet care, single-family rooms, and rooming-in options in a neonatal level 2 ward. In addition, we studied parents' and health professionals' experiences with the empowerment of parents in this setting.

In this chapter, we present an overview of the main findings of this thesis, leading to answers to the major research questions. Subsequently, we discuss three issues that emerged from this thesis. Finally, we present some practical implications and suggestions for future research.

Main findings and conclusions

In the previous chapters, different study approaches were described which we used to understand parental empowerment in a neonatal level 2 setting and to study its effects on parents and health professionals. We present the main findings of this thesis in the next section, including answers to the major research questions.

What can we learn from empowering parents in a neonatal level 2 setting after implementing FICare in combination with couplet-care, single-family rooms and rooming-in options?

From our study of the infrastructural changes made (see Table 1) to integrate maternity and neonatal level 2 care in order to empower parents, which were described in *Chapter 2*, we learned that:

1. A prerequisite for the empowerment of parents is the close physical proximity to their newborns and their involvement in neonatal care.

2. Health care institutions should consider integrating maternity and neonatal wards to prevent separation of parents and newborns and to facilitate parent empowerment.
3. Building an infrastructure with a combination of care models of FICare, couplet-care, single-family rooms, and rooming-in will facilitate empowerment of parents of hospitalized newborns.

From the study of parents' experiences with a model of integrated maternity and neonatal care designed to empower parents, which was described in Chapter 3, we learned that:

4. Health care professionals must know the positive experiences and challenges (see Table 2) that parents of newborns experience when empowering them for autonomous parenting during hospitalization by involving parents in the care of newborns 24 hours a day.
5. Parents experienced an intensive learning process due to the combination of FICare, couplet care, single-family rooms, and rooming-in facilities.

From the study of in-hospital education of parents of newborns, which was described in Chapter 4, we learned that:

6. Competency-based education (CBE) is useful for empowering parents of hospitalized newborns, as adult learners, to achieve parent autonomy.
7. CBE urges health professionals to empower parents of hospitalized newborns to be active learners and to participate in the improvement of the education program.
8. In-hospital parent education programs could be improved via an appraisal based on competency-based education.

From the study of perceived changes in health professionals' professional identities when practice moved from a "paternalistic" model, in which health professionals were in charge, to a shared or "consumerist" model with increased parent autonomy, which was described in Chapter 5, we learned that:

9. Preparing the multidisciplinary team is needed if the aim is that parents become autonomous during hospitalization. The team must be aware of the upcoming shifts in connectedness, in required competencies, and in the lines of communication with parents, and thus of the new role of each discipline and its value.
10. Ongoing continuing professional development to take up their roles as coaches and educators for parents is needed as an intervention for the empowerment of health professionals, in order to enable them to guide parents towards autonomous parenting during hospitalization.

Tabel 1 Infrastructual changes made to integrate maternity and neonatal level 2 care

Themes	Concreet
Health Care System Level	
1. *Joint Vision and Goal*	Mothers (parents) and newborns can always *stay together during hospital admission*.
2. *Integration of Three Wards into One with Single-Family Rooms*	Three types of single-family rooms with rooming-in options and equipped for complex maternity & levels1-2 neonatal care.
3. *Reorganization of the Health Care Team*	Into a combined maternity-neonatal team which could provide care for four couplet-care, mothers and newborns, combinations.
4. *New Equipment*	Supplies for maternity care and neonatal care
	Facilities that were specifically requested by the parents and the staff that facilitates the parenting role and ensures sufficient nursing supervision and safety for the newborn
Health Care Provider Level	
1. *Training for Extension of Professional Goals*	Creating a new nurse position, the specialized mother and newborn nurse
	Extra training courses for all nurses in the other area than that they were originally trained
2. *Intensified Coaching of Parents*	Team sessions, discussions on how to coach and encourage parents to participate in all situations related to the care of their sick or preterm infants and to gradually take over from the nurses.
3. *Implementing Patient Centeredness*	Invite parents participate in the development of the personal care plans for mother and newborn.
	Medical rounds with the parents in the single-family rooms
	Parents control visiting hours from family members and friends, in collaboration with nurses
Patient Level	
Opinions and Experiences of Parents	Parents expressed their views in focus group discussions on how to organize the future infrastructure to enhance family-integrated care

Table 2 Examples of positive experiences and challenges parents perceived

Positive experience for parent empowerment	Challenges
1. Feeling respected	
As responsible autonomous parents, complete family, and full equal members of the care team.	Fathers could still felt left out. Staff imposing their working methods over those of parents.
Private, safe, homely environment of the single-family room.	
Coaching and encouragement by staff during medical rounds and daily care moments to participate.	
2. Gaining self-management tools	
24-hour practical training and coaching in parental skills by all staff members	Conflicting advice from different specialized staff.
	No longer being able to observe other parents caring for their newborn, as in the former open ward.
3. Insight of condition of the newborn	
Be able to observe the newborn 24 hours a day, be informed, and work together with staff to formulate a health policy during medical rounds	Not always feel competent to make shared decisions or felt overwhelmed when confronted with certain questions.
	Difficulties in distance themselves from invasive treatments for their newborn
4. Feelings of control	
Being able to stay close to and support each other, rest and safety of their newborns, being able to take care of their newborns and influence decisions.	Mothers; difficulties to participate in newborn care when they need care themselves.
	Parents, how to ensure their own sleep and rest, uncertainties about the division of tasks and responsibilities between themselves and staff.
	Feelings of quilt if they choose not to participate.
5. Self-efficay	
Feeling ready for discharge and to take care of their newborns themselves	Power struggles if parents consider themselves / became more competent than certain health professionals, afraid of being labeled a 'difficult parent'

Issues emerging from empowering parents in neonatal level 2 care

In this thesis, we found that parents are indeed empowered toward autonomous, independent parenting through the combination of FICare, couplet care, single-family rooms and rooming-in facilities. This combination allows parents to remain in close proximity to their newborns 24 hours per day to bond well and develop their parental role before discharge in a private and comfortable environment. It enables health professionals to empower parents 24 hours per day to act as primary caregivers for their newborn in the hospital, specifically by involving, educating, and guiding parents on the care needs of their newborns and themselves, including making shared decisions. However, we also saw that certain imbalances might emerge if parent empowerment is pursued by this combination of interventions within neonatal care. We discuss three imbalances.

Balance between empowering and 'overburdening' parents

As outlined in introducing this thesis, in the literature, multiple interventions for the empowerment of parents towards autonomous, independent parenting in neonatal care were evaluated positively. These include the involvement of parents in the care of their newborns as primary caregivers (Benzies et al., 2020; Ding et al., 2019; O'Brien et al., 2018), in decision-making processes (Aarthun et al., 2019; Harris, 2014; van Oort et al., 2019) as well as facilitating the proximity between parents and newborns (Feeley et al., 2020; Flacking et al., 2013; Jaafar et al., 2016; van Veenendaal et al., 2020). Recent research on the effects of the same setting as the one used in this thesis shows that parents participated more in the care of their newborns, which was beneficial for parental mental health, for the bond between parents and newborns, and specifically for mothers' self-efficacy (Van Veenendaal et al., 2022 a; Van Veenendaal et al., 2022 b).

However, according to Janvier et al. (Janvier et al., 2021), these interventions may cause inherent ethical problems or even harm some parents if they are not applied in a way that is tailored to each parent's social and psychological realities, wishes, and desires. Parents, for example, may feel guilty for not being involved in their newborns' care even more. In this thesis, we found similar feelings in parents who could not prioritize to care for themselves, for their sick newborns or for siblings at home. Some parents felt guilty over the choice to sleep at home to compensate for the lack of sleep because of rooming-in and because of the option to participate in care 24/7. Sleep deprivation in parents of hospitalized newborns is associated with negative health outcomes (Marthinsen et al., 2018). Therefore, the empowerment of parents should be the major goal of FICare, rather than the participation of the parents themselves 24 /7, and this should be evaluated on a case-by-case basis with a professional coach. Benzies et al. (2021) showed that in prevention-oriented parenting programs with a focus on, for example, different parenting styles, parents recognize the value of self-care with no guilt.

The question arises what degree of involvement is reasonable to ask from parents. Is a serious role in the interdisciplinary team or a role as stakeholder in parental curriculum evaluation and improvement too much and overburdening for them? We need to know in what ways an in-hospital education program, based on competency-based education, can help to provide a balanced learning situation for parents. Besides, health professionals must be trained to coach parents in keeping a healthy balance between aiming for autonomy and recovering.

Balance between empowering parents and health professionals' identity challenges

Health professionals in NICUs have a long history of working without the continuous presence of parents at the bedside of their newborn (Janvier et al., 2021). Health professionals providing neonatal level 1 care or pediatric care for older children have a longer history of performing their work under the watchful eyes of parents, as the constant factor at their child's bedside (Jolley & Shields, 2009). We question whether health professionals in neonatal level 2 care are already well prepared for the sudden shift to 24/7 collaboration with parents. The change of health professionals' identity from a technically competent primary caregiver of the newborn to a family-integrated coach and educator is quite challenging (Benoit & Semenic, 2014; Oude Maatman et al., 2020; Uniacke et al., 2018). In this thesis, we found, that in the process of patient empowerment, health professionals had to reconsider their professional identity. Nurse participants, in particular, could feel unseen, unvalued, and even redundant, which is a trend seen throughout society (Nouri et al., 2019). It is essential to promote a healthy work environment for health professionals by recognizing the challenges and applying strategies for self-efficacy, self-confidence, and organizational commitment (Nouri et al., 2019).

Structural empowerment of critical care nurses is positively related to job satisfaction, which is negatively related to the intention to leave (Kelly et al., 2022), and to an increased work motivation as well as reduced feelings of stress among nurses (Saleh et al., 2022). Learning to build successful partnerships between neonatal nurses and parents through co-creation of mutual knowledge and negotiation of roles is essential (Brødsgaard et al., 2019). Health organizations should invest in the development of health professionals based on issues raised in this thesis and other literature (Spence Laschinger et al., 2010).

Balancing investments made for and benefits of empowering parents

FICare in combination with couplet care, single-family rooms, and rooming-in facilities has been found to be associated with less parental stress at discharge and to be beneficial for parental health, self-efficacy, and parent-newborn bonding

(Van Veenendaal et al., 2022 a; van Veenendaal et al., 2022 b). This thesis and other research (Van Veenendaal et al., 2022) showed that parents sometimes stay in the hospital longer, as a side effect of the empowerment process. In addition, in this thesis, we found that some parents were sometimes reluctant to disengage sufficiently from the hospital environment and that nurses sometimes found themselves insufficiently competent to prepare parents for caring for their newborns after discharge at home. The investments made to empower patients are substantial and must be in balance with the benefits of empowering parents. In this thesis, we did not study the costs of the infrastructure for empowerment, but this topic warrants future research.

Strengths and limitations

This thesis offers a multi-facetted perspective on patient empowerment in a mother and child centre. Together, the perspectives of the design process, of the parents' experiences, of health professionals' coping strategies and of the educational process offer a rich picture and a critical assessment of the outcomes of an enormous enterprise for patient empowerment.

Certain limitations should be considered when interpreting the findings of this thesis. Our study is limited to a single case. Moreover, all participants experienced the setting of one level 2 neonatal ward, and consequently, our findings are not generalizable to all settings. Our studies focused on the views of highly educated Dutch participants, with few differences in cultural backgrounds, so the findings might have been different if the study had been conducted in a different culture and context (Helmich et al., 2017). The CBE approach reflects ideas about adult learning, but more validation is needed for its use with patients. The transferability lies in the idea that such CBE-inspired appraisal may be feasible in many other contexts, but the outcomes and recommendations may differ significantly. The importance of curriculum recommendations might be mitigated by the need for an individual approach with parents of different backgrounds and different levels of health literacy (Blom et al., 2018; van der Gaag et al., 2017).

Future research

This thesis leaves many open questions. The questions presented here are some of the most obvious ones. Future research is needed on the delicate balance between a fast development of parent autonomy and the risk of overburdening the parents. Evidently, health professionals need adjusted training programs for tailored care. We need to study competency-based parenting programs in hospitals to contribute to a balanced empowering situation for parents. The implications of implementing a combination of FICare, couplet care, single-family rooms and rooming-in facilities to empower parents must be investigated in other countries

and cultures (Brooks et al., 2015). The question of whether this development towards patient empowerment requires a radically different professional identity of health professionals needs attention, not least because of emerging risks for decreased job satisfaction. Another question concerns the extent to which health professionals in neonatal care should focus on in-hospital empowerment of parents. Perhaps it would be more beneficial for parents and for health professionals to focus also on early discharge programs, such as sending preterm newborns home with home care by neonatal nurses from the age of 34 weeks (Brodsgaard et al., 2020).

Conclusion

Empowering parents of newborns in neonatal level 2 care toward autonomous, independent parenting starting at the time of admission is feasible after the implementation of FICare in combination with couplet care, single-family rooms and rooming-in facilities. This process can be optimized if several preconditions are fulfilled, including a good balance between empowered parents and well-prepared health professionals. Parents and health professionals must co-create their roles in the multidisciplinary team. Ongoing professional development will help professionals to assume a new professional identity. Both parents and health professionals require facilities and support from a well-organized and supportive organization, in which learning and coaching take place according to contemporary learning principles, which may be found in competency-based education.

References

Aarthun, A., Øymar, K. A., & Akerjordet, K. (2019). Parental involvement in decision-making about their child's health care at the hospital. *Nurs Open, 6*(1), 50-58.

Benoit, B., & Semenic, S. (2014). Barriers and facilitators to implementing the Baby-Friendly hospital initiative in neonatal intensive care units. *Journal of Obstetric,Gynecologic & Neonatal Nursing, 43*(5), 614-624.

Benzies, K. M., Aziz, K., Shah, V., Faris, P., Isaranuwatchai, W., Scotland, J., et al. (2020). Effectiveness of Alberta Family Integrated Care on infant length of stay in level II neonatal intensive care units: a cluster randomized controlled trial. *BMC Pediatr, 20*(1), 535.

Benzies, K. M., Kurilova, J., & van der Merwe, M. (2021). Parental Attitudinal and Behavioral Change Associated With Prevention-Focused Parenting Education: An Interpretive Description. *Health Educ Behav*, 10901981211033233.

Blom, I. M., Cohen, E. S., Eshuis, L. V., Woudstra, A. J., Snijder, M. B., Kunst, A. E., et al. (2018). Ethnic Differences in Health Literacy Among Young Adults in Amsterdam. *Health Lit Res Pract, 2*(4), e192-e204.

Brødsgaard, A., Pedersen, J. T., Larsen, P., & Weis, J. (2019). Parents' and nurses' experiences of partnership in neonatal intensive care units: A qualitative review and meta-synthesis. *J Clin Nurs, 28*(17-18), 3117-3139.

Brodsgaard, A., Zimmermann, R., & Petersen, M. (2015). A preterm lifeline: Early discharge programme based on family-centred care. *J. Spec. Pediatr. Nurs, 20*(4), 232-243.

Brooks, J. L., Holdtich-Davis, D., Docherty, S. L., & Theodorou, C. S. (2015). Birthing and Parenting a Premature Infant in a Cultural Context. *Qual. Health Res*.

Ding, X., Zhu, L., Zhang, R., Wang, L., Wang, T. T., & Latour, J. M. (2019). Effects of family-centred care interventions on preterm infants and parents in neonatal intensive care units: A systematic review and meta-analysis of randomised controlled trials. *Aust Crit Care, 32*(1), 63-75.

Feeley, N., Robins, S., Genest, C., Stremler, R., Zelkowitz, P., & Charbonneau, L. (2020). A comparative study of mothers of infants hospitalized in an open ward neonatal intensive care unit and a combined pod and single-family room design. *BMC Pediatr, 20*(1), 38.

Flacking, R., Thomson, G., Ekenberg, L., Lowegren, L., & Wallin, L. (2013). Influence of NICU co-care facilities and skin-to-skin contact on maternal stress in mothers of preterm infants. *Sexual & Reproductive Healthcare, 4*(3), 107-112.

Harris, G. M. (2014). Family-centered rounds in the neonatal intensive care unit. *Nursing for Womens Health, 18*(1), 18-27.

Helmich, E., Yeh, H. M., Kalet, A., & Al-Eraky, M. (2017). Becoming a Doctor in Different Cultures: Toward a Cross-Cultural Approach to Supporting Professional Identity Formation in Medicine. *Acad Med, 92*(1), 58-62.

Jaafar, S. H., Ho, J. J., & Lee, K. S. (2016). Rooming-in for new mother and infant versus separate care for increasing the duration of breastfeeding. *Cochrane. Database. Syst. Rev*(8), CD006641.

Janvier, A., Asaad, M. A., Reichherzer, M., Cantin, C., Sureau, M., Prince, J., et al. (2021). The ethics of family integrated care in the NICU: Improving care for families without causing harm. *Semin Perinatol*, 151528.

Jolley, J., & Shields, L. (2009). The evolution of family-centered care. *J Pediatr Nurs, 24*(2), 164-170.

Kelly, C., Barattucci, M., & Shakil Ahmad, M. (2022). Job satisfaction as a mediator between structural empowerment and intent-to-leave: A study of critical care nurses. *Intensive Crit Care Nurs*, 103194.

Koreska, M., Petersen, M., Andersen, B. L., & Brødsgaard, A. (2020). Supporting families on their journey towards a normal everyday life - facilitating partnership in an early discharge program for families with premature infants. *J Spec Pediatr Nurs, 25*(1), e12274.

Marthinsen, G. N., Helseth, S., & Fegran, L. (2018). Sleep and its relationship to health in parents of preterm infants: a scoping review. *BMC Pediatr, 18*(1), 352.

Nouri, A., Sanagoo, A., Jouybari, L., & Taleghani, F. (2019). Challenges of respect as promoting healthy work environment in nursing: A qualitative study. *J Educ Health Promot, 8*, 261.

O'Brien, K., Robson, K., Bracht, M., Cruz, M., Lui, K., Alvaro, R., et al. (2018). 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, 2*(4), 245-254.

Oude Maatman, S. M., Bohlin, K., Lilliesköld, S., Garberg, H. T., Uitewaal-Poslawky, I., Kars, M. C., et al. (2020). Factors Influencing Implementation of Family-Centered Care in a Neonatal Intensive Care Unit. *Front Pediatr, 8*, 222.

Saleh, M. O., Eshah, N. F., & Rayan, A. H. (2022). Empowerment Predicting Nurses' Work Motivation and Occupational Mental Health. *SAGE Open Nurs, 8*, 23779608221076811.

Spence Laschinger, H. K., Gilbert, S., Smith, L. M., & Leslie, K. (2010). Towards a comprehensive theory of nurse/patient empowerment: applying Kanter's empowerment theory to patient care. *J Nurs Manag, 18*(1), 4-13.

Uniacke, S., Browne, T. K., & Shields, L. (2018). How should we understand family-centred care? *J Child Health Care, 22*(3), 460-469.

Van der Gaag, M., van der Heide, I., Spreeuwenberg, P. M. M., Brabers, A. E. M., & Rademakers, J. (2017). Health literacy and primary health care use of ethnic minorities in the Netherlands. *BMC Health Serv Res, 17*(1), 350.

Van Oort, P. J. S., Maaskant, J. M., Smeulers, M., van Oostrum, N., Vermeulen, E., & van Goudoever, J. B. (2019). Participation of Parents of Hospitalized Children in Medical Rounds: A Qualitative Study on Contributory Factors. *J Pediatr Nurs, 46*, e44-e51.

Van Veenendaal, N. R., van der Schoor, S. R. D., Broekman, B. F. P., de Groof, F., van Laerhoven, H., van den Heuvel, M. E. N., et al. (2022 a). Association of a Family Integrated Care Model With Paternal Mental Health Outcomes During Neonatal Hospitalization. *JAMA Netw Open, 5*(1), e2144720.

Van Veenendaal, N. R., van Kempen, A., Broekman, B. F. P., de Groof, F., van Laerhoven, H., van den Heuvel, M. E. N., et al. (2022 b). Association of a Zero-Separation Neonatal Care Model With Stress in Mothers of Preterm Infants. *JAMA Netw Open, 5*(3), e224514.

Van Veenendaal, N. R., van Kempen, A., Franck, L. S., O'Brien, K., Limpens, J., van der Lee, J. H., et al. (2020). Hospitalising preterm infants in single family rooms versus open bay units: A systematic review and meta-analysis of impact on parents. *EClinicalMedicine, 23*, 100388.

7

Summary

Chapter 1 introduces the research in this thesis. It explains the importance of parent empowerment in neonatal care and how several intervention strategies are used to address barriers to empower parents toward autonomous, independent parenting during hospital admission. To address these barriers, some intervention strategies aim at proximity between parents and newborns through kangaroo-care/ skin-to skin care, single-family rooms, couplet care for mothers and newborns, and rooming-in facilities. Other strategies aim at involving parents as primary caregivers for their newborns during hospital admission, as described in the concept of family-integrated care (FICare). These FICare strategies include parent education, psychosocial support for parents and shared decision-making with parents by providing medical visit rounds with parents, called family-centered rounds (FCR). These intervention strategies require adequate communication and collaboration between health professionals and parents, in which improvement still appears to be needed. In addition, little is known about the experiences of parents and health professionals with a combination of the described intervention strategies aimed to empower parents in neonatal level 2 care. This thesis investigated what we can learn from empowering parents in a neonatal level 2 setting with FICare in combination with couplet-care, single-family rooms and rooming-in facilities. In this way, we aim to understand what this setting means for parents and health professionals.

Chapter 2 describes the changes made to implement an integrated infrastructure of maternity and neonatal level 2 care to empower parents. A case study was conducted in which we analyzed 38 documents and interviewed 6 stakeholders about the design and implementation of an integrated maternity and neonatal ward that includes FICare, single-family rooms, couplet-care, and rooming-in facilities. We found a good fit between the changes made for the integrated infrastructure and the patient empowerment model of Bravo et al. The changes primarily served the prerequisite for parental empowerment, namely 24/7 proximity between parents and newborns. In particular, this requirement was met by training the care team and reorganizing care around mothers and their newborns in single-family rooms on one ward, rather than organizing specialized maternity care and neonatal level 2 care on two separate wards. We noted that for health professionals, this transition mainly meant being trained to provide care at different levels to mother and newborn couplets in single-family rooms.

Chapter 3 describes the outcomes of a focus group and interview study on the experiences of 26 parents with empowerment within the integrated infrastructure described in *chapter 2*. Above all, parents felt ‘respected’ as a whole family by being able to stay close to each other 24/7 from the start of hospital admission

until discharge in their own single-family room, rather than being visitors on a traditional neonatal ward. Having their own single-family room provided parents with a safe and private learning context in preparation of independent, autonomous parenting at the time of discharge. In addition, parents learned from close observation of health professionals and from participating in daily medical rounds. These learning opportunities were helpful for understanding their newborns' conditions and treatment policies, and for informed shared decision making. We noted that the parents felt like full and respected members of the team, besides going through an intensive learning process that engendered a sense of competence in their role as parents before discharge. However, parents also faced challenges with FICare in combination with couplet-care, single-family rooms and rooming-in facilities. The challenges mentioned were; alignment of responsibilities with health professionals about newborn care, sleep deprivation, uncertainties about what priorities to set in caring for their newborns as well as themselves and siblings at home, and feelings of separation from staff and from parents of other newborns on the ward. In addition, some parents experienced power struggles with staff members, for example, when the parents wanted to take initiatives to manage their newborn's health care themselves because they considered themselves more skilled at caring for their newborn than the staff.

In *Chapter 4*, we appraised 45 health professionals' self-reported practices in educating parents within the integrated infrastructure from the perspective of competency-based education (CBE) to identify areas for improvement. We found that the education of parents in the integrated infrastructure depended mainly on role modeling and coaching in a safe and private learning environment, mimicking the classic master-apprentice model. Health professionals considered the learning process of parents as an unconscious process that developed naturally in the parents, as opposed to the 'intensive' learning process experienced by the parents, as reported in chapter 3. We concluded that parent education programs could benefit from designing adult learning programs based on the principles of CBE. The greatest benefit of CBE for parent empowerment in hospital settings is that CBE urges health professionals to empower parents to be active learners and to take part in the improvement of the education program. This parent involvement could improve the quality of parent education, and parents may benefit after discharge in the home situation from the enriched learning skills acquired during hospital admission.

Chapter 5 describes the experienced changes in professional identity of health professionals when practice transitioned from a 'paternalistic' model, in which physicians and nurses were in charge, to a shared or 'consumerist' model with

increased parent autonomy. We analyzed transcripts of focus groups and interviews with 60 health professionals on their experiences with empowering parents on the integrated maternity and neonatal level 2 ward and described factors associated with themes of professional identity. The parents' constant proximity to their newborns and the single-family room design were found to be two major changes in work that influenced the following three themes of professional identity: (1) connectedness and relationships (2) communication, and (3) competencies. A fourth theme, (4) values, beliefs and ethics, affected how the participants coped with the changes described in the first three themes. When empowering parents of newborns in a hospital setting, health professionals experience beneficial and threatening shifts in their professional identity. Values, norms, and beliefs associated with family-integrated care helped health professionals to embrace new roles, but other values, norms and beliefs could act as barriers. Continuous professional identity development in a parent-inclusive team is a topic for future research.

The last chapter, *chapter 6,* summarizes the main findings of our studies as well as the answers to the main research questions of this thesis, followed by a general discussion of three imbalances that might emerge by a combination of empowerment interventions within neonatal care and when parent empowerment is pursued. The first concerns the imbalance between empowering and 'overburdening' parents, the second concerns the imbalance between empowering parents and challenging health professionals' identities, and the third concerns the imbalance between investments made for and benefits of empowering parents. The imbalances that may emerge leave questions for future research about how to achieve a good balance between empowered parents and motivated health professionals.

8

Samenvatting

Hoofdstuk 1 bevat een introductie van het belang van empowerment van ouders in de neonatale zorg en de studies in dit proefschrift. Het beschrijft verschillende interventiestrategieën die kunnen worden ingezet om barrières op te heffen die ouders belemmeren om de rol van zelfstandig ouderschap tijdens ziekenhuisopname te ontwikkelen en vervullen. Bepaalde interventiestrategieën zijn vooral gericht op het bevorderen van nabijheid tussen ouders en pasgeborenen. Voorbeelden hiervan zijn het mogelijk maken van 'kangoeroezorg'/'huid-op-huid-contact', gecombineerde gespecialiseerde zorg voor moeders en pasgeborenen, ook wel gekoppelde zorg/co-care genoemd, individuele familiekamers en 'rooming-in' faciliteiten. Daarnaast bestaan er interventiestrategieën die zich vooral richten op de mogelijkheid ouders de hoofdverzorgers voor hun pasgeborenen te laten zijn tijdens de ziekenhuisopname, zoals beschreven in de familiegerichte zorgvisie: familie-geïntegreerde zorg (FICare). Deze FICare-strategieën omvatten oudereducatie, psychosociale ondersteuning van ouders en gedeelde besluitvorming met ouders over zorg en behandeling door het houden van medische visiterondes samen met ouders: de zogenaamde familie-gecentreerde rondes. Al deze interventiestrategieën vereisen goede communicatie en samenwerking tussen zorgprofessionals en ouders. Hierin blijkt nog veel verbetering nodig. Daarnaast is er weinig bekend over de ervaringen van ouders en zorgprofessionals met een combinatie van de beschreven interventiestrategieën die gericht zijn op het empoweren van ouders binnen een neonatologie level 2 setting. In dit proefschrift wordt onderzocht wat we kunnen leren van het empoweren van ouders in een neonatologie level 2 setting, waar gecombineerde gespecialiseerde zorg voor moeders en pasgeborenen uitgevoerd wordt volgens de zorgvisie FICare, in individuele familiekamers met rooming-in faciliteiten. Op deze manier willen we begrijpen wat deze setting betekent voor ouders en zorgprofessionals.

Hoofdstuk 2 beschrijft de veranderingen die zijn doorgevoerd binnen een ziekenhuissetting om ouders te empoweren. Dit is gedaan door het implementeren van een geïntegreerde verlos-, kraam- en neonatologieafdeling met individuele familiekamers, gecombineerde gespecialiseerde zorg voor moeders en pasgeborenen uitgevoerd volgens FICare en rooming-in faciliteiten. Er is een casestudy uitgevoerd waarin we 38 documenten hebben geanalyseerd en 6 betrokkenen hebben geïnterviewd over de implementatie. We vonden een goede aansluiting tussen de veranderingen voor de geïntegreerde infrastructuur en het 'patiënt empowerment' model van Bravo et al. (2015). De veranderingen hebben vooral invulling gegeven aan een belangrijke voorwaarde voor ouder empowerment, namelijk: 24 uur per dag de mogelijkheid van nabijheid tussen ouders en pasgeborenen. In het bijzonder werd aan deze voorwaarde voldaan door gespecialiseerde zorg te organiseren rondom moeders en hun pasgeborenen in hun eigen familiekamers gesitueerd

op één afdeling in plaats van op meerdere aparte afdelingen. We stelden vast dat deze overgang voor de zorgprofessionals vooral betekende dat ze op verschillende niveaus gecombineerde zorg moesten kunnen verlenen aan moeders en pasgeborenen in individuele familiekamers. En dat zij hiervoor moesten worden opgeleid.

Hoofdstuk 3 beschrijft de uitkomsten van een focusgroep- en interviewstudie naar de ervaringen van 26 ouders met empowerment binnen de in hoofdstuk 2 beschreven geïntegreerde infrastructuur. Ouders voelden zich bovenal 'gerespecteerd' als een compleet gezin. Vooral doordat ze 24 uur per dag dicht bij elkaar konden blijven in hun eigen familiekamer vanaf het begin van de ziekenhuisopname tot aan het ontslag, in plaats van bezoekers te zijn op een traditionele neonatologieafdeling. Het hebben van een eigen familiekamer bood ouders een veilige en privé leercontext ter voorbereiding op het zelfstandig, autonoom ouderschap op het moment van ontslag. Ouders leerden vooral doordat ze de zorgprofessionals van dichtbij konden observeren en doordat ze deelnamen aan de dagelijkse medische visiterondes, gehouden op hun eigen familiekamer. Deze leermomenten waren nuttig voor het begrijpen van de aandoeningen en het behandelbeleid van hun pasgeborenen en voor het nemen van weloverwogen, gezamenlijke beslissingen. We merkten op dat de ouders zich volwaardige en gerespecteerde leden van het team voelden, naast het feit dat ze een intensief leerproces doormaakten. Dit leerproces zorgde ervoor dat ze zich bekwaam voelden in hun rol als ouders vóór hun ontslag naar huis. Ouders ervoeren echter ook uitdagingen binnen de geïntegreerde infrastructuur, zoals: het afstemmen van verantwoordelijkheden met zorgprofessionals over de zorg voor hun pasgeborene(n); slaaptekort; onzekerheden over hoe ze moesten prioriteren in het geven van zorg (tussen hun pasgeborene(n), broers en zussen thuis of zichzelf) en het gevoel van geïsoleerd te zijn van personeel en van andere ouders op de afdeling. Bovendien ervoeren sommige ouders een machtsstrijd met het personeel, bijvoorbeeld wanneer de ouders initiatief tot acties wilde nemen in de zorg voor hun pasgeborene(n), omdat ze zichzelf vaardiger beschouwden dan het personeel.

In *hoofdstuk 4* beoordeelden we de door 45 zorgprofessionals zelf gerapporteerde werkwijzen in het opleiden van ouders binnen de geïntegreerde infrastructuur. We analyseerden deze vanuit het perspectief van competentiegericht onderwijs om mogelijke verbeteringen te kunnen identificeren. We ontdekten dat het opleiden van ouders in de geïntegreerde infrastructuur vooral plaatsvond binnen een veilige leeromgeving met veel privacy. De uitvoering vond vooral plaats via rolmodellering en coaching, vergelijkbaar met het klassieke meester-gezel model.

De zorgprofessionals beschouwden het leerproces van de ouders als een onbewust proces dat zich op een natuurlijke manier ontwikkelde, in tegenstelling tot het 'intensieve' leerproces dat de ouders ervoeren, zoals beschreven in hoofdstuk 3. We concludeerden dat programma's voor oudereducatie baat zouden kunnen hebben bij het ontwerpen van leerprogramma's voor volwassenen, gebaseerd op de principes van competentiegericht onderwijs. Het grootste voordeel hiervan voor empowerment van ouders is dat een belangrijk principe van competentiegericht onderwijs erin bestaat volwassenen in staat te stellen actief te leren en deel te nemen aan de verbetering van het leerprogramma. Deze betrokkenheid kan de kwaliteit van de oudereducatie verbeteren. Bovendien kunnen ouders, na ontslag in de thuissituatie, direct profiteren van de opgedane leervaardigheden tijdens de ziekenhuisopname.

Hoofdstuk 5 beschrijft hoe de zorgprofessionals veranderingen in professionele identiteit hebben ervaren op het moment dat hun werkwijze veranderde van een 'paternalistisch' model, waarin artsen en verpleegkundigen de leiding hadden, naar een gedeeld of 'consumentistisch' model met meer autonomie voor de ouders. Er zijn focusgroepen en interviews met 60 zorgverleners gehouden over hun ervaringen met het empoweren van ouders binnen de geïntegreerde infrastructuur. De resultaten werden geanalyseerd met thema's van professionele identiteit. Twee belangrijke veranderingen, namelijk de constante nabijheid van de ouders bij hun pasgeborenen en het werken binnen individuele familiekamers, bleken de volgende drie thema's van professionele identiteit te beïnvloeden: (1) verbondenheid en relaties, (2) communicatie, en (3) competenties. Een vierde thema - (4) waarden, overtuigingen en ethiek - beïnvloedde hoe de deelnemers omgingen met de veranderingen die beschreven zijn binnen de eerste drie thema's. Zorgprofessionals ervaren, bij het empoweren van ouders van pasgeborenen in een ziekenhuisomgeving, zowel gunstige als bedreigende verschuivingen in hun professionele identiteit. Waarden, normen en overtuigingen geassocieerd met FICare hielpen zorgverleners om nieuwe rollen te omarmen, maar andere waarden, normen en overtuigingen konden juist optreden als barrières. Een belangrijk onderwerp voor toekomstig onderzoek is hoe binnen een interprofessioneel team, dat ouders includeert, de professionele identiteit zich ontwikkelt van teamleden met verschillende professionele achtergronden.

Het laatste hoofdstuk, *hoofdstuk 6*, start met het weergeven van een samenvatting van de belangrijkste bevindingen van de studies en antwoorden op de hoofdonderzoeksvragen van dit proefschrift. Hierna volgt een algemene discussie over drie onevenwichtigheden die kunnen ontstaan door het combineren van meerdere interventies ten behoeve van het nastreven van ouderempowerment binnen de

neonatale level 2 zorg. De eerste onevenwichtigheid betreft de disbalans tussen het empoweren en 'overbelasten' van ouders. De tweede onevenwichtigheid betreft de disbalans tussen het empoweren van ouders en de uitdagingen hierbij voor de identiteit van zorgprofessionals. De derde en laatste onevenwichtigheid betreft de disbalans tussen de investeringen die worden gedaan voor het empoweren van ouders en de voordelen hiervan. Deze drie onevenwichtigheden vragen om meer onderzoek over de manier waarop een goede balans kan worden bereikt tussen empowerde ouders en gemotiveerde zorgprofessionals.

9

The final word (dankwoord)

In dit dankwoord wil ik graag iedereen bedanken die, ieder op zijn eigen wijze, heeft bijgedragen aan het tot stand komen van dit proefschrift en aan de bijzondere tijd die ik de afgelopen jaren heb mogen ervaren. Zonder deze steun, was ik nooit zo ver gekomen. Het spreekwoord '*It takes a village to raise a child*' zou ik willen transformeren naar: '*It takes a village to make a thesis*'. Het is te veel om alle mensen van 'het dorp' afzonderlijk te kunnen bedanken, toch waag ik een poging om de belangrijkste recht te doen.

Natuurlijk wil ik als eerste mijn promotor en copromotoren bedanken.

Beste Fedde, wat een geluk dat ik jou ontmoette door een fusie van de ziekenhuizen waar wij werkten. Je reageerde direct positief op mijn onderzoeksplannen. Al snel werd je mijn promotor en trok je mijn praktijkonderzoek naar een wetenschappelijk niveau. Wat heb ik veel geleerd van jou, niet alleen over alle aspecten ten aanzien van een promotietraject, maar ook over het begeleiden van anderen in leerprocessen, ondanks dat ik daarmee zeker 20 jaar ervaring had. Hierin ben je voor mij echt een rolmodel geweest. Dit keer was ik diegene die '*in the picture*' stond in de voortgangsgesprekken en kon ik bouwen op jouw zorgvuldigheid, toegankelijkheid en beschikbaarheid. Je steevaste vertrouwen, positiviteit en geruststelling hielpen mij om gestaag door te gaan. Naast begeleider, was je als praktiserend gynaecoloog ook goed op de hoogte van de processen op de werkvloer. Je leerde mij om als onderzoeker altijd met een kritische blik te blijven kijken. Jouw uitnodigingen voor deelname aan educatiecongressen en wekelijkse bijeenkomsten op de promovendikamer, waren welkome en noodzakelijke sociale inspirerende leermomenten, vooral tijdens de Coronaperiode. Dank je wel hiervoor!

Beste Alvin, toen jij werd gevraagd om mij te begeleiden in het opzetten van kwalitatief onderzoek, was je direct welwillend. Wij leerden elkaar kennen in een voor mij heftige periode waarin je mij ondersteunde en stimuleerde om rustig door te gaan. Jij was diegene die mij motiveerde en hielp om mijn onderzoeksplannen voort te gaan zetten in een promotietraject. Jouw onuitputtelijke enthousiasme, de fijne gesprekken en het vertrouwen in mij, hebben mij enorm geholpen om deze stap te nemen en het traject daadwerkelijk af te ronden. Naast je expertise in kwalitatief onderzoek en je ervaring als vader van jonge (pasgeboren) kinderen, waren je verpleegkundige, onderwijskundige, sociologische en psychologische achtergrond van onschatbare waarde voor het tot stand komen van dit proefschrift. Dank je wel hiervoor!

Beste Anne, jij was vanaf het begin bij mijn onderzoeksplannen betrokken. Samen maakten wij de plannen concreet om het ouderperspectief ten aanzien van de bouw van een nieuw moeder- en kind centrum en het implementeren van FICare in OLVG te onderzoeken. Je toonde veel interesse in het kwalitatieve onderzoeksdesign, ook al was je hiermee niet bekend. Je nam uitgebreid de tijd voor voortgangsgesprekken en gaf gedetailleerde feedback, vaak onder het genot van 'lekkere' koffie. Je bleek een uitstekend goed gevoel te hebben voor het rapporteren en analyseren van kwalitatieve data. Als neonatoloog was jij goed op de hoogte van de processen op de werkvloer en ontwikkelingen binnen de neonatologie. Ook wist je mij in contact te brengen met belangrijke personen. Naast alle aspecten van het promoveren heb ik van jou vooral geleerd om het aangename met het werk te combineren. Ik heb genoten van de congressen die wij samen bezochten met andere promovendi. Ik zie ons nog zitten in de lobby van een hotel, werkend aan tabellen met de nodige gastronomische ondersteuning. Dank je wel hiervoor!

Graag wil ik de leden van de lees- en promotiecommissie bedanken voor de tijd en de moeite die zij hebben genomen om dit proefschrift te lezen en te beoordelen.

Lieve paranimfen Saskia en Fredy, niet alleen vandaag staan jullie mij bij tijdens de promotieceremonie, jullie stonden ook aan de wieg van dit promotietraject. Jullie hebben mij al die tijd bijgestaan en gestimuleerd om dit traject te gaan starten en om het af te maken. Saskia, je was mijn voorbeeld, als eerste OLVG-verpleegkundige promoveerde jij, alweer 4 jaar geleden. Nu treed ik in jouw voetsporen. Fredy, jij pakt je plannen binnenkort weer op en ik zal jou steunen waarmee ik kan. Inmiddels zijn wij vriendinnen voor het leven met wie ik dezelfde passie voor ons vak verpleegkunde deel, naast gezellige dans-, muziek- en cultuuravonden om te ontspannen en het leven te vieren. Dank jullie wel voor jullie expertise en vriendschap.

Lieve collega's van het Leerhuis, het Vrouw-Moeder Kind-cluster en vele anderen uit OLVG en daarbuiten, die mij geholpen en gesteund hebben en interesse getoond hebben in het tot stand komen van dit proefschrift. Het is onmogelijk om iedereen persoonlijk te bedanken, maar een speciale dank gaat uit naar alle collega's die mee hebben gedaan aan de interviews, de focusbijeenkomsten en het organiseren hiervan. Naast de collega's die mee hebben gedaan aan de interviews wil ik mijn speciale dank uitspreken voor de hulp van Yvonne , Belinda, Judith, Erica, Nicole, Lotte, Saskia en de wetenschappelijke stagiares Willemijn, Annabel, Angelique en Sarah met het meehelpen verzamelen en analyseren van de gegevens. Mijn dank hiervoor is groot. Zonder jullie was dit proefschrift niet verschenen.

Speciale dank voor Lisette van Hulst voor de ondersteuning bij het Engels taalgebruik en Machteld Wijnbergh voor het ontwerp van de mooie omslag van dit proefschrift. Dank voor jullie bereikbaarheid en engelengeduld in het meedenken over hoe ik mijn gedachten het beste kon overbrengen.

Ook speciale dank aan de collega-promovendi waarmee ik hoogte- en dieptepunten heb gedeeld op de promovendi-kameren daarbuiten tijdens koffiemomentjes, congressen en symposia. Ik ga deze momenten missen. Dank voor jullie support en feedback!

En '*last but not least*', natuurlijk wil ik mijn naaste familie en vrienden bedanken.

Lieve vrienden: jeugdvrienden, dansvrienden, 'clubjes Maastricht'-vrienden, 'Zusters 1985 2.0'-vrienden, collega-vrienden, vakantievrienden, buurtjes, vrienden van vrienden en vrienden uit het dagelijks leven. Bedankt voor de gezellige etentjes, borrels, koffietjes, dansjes, danslessen, wandelingen, muziek- en cultuur uitjes, kano en sup-tochtjes, weekendjes weg en zelfs ski- en dansvakantieweken, maar vooral alle 'bijklets'-momenten. Voor mij van essentieel belang om naast de uren achter de laptop in beweging te komen en te kunnen ontspannen.

Tineke, mijn lieve mama, Wenda en Marianka, mijn twee lieve zussen. Aan de start van dit promotietraject moesten wij afscheid nemen van papa. Voor mij een van de heftigste perioden in mijn leven. Het was zo fijn om te ervaren dat wij samen sterk bleven, ook al missen wij daarbij nog een lieverd in ons midden: Madelief. Dank voor jullie support en de vele slappe lachmomenten. Ik ben heel blij en dankbaar dat jullie altijd in mij hebben geloofd en super enthousiast, trots en positief waren. Alles komt goed!

Lieve Marijn en Sam, prachtige dochters. Jullie waren beginnende pubers toen ik startte met dit promotieonderzoek en nu zijn jullie zelf echte enthousiaste wetenschappers. Marijn, voor mij was het een feest van herkenning dat jij, net als ik, in Maastricht ging studeren. En wat was ik trots op je afgelopen november toen jij cum laude je diploma ontving van de *Research Master in Cognitive and Clinical Neuroscience*. Sam, na de feestjes van Marijn en mij verwacht ik deze zomer weer een afstudeerfeestje. Dit keer voor jou voor het behalen van je bachelor Psychologie. Wat heb ik genoten van jullie en van onze gezamenlijke ontwikkelingen, op persoonlijk en op wetenschappelijk vlak. Het is een voorrecht om zulke mooie, lieve en slimme dochters om mij heen te hebben, met hun leuke vrienden Thijs en Teun die mij steunen, waarvan ik nog steeds elke dag veel leer en die zelfs met mij een dansje wilden doen op een heus technofestival. Dank lieverds, dat jullie zoveel willen delen met mij!

Lieve Kees, dankzij jouw nuchtere visie op het leven, je enorme relativerende humor, je drive om je uitgebreide juridische, politieke en economische kennis met ons te delen, je liefde voor reizen en je praktische inslag, ontving ik veel steun en gezelligheid van jou en was er weinig 'vuil te vinden op en rond het aanrecht'. Je stond altijd vanzelfsprekend achter mij met alles, geloofde onvoorwaardelijk in mijn kunnen en gaf mij de ruimte die ik nodig had om dit project te kunnen volbrengen. Na 27 jaar samen, zijn we nog steeds de beste (reis)maatjes en ben ik trots op hoe wij door het leven gaan. Dank je wel hiervoor!

'Let us never consider ourselves finished nurses ....
We must be learning all of our lives.'

Florence Nightingale

Curriculum Vitae

Op 15 mei 1966 werd Mireille Anna Stelwagen thuis geboren in Wijdewormer, als 3e kind. Ze had een fijne en onbezorgde jeugd, uiteindelijk als middelste met haar zus en zusje, waarmee zij met haar ouders fijne zeilvakanties op hun platbodem beleefde. In haar vroege jeugd verhuisde het gezin naar een klein dorpje De Kwakel ten zuiden van Amsterdam, waar zij haar middelbareschooldiploma behaalde.

Als jong meisje wist zij al dat zij verpleegkundige wilde worden, om in de voetsporen van haar moeder te treden. Na haar middelbareschooltijd ging Mireille in Amstelveen wonen om daar haar Verpleegkundige A-diploma te behalen in het destijds genoemde Tulp-Ziekenhuis. Nieuwsgierig naar de verpleging van andere patiëntencategorieën en verdere verdieping van haar vak, ging zij direct aansluitend naar de Hbo-v bij de Hogeschool Holland in Diemen. Na het behalen van dit diploma in 1991 verhuisde zij naar Maastricht, ging zij Gezondheidswetenschappen studeren en studeerde zij af als Verplegingswetenschapper. Haar afstudeeronderzoek ging over hoe neonatologieverpleegkundigen pijn beoordeelden bij neonaten op de NICU. Hiermee droeg zij bij aan de inmiddels gevalideerde pijnmeetinstrumenten voor neonaten. Tijdens haar studies werkte Mireille als verpleegkundige via uitzendbureaus in verschillende werkvelden in Amsterdam en Maastricht, onder andere op de kraam-, neonatologie- (het oude Anna Paviljoen) en de kinderafdeling van het Onze Lieve Vrouwe Gasthuis, nu OLVG.

Na haar studie Verplegingswetenschap werkte Mireille een jaar als waarnemend staffunctionaris in het Beatrixziekenhuis te Gorinchem om vervolgens te gaan werken bij de GGD te Amsterdam als centralist bij de meldkamer ambulancedienst. In die tijd leerde zij Kees kennen, waarmee zij samen ging wonen in Mijdrecht en de 1e graads lerarenopleiding HGZO aan de VU behaalde. Via stages als docent bij de Hogeschool In Holland kwam zij te werken het Onze Lieve Vrouwe Gasthuis, te Amsterdam oost, als Klinisch Verpleegkundig Opleider voor de verpleegkundige vervolgopleidingen Kinder-, Neonatologie en Obstetrieverpleegkundige. Ondertussen werden haar dochters Marijn (1999) en Sam (2002) geboren.

Op het moment dat de verlos-, kraam en neonatologieafdeling toe waren aan nieuwbouw werd Mireille als getrainde gespreksleider voor focus- en spiegelbijeenkomsten gevraagd om bijeenkomsten met ouders te begeleiden. Het doel hiervan was wensen van ouders voor de nieuwbouw te inventariseren. Vervolgens ontwikkelde zij met het verpleegteam een in-company training voor de nieuwe verpleegkundige functie ‘Verpleegkundige Moeder en Pasgeborene. Daarnaast ontwikkelde zij bijscholing voor de zittende gespecialiseerde neonatologie- en obstetrieverpleegkundigen, zodat zij gekoppelde zorg voor moeder en pasgeborenen op de familiekamers konden verlenen.

De voorbereidingen voor het nieuwe vrouw-moeder-kind centrum, waren de start van het idee van dr. Anne van Kempen en Mireille om ouders van opgenomen

pasgeborenen te blijven volgen door hun ervaringen en belevingen met het nieuwe Anna Paviljoen verder te onderzoeken. Dankzij de aansluiting van dr. Alvin Westmaas en prof.dr. Fedde Scheele, startte Mireille in januari 2017 officieel met haar promotietraject. Zij werkt als adviseur wetenschap en opleidingen bij team Wetenschap van het Leerhuis van OLVG. Waar zij onder andere een EBP-leertraject voor verpleegkundigen hielp ontwikkelen en coördineren, het jaarlijks Mini-Symposium Verpleegkundig Onderzoek helpt organiseren, redactielid is van het blad Wetenschap@OLVG Verpleegkunde en zich inzet als docent en begeleider voor verpleegkundigen die afstudeeronderzoek doen.

Mireille houdt van dansen, vooral op West-Afrikaanse percussie, zelf percussie spelen en (dans)reizen. Dit wisselt zij graag af met het genieten van rustige momenten op haar eigen campingplekje in de natuur bij de Nieuwkoopse plassen. Daar geniet zij van wandelen, suppen, kanoën en zeilen met familie en vrienden.