Factors influencing implementation of Family-Centered Care in a Neonatal Intensive Care Unit, a qualitative approach.

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ABSTRACT

Background: Approximately 9,6% of all births worldwide are preterm. These infants are often admitted at a Neonatal Intensive Care Unit (NICU). The NICU environment is very stressful for preterm infants and separation of the parents causes stress for both infant and parent. Family-Centered Care (FCC) is an approach of planning, delivery, and evaluation of healthcare and based on a partnership between healthcare professionals and families of patients. Parents of infants who were admitted to an FCC unit were less stressed compared to parents at a Standard Care unit. Although FCC is beneficial to families and patients, implementation can be challenging. Therefore it is important that factors influencing the implementation of FFC are known.

Aim: To explore factors that influence implementation of Familiy-Centered Care in a Neonatal Intensive Care Unit according to healthcare professionals that already work with Family-Centered Care in three different countries

Method: A descriptive generic qualitative design with semi-structured interviews and thematic analyses was used. This multi-center study was conducted in three hospitals in three countries: Sweden, Norway and The Netherlands.

Results: The sample consists of seven neonatal care nurses, one nurse assistant, five neonatologists and three managers. Four themes were identified: Behavioural change in staff, Family needs, Environment and Communication. Healthcare professionals described that the mindset of the professional influences the implementation of FCC.

Conclusion: The mindset of healthcare professionals in seeing parents as primary caregiver is important. This influences the way FCC is practiced and how parents are involved in the care for their infant.

Implications of key findings: In FCC the role of healthcare professional changes, it is important to prepare the staff for this change by involving the staff early in the implementation process of FCC.

Keywords: Neonatal Intensive Care Unit, NICU, Family-Centered Care, FCC, implementation.

SAMENVATTING

Achtergrond: Ongeveer 9.6% van alle pasgeborenen wordt te vroeg geboren. Vaak worden deze kinderen opgenomen op een Neonatale Intensive Care Unit (NICU). De NICU omgeving veroorzaakt veel stress bij te vroeg geboren kinderen. Daarnaast veroorzaakt de scheiding tussen kind en ouders, stress bij kind en ouders. Family-Centered Care (FCC) is een zorgmodel gebaseerd op een gelijkwaardige samenwerking tussen zorgprofessionals en family, in de zorg voor een kind. Ouders van kinderen die opgenomen zijn geweest op een FCC unit waren minder gestrest in vergelijking met ouders op een standaard unit. Ondanks dat FCC gunstig is voor families en hun kinderen is de implementatie vaak lastig. Daarom is het belangrijk om te weten welke factoren de implementatie van FCC beïnvloeden.
Doel: Exploreren van factoren die de implementatie van FCC op een NICU kunnen beïnvloeden, volgens zorgprofessionals die werken met FCC in drie verschillende landen.
Methode: Een beschrijvend algemeen kwalitatieve studie met semigestructureerd interviews en thematische analyse. Deze multicenter studie is uitgevoerd in drie ziekenhuizen in drie landen: Zweden, Noorwegen en Nederland.
Resultaten: De populatie bestaat uit 7 neonatologie verpleegkundigen, één verpleegkundig assistent, 5 neonatologen en 3 managers. Vier thema's zijn geïdentificeerd: Gedragsverandering bij personeel, Behoeftes van het gezin, Omgeving en Communicatie. Zorgprofessionals beschrijven dat de manier van denken van zorgprofessional de implementatie van FCC beïnvloed.
Conclusie: De manier van denken bij zorgprofessionals in het zien van ouders als primaire zorgverlener is belangrijk. Dit beïnvloed de manier waarop FCC wordt uitgeoefend en hoe ouders worden betrokken in de zorg.
Implicatie van de belangrijkste bevindingen: Door FCC verandert de rol van de zorgprofessional, het is belangrijk om personeel hier op voorbereiden door hen vroeg in het implementatieproces te betrekken.

Trefwoorden: Neonatale Intensive Care Unit, NICU, gezinsgerichte zorg, Family-Centered Care, FCC, implementatie.

INTRODUCTION AND RATIONALE

Infants born before 37 weeks of gestational age are called preterm. Approximately 9,6% of all births worldwide are preterm[1]. These children are often admitted at a neonatal ward or Neonatal Intensive Care Unit (NICU). Today's NICU environment reflects advances in technology and medical treatment of preterm and sick new-borns. For preterm infants, the NICU environment is stressful, with periods of unnatural light and noise, repeated disturbances caused by caretaking procedures and interference with parent-child interactions[2]. In addition separation from parents may cause stress for both infant[3] and parent[4].

Family-Centered Care (FCC) is an approach in planning, delivering, and evaluating healthcare that is based on a partnership between healthcare professionals and families of patients. FCC distinguishes four basic values, which are: dignity and respect, information sharing, family participation in care, and family collaboration[5]. FCC maintains that families should be included in the planning, implementation and evaluation of care and that their opinions should be as important as those of the health care professionals[6].

FCC is beneficial in reducing the length of hospital admissions for infants admitted on a NICU[7]. FCC improves neurobehavioral outcomes in preterm infants[8]. Besides, parents of infants who were admitted to an FCC unit were less stressed than parents of infants admitted to a Standard Care unit[9]. In addition, infants admitted to an FCC unit tend to grow faster and were more likely to get breastfeeding at discharge[9]. Parents who participated during rounds, had easier access to information, were well-informed, more satisfied and could take part in the decision-making process[10]. In FCC the role of healthcare professional shifts from primary caregiver to being a mentor for parents[11]. A review about FCC in the paediatric setting revealed that communication in FCC is challenging for nurses[12]. Communication is of great importance for good partnership between parents and healthcare professionals. Insufficient communication may lead to role stress, negotiation failure, feelings of insecurity and stress by both, parents and nurses[12,13]. Also organizational factors such as inadequate resources, documentation of family needs and the need for facilities were described as barriers in practicing FCC[12,14]. However, these findings are related to the paediatric setting and might not be applicable to the NICU. In a paediatric setting, parents are used to take care of their child. In contrast to the NICU were parents have to adapt to their parenteral role.

Although FCC is beneficial for infants and families, implementation can be challenging. Historically, NICUs were designed to support the medical care of infants and meet staff needs. This typical NICU design does not support the relationship between infant and family[5]. In contrary nurses as well as physicians take over roles of parents as primary care

givers for their infant. In FCC the role of nurses is central in involving parents in infant care. Nurses can influence the development of the mother-infant relationship[15]. In addition they can support parents with a collaborative care approach[16]. Meaning that in FCC not only daily activities are changing.

Implementation is defined as the introduction of an innovation in to daily routine; this demands effective communication strategies and removal of barriers to change, by using effective educative and policy techniques[17]. FCC is successfully implemented when care is delivered based on the principals of FCC and families and staff are satisfied working with it.

A recent research on parent and nurse perception on the quality of FCC in eleven European NICU's[18], showed that all NICU's had a high perceived quality of FCC, indicated by parents and nurses. A NICU in Norway had the highest score on mothers perceptions on the quality of FCC while the mean score on nurse evaluation on the quality of FCC was the highest in Sweden. These NICU's can function as role model for other NICU's that intend to adopt FCC.

For a successful implementation of FCC in the NICU, it is important to explore factors that influence implementation of FCC. Knowing which factors may contribute or withhold a successful implementation makes it easier to decide which strategies should be taken to implement this concept successfully in a neonatal setting.

AIM

To explore factors that influence implementation of Familiy-Centered Care in a Neonatal Intensive Care Unit according to healthcare professionals that already work with Family-Centered Care in three different countries, using a qualitative approach.

METHOD

Design

A descriptive generic qualitative design[19,20] with semi-structured interviews[19,20] and thematic analysis[21] is used. A qualitative design was considered the most appropriate to explore the inner perspective and experiences of healthcare professionals that work with FCC[22].

Population and setting

The population of interest are healthcare professionals and managers working on a NICU that adopted FCC. Healthcare professionals were eligible to participate when (I) they worked as healthcare professional or manager on a NICU, (II) they spoke English or Dutch, (III) they

had at least one year of work experience with FCC in their current profession and (IV) they worked at least 16 hours per week.

This study was conducted in three hospitals, located in urban areas in Sweden, Norway and The Netherlands. All the three hospitals have a level III NICU and deliver post intensive care. The university hospital in Huddinge, Sweden provides care for infants born form 26 weeks of gestation. The general hospital in Drammen, Norway, provides care for infants born from 28 weeks of gestation. The general hospital in Veldhoven, The Netherlands, provides care for infants born from 24 weeks of gestation.

All included hospitals rebuild their wards between 2010 and 2012. All wards have sleeping facilities for parents near their infants.

Sampling

A purposeful sample consisting of healthcare professionals working at one of the NICU's included in this study, was used. Allowing to maximize the collection of available data, insights and factors that influence the implementation of FCC[20]. Therefor a variety of healthcare professionals that play a role with the implementation of FCC were included: neonatal care nurses, assistant nurses, neonatologists, and managers. Healthcare professionals were selected based on their work experience with FCC and their profession.

Recruitment started in February 2018. Selection of eligible participants was done by a contact person of the hospital at site and the researcher (SOM). Eligible participants (N=20), equally distributed per hospital were approached by the researcher through email. This email contained brief information about the study, contact details of the researcher and an invitation for participation in the study. When a participant was interested in participation, the information letter was sent and the interview was scheduled.

Data collection

Data was collected in February and March of 2018 using semi-structured, face-to-face interviews. Before the start of data collection, three pilot interviews were conducted, enabling refinement of the interview guide and improvement of the interview skills of the first researcher (SOM). This data is not included in this study.

An interview guide (appendix 1) was constructed based on literature regarding perspectives and expectations of FCC[12,16,17,25,26]. The interview guide was divided into themes: Communication, Role and Relationship, Caring for parents and Recourses. The interview started with a short introduction followed by the opening question *How did you experience the implementation of FCC at your ward?* Before the start of the interview, the baseline characteristics (gender, age, profession, years of work experience and years of

work experience with FCC) were obtained. The participants were interviewed in the hospital of employment, in a private room on the ward. All interviews were digitally recorded. The duration of the interview varied from 25 minutes to 1 hour. All interviews were conducted by SOM. The interviews in Sweden and Norway were conducted in English, while the interviews in The Netherlands were conducted in Dutch.

Data analysis

Baseline characteristics were analysed using IBM SPSS Statistics[25]. All the interview data was managed in NVivo[26]. A thematic analysis following the six phase model of Braun and Clark[21] was used to identify influencing factors on the implementation FCC.

In the first phase, 'familiarizing yourself with your data', the data from interviews were transcribed verbatim. Transcribing the data, reviewing the data line by line and reading through the entire data set helped the researcher become familiar with the data. In the next phase, 'generating initial codes', the researcher generated codes for all potential categories or patterns.

Data collection and analysis was an iterative process. Constant comparison is used to determine commonalities and variations and adjustment of the interview guide. Meaning that codes and themes elicited from the 'new' data will be constantly compared to previously collected data[20,22]. Coding and generating initial themes is done by two researchers (SOM and AvdH), differences were discussed until consensus was reached about the codes and the initial themes.

In the following phases, 'searching for themes', 'reviewing themes' and 'defining and naming themes', the list of codes were analysed by SOM and AvdH to determine how each code may fit into an overarching theme. Each theme was identified and analysed in relation to the aim of the study. Phase six, 'producing the report', followed after completing the aforementioned phases.

Ethical issues

Ethical approval was obtained by the Medical Ethical Board of the UMCU in January 2018 and agreed in the included hospitals. Participant data is handled confidentially in accordance with the Dutch Personal Data Protection Act (Wbp)[27], the European General Data Protection Regulation[28] and the Norwegian Personal Data Act[29]. All data was made anonymously, by removing the name of the participant and replacing it for a unique code. All participants received written and oral information and could withdraw at any time of the study. Written informed consent was obtained from all participants.

RESULTS

Sample

The sample consisted of sixteen healthcare professionals: neonatal care nurses (N=7), nurse assistant (N=1), neonatologists (N=5) and managers (N=3).

(Table 1: Baseline characteristics of the Healthcare Professionals)

Main results

Four themes were identified from the data: Behavioural change in staff, Family needs, Environment and Communication. Some themes are based on several categories.

Behavioural change in staff

Mindset

All healthcare professionals described that FCC is a mindset off working. It's a mindset to see the parents as primary caregiver for the infant and to involve them in the care. Having this mindset is important in practicing FCC, because it enhances the involvement of parents in the care. Healthcare professionals described that they already had this mindset before FCC was implemented. For them the implementation of FCC was a natural step in the care for the infant and their family. Being a mentor for parents instead of primary caregiver is considered a big change in daily care and is not how healthcare professionals traditionally are educated. Preparing and guiding the staff for this change is crucial in practicing FCC.

> *'..intellectually we would all agree that parents are the ones that should and ought to be, and are closest to their infants [..] but traditionally that's not the way we have organised our care.'* (SWMA07)
>
> *'Parents are the primary care giver, they are the ones that take care of the babies.. of course, of course, of course!'*
> (SWNU05)

Motivation

Most of the healthcare professionals described that seeing how good FCC was for the infant and the parents motivated them during the implementation of FCC. Positive experiences from parents with FCC, shared with healthcare professionals, stimulated healthcare professional to continue with FCC. They said it made them aware how important it was for infant and family.

Another factor that stimulated the staff in all three hospitals was the publicity and attention they got after implementing FCC. Healthcare professionals from other hospitals and other countries came over to visit their ward, to see how FCC was practiced. Having this publicity and attention made healthcare professionals more proud of their ward.

> *'But when you see the parents, how the outcome is for them. You never want to do anything else, no really!'* (NONU10)

Experiences

Examples from hospitals that already worked with FCC and contact with these staff helped healthcare professionals to adapt FCC. Having this impression would have helped them to better understand what is expected from them in their new role within FCC. By providing examples and experiences from other hospitals, healthcare professionals see that it is possible to deliver care according to the FCC principals.

> *'I think, the first thing is that they (healthcare professionals) know that it's possible.'* (NODR12)

Involving staff

All managers and most of the healthcare professionals described that it is important to involve the staff in the implementation of FCC. Involving staff from the first idea until the actual implementation. Healthcare professionals described this in various ways. First, involving staff by educating them in FCC and share scientific evidence with them, to achieve a better understanding of the importance of FCC. Second, have reflection sessions with the staff where they can express their ideas and concerns about FCC. Third involve them by

creating working groups, medical champions and make them responsible for certain components of the implementation. By involving staff in the implementation, they feel that they are a part of the implementation which helps in accepting a new role.

> *'But it has all to do with informing them (staff), sharing with them and involve them in the development'* (NLNU13)

Family needs

Participation in care

All healthcare professionals involve parents in caring for their infant. Doctors describe that if they have the opportunity, they involve parents before the infant is born, by giving parents information about preterm infants and what parents can expect. Some doctors mention in this conversation how important it is that parents are involved in the care for their infant. Some of the nurses and managers state that this conversation helps them to involve parents in the care when the infant is born.

When talking with parents, nurses try to found out where parents might need support in caring for their infant. Nurses adapt their level of support to the level of guidance that parents need. Several nurses described that they empower parents, by giving them compliments, and so doing, stimulate the involvement of parents in the care.

> *'..we meet them (parents) before they give birth to preterm babies, we inform them, already at that stage of how the FCC would be caring out. Why we believe it is important.'* (SWDR06)

Care for the family

All healthcare professionals described that they found out in conversation what the needs of the family are. Most of the time, this is a spontaneous question about how parents are feeling and if they need support to help them during the hospital stay. Nurses often ask these question during or after care procedures for the infant. Some doctors described that they could do more to find out the needs of the family and what they can do to support or to facilitate the family. The support that healthcare professionals give consists of emotional

support by listening, helping the family in how to structure their life during hospitalisation and by consulting other healthcare professionals when needed.

> *'Because.. if I ask all these questions, that's kind of the only way I can figure out what they need.'* (SWNU05)

Medical rounds

Among healthcare professionals there is no consensus in involving parents in medical rounds. In Sweden they have medical rounds where parents are included. In Norway and The Netherlands however, parents are not included in the medical rounds. Some of the doctors among the healthcare professionals of Norway and the Netherlands described that it might be a burden for parents to hear about possible diagnoses and complications.

Most nurses and managers are positive about the involvement of parents during rounds. They think it is natural to include them, because parents know their infant best.

> *'They are more informed on what is going on, we have no secrets, they feel secure of that, we don't have secrets. And we also pick their questions or their worries up very quickly.'* (SWDR06)

> *'Because I don't think it's necessarily thing to drag every diagnose close up to the parents and then later evaluate it. I think it's not a very psychologically thing to do.'* (NODR11)

Environment

Ward

Healthcare professionals described that the ward is of influence in practising FCC. It gave them the final step to optimize FCC. Healthcare professionals described that it is important that parents have a place on the ward where they can stay and sleep, preferably close to their infant. Single rooms gives parents privacy during the hospital stay. Also, professionals mentioned that a private bathroom is important. The ward should provide everything that

parents need on a daily basis, like a canteen or kitchen, a washing machine and a place where they can withdraw, away from the infant.

Most of the professionals mentioned that the ward must give the parents a welcoming feeling and the environment should not look like a hospital.

> *'Because for everything what you remove or not take into the unit, the parents have to leave the unit.'* (NONU09)

Legislation

Healthcare professionals in Sweden and Norway described that parents are continuously present. This helps them to involve parents in the care. Legislation in these countries makes it possible for parents to stay in the hospital with their infant. This legislation is in contrast with The Netherlands, where fathers have to go back to work a few days after the infant is born. Healthcare professionals in The Netherlands described that it is not common that parents are sleeping over and are continuously, day and night present.

> *'But then I wonder, in some countries they manage that parents are with their infant, up to 8 hours a day! And why can't we make that happen here?'* (NLDR15)

Communication

Healthcare professionals described that communication is important in FCC. Communication with parents about the care of their infant, communication in guiding and coaching parents in the care for their infant and communication in supporting and facilitating parents in their needs. Most of the professionals described the communication with parents as an 'open communication',.

Most of the nurses did experience changes in communication with parents, because parents are almost continuously present in FCC. Therefor nurses are more confronted with parents who are in a crisis because their infant is born to early. For that reason, nurses have to deal with different emotions from parents, like anger and sadness. Nurses described that they needed some extra tools in how to deal with parents in crisis.

'To communicate good with parents in crisis is a bit hard.' (NONU10)

DISCUSSION

Four themes were identified when exploring factors that influence the implementation of FCC according to healthcare professionals experienced with FCC namely, Behavioural change in staff, Family needs, Environment and Communication. Main important finding is that seeing parents as primary caregiver, influences the implementation of FCC. In addition the involvement of parents as soon as possible in the care enhances the participation of parents during hospitalisation. Other influencing factors that are found are the involvement of parents in the medical rounds, the design of the ward and legislation of a certain country.

One of the themes was 'behavioural change in staff'. In this theme, the transition from primary caregiver to become a mentor for parents is discussed. This study highlights the importance of preparing the staff on this change in their role. Especially because healthcare professionals are traditionally not educated to deliver care in this way. This is supported by other studies[11,30], one of the studies concluded that healthcare professionals need ongoing organisational support, guidance and education to deliver FCC in the NICU[11].

The theme 'family needs' in this study described that nurses adapt their level of support based on a conversation they have with parents. They feel that this is sufficient in supporting parents in taking care for their infant. However, research that studied the perceptions of parent support by parents, nurses and physicians revealed that it is important that healthcare professionals are encouraged to critically reflect on whether the type and consistency of support they provide to parents is in line with parents' perceptions and needs[31]. Moreover, other studies suggest that families experience emotional support as inadequate and value staff that empathizes with their situation[32,33]. Maybe this finding can be explained by the fact that nurses may think that they are providing support, but families may not experiences this as support. So healthcare professionals must not think lightly about how to support parents in a way that is sufficient for parents and must reflect with parents on the support that is given.

Another factor discussed in the theme 'family needs' is whether parents must be included in the medical rounds or not. In this study doctors are more concerned about this involvement, because of the burden for parents of hearing possible diagnoses and complications. However, currently available evidence suggests that parents are less concerned with the stress imposed by rounds than with their need for information. When given the choice, between 85 and 100% of the parents would prefer to be present at

rounds[34]. Healthcare professionals should let parents decide if they want to be involved in the medical rounds, instead of deciding for them.

Within the theme 'environment' the design of the ward was discussed. Healthcare professionals state that the design of the ward gave them the final step in optimizing FCC. Research about ward design reveals that a single patient room is perceived by parents as an improvement in privacy and the design can complement an implemented concept of FCC[35]. Moreover, parents in single patient rooms where more involved in care[36]. However, these results are related to single room versus an open bay unit. To the authors knowledge, there is currently no available research about the facilities that are offered on a ward, like a kitchen or laundry facilities for parents, that might support FCC. Further research about ward design should also consider facilities that are offered on the ward.

In the last theme 'communication', healthcare professionals described that having parents constantly present makes it sometimes difficult to communicate with parents. Guiding and coaching parents is more than simply giving information about the technical and medical aspects. A recent quantitative study among healthcare professionals' view on parent participation in the NICU[37] supports this finding by concluding that it is important that nurses as well as doctors need training in communication skills to more effectively support and encourage parental participation[37]. This shows that it is important to train healthcare professionals in communication so they have some extra tools to communicate well with parents and family.

This study has several limitations. First, due to the variety of the sample, including several disciplines of healthcare professionals form several hospitals, data saturation was not achieved on all themes, only in 'behavioural change of staff'. Therefore, the results must be considered with caution. To increase transferability, future studies should include more healthcare professionals. Second, selection bias might have occurred, because all participating healthcare professionals were selected by the contact person of the included hospitals. They might be selected because of their positive attitude towards FCC. Third, the time between the implementation of FCC and the interview can cause recall bias. In some cases this time was ten years, therefor participants might think more positive about the implementation based on their current experiences with FCC. Fourth, the researcher works as a nurse at a NICU, this might have influenced the objectivity of the data collection[19]. However, an interview guide is used aiming to improve the quality and objectivity of the data collection[19].

A strength of the study is that the trustworthiness[19] was improved by two researchers that independently coded all the interviews and created initial themes. Together they reached consensus about the final themes. Other methods to improve trustworthiness were: recording

interviews, a member check of the interview transcripts, peer review and transparent reporting following the COREQ guidelines[38].

CONCLUSION AND RECOMMANDATIONS

The mindset of healthcare professionals in seeing parents as primary caregiver is important. This influences the way FCC is practiced and how parents are involved in the care. Recommendations for clinical practice is to influence this mindset by showing healthcare professionals why FCC is important. This could be done by providing scientific evidence about outcomes for infants and families and by giving examples form other hospitals that work with FCC, so they see that it is possible to work according to FCC principles.

Healthcare professionals described that it is important to find out what parents need, to adapt to their needs. Sometimes healthcare professionals and parents have different perceptions in what parents need to be involved in care. Therefore recommendations for future research are to explore the needs of parents of infants admitted to an FCC unit.

REFERENCES

1. Beck S, Wojdyla D, Say L, Pilar Bertran A, Meraldi M, Harris Requejo J, et al. The worldwide incidence of preterm birth: a systematic review of maternal mortality and morbidity. Bull World Health Organ [Internet]. 2010 Jan 1 ;88(1):31–8.
2. Altimier L, Phillips RM. The Neonatal Integrative Developmental Care Model: Seven Neuroprotective Core Measures for Family-Centered Developmental Care. Newborn Infant Nurs Rev [Internet]. 2013 Mar 13(1):9–22.
3. Bialoskurski M, Cox CL, Hayes JA. The nature of attachment in a neonatal intensive care unit. J Perinat Neonatal Nurs [Internet]. 1999 Jun ;13(1):66–77.
4. Cleveland LM. Parenting in the Neonatal Intensive Care Unit. J Obstet Gynecol Neonatal Nurs [Internet]. 2008 Nov ;37(6):666–91.
5. Griffin T. Family-centered care in the NICU. J Perinat Neonatal Nurs [Internet]. ;20(1):98–102.
6. Neal A, Frost M, Kuhn J, Green A, Gance-Cleveland B, Kersten R. Family centered care within an infant-toddler unit. Pediatr Nurs [Internet] ;33(6):481–5.
7. The Stockholm Neonatal Family Centered Care Study: Effects on Length of Stay and Infant Morbidity.
8. Yu Y-T, Hsieh W-S, Hsu C-H, Lin Y-J, Lin C-H, Hsieh S, et al. Family-centered Care Improved Neonatal Medical and Neurobehavioral Outcomes in Preterm Infants: Randomized Controlled Trial. Phys Ther [Internet]. 2017 Dec 1;97(12):1158–68.
9. O'Brien K, Bracht M, Macdonell K, McBride T, Robson K, O'Leary L, et al. A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. BMC Pregnancy Childbirth [Internet]. 2013 ;13 Suppl 1(Suppl 1):S12.
10. Aronson PL, Yau J, Helfaer MA, Morrison W. Impact of Family Presence During Pediatric Intensive Care Unit Rounds on the Family and Medical Team. Pediatrics [Internet]. 2009 Oct 1 ;124(4):1119–25.
11. Trajkovski S, Schmied V, Vickers M, Jackson D. Neonatal nurses' perspectives of family-centred care: a qualitative study. J Clin Nurs [Internet]. 2012 Sep ;21(17–18):2477–87.
12. Foster M, Whitehead L, Maybee P. Parents' and health professionals' perceptions of family centred care for children in hospital, in developed and developing countries: a review of the literature. Int J Nurs Stud [Internet]. 2010 Sep;47(9):1184–93.
13. Coyne I. Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles. Health Expect [Internet]. 2015 Oct ;18(5):796–808.

14. Lam LW, Chang AM, Morrissey J. Parents' experiences of participation in the care of hospitalised children: A qualitative study. Int J Nurs Stud [Internet]. 2006 Jul;43(5):535–45.
15. Fenwick J, Barclay L, Schmied V, Fenwick J. Craving closeness: A grounded theory analysis of women's experiences of mothering in the Special Care Nursery. Women and Birth [Internet]. 2008 ;21.
16. Axelin A, Ahlqvist-Björkroth S, Kauppila W, Boukydis Z, Lehtonen L. Nurses' Perspectives on the Close Collaboration with Parents Training Program in the NICU. MCN, Am J Matern Nurs [Internet]. 2014 ;39(4):260–8.
17. Grol R, Wensing M, Eccles M, Davis D. Improving Patient Care The Implementation of Change in Health Care [Internet]. John Wiley & Sons; 2013
18. Separation and Closeness Experiences in Neonatal Environment (SCENE) research group S, Lehtonen L, Tandberg BS, Normann E, Ewald U, Caballero S, et al. Parent and nurse perceptions on the quality of family-centred care in 11 European NICUs. Aust Crit Care [Internet]. 2016 Nov ;29(4):201–9.
19. Holloway I, Wheeler S, Holloway I. Qualitative research in nursing and healthcare [Internet]. Wiley-Blackwell; 2010. 351 p.
20. Boeije H. Analysis in qualitative research. SAGE; 2010. 223 p.
21. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol [Internet]. 2006;3(2):77–101.
22. Creswell JW, Creswell JW. Qualitative inquiry & research design : choosing among five approaches. SAGE Publications; 2013. 448 p.
23. Boztepe H, Kerimoğlu Yıldız G. Nurses perceptions of barriers to implementing family-centered care in a pediatric setting: A qualitative study. J Spec Pediatr Nurs [Internet]. 2017 Apr;22(2):e12175.
24. Beck SA, Weis J, Greisen G, Andersen M, Zoffmann V. Room for family-centered care – a qualitative evaluation of a neonatal intensive care unit remodeling project. J Neonatal Nurs [Internet]. 2009 Jun;15(3):88–99.
25. IBM. IBM SPSS Statistics. North Castle, New York, United States: IBM; 2016.
26. QSR International Pty Ltd. NVivo Qualitative Data-analysis Software. Melbourne, Australia; 2015.
27. wetten.nl - Regeling - Wet bescherming persoonsgegevens - BWBR0011468 [Internet]. Available from: http://wetten.overheid.nl/BWBR0011468/2017-07-01
28. Council of the European Union. General Data Protection Regulation | Rapport | Rijksoverheid.nl [Internet]. 2015. Available from: https://www.rijksoverheid.nl/documenten/rapporten/2016/01/07/tk-bijlage-1-council-of-

the-european-union
29. Act of 14 April 2000 No. 31 relating to the processing of personal data (Personal Data Act); Available from: http://unpan1.un.org/intradoc/groups/public/documents/unpan/unpan033937.pdf
30. Gooding JS, Cooper LG, Blaine AI, Franck LS, Howse JL, Berns SD. Family Support and Family-Centered Care in the Neonatal Intensive Care Unit: Origins, Advances, Impact. Semin Perinatol [Internet]. 2011 Feb;35(1):20–8.
31. Franck LS, Axelin A. Differences in parents', nurses' and physicians' views of NICU parent support. Acta Paediatr [Internet]. 2013 Jun;102(6):590–6.
32. Sarajarvi A, Haapamaki ML, Paavilainen E. Emotional and informational support for families during their child's illness. Int Nurs Rev [Internet]. 2006 Sep;53(3):205–10.
33. Gooding JS, Cooper LG, Blaine AI, Franck LS, Howse JL, Berns SD. Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. Semin Perinatol [Internet]. 2011 Feb ;35(1):20–8.
34. Davidson JE. Family Presence on Rounds in Neonatal, Pediatric, and Adult Intensive Care Units. Ann Am Thorac Soc [Internet]. 2013 Apr;10(2):152–6.
35. Bodack E, Schenk O, Karutz H. Die Einrichtung von Einzelzimmern auf neonatologischen Intensivstationen – Auswirkungen auf die Betreuung aus Sicht der Eltern. Z Geburtshilfe Neonatol [Internet]. 2016 Apr 28;220(03):124–9.
36. Shahheidari M, Homer C. Impact of the Design of Neonatal Intensive Care Units on Neonates, Staff, and Families. J Perinat Neonatal Nurs [Internet]. 2012;26(3):260–6.
37. Kjellsdotter A, Lantz B, Ottosson C. Healthcare Professionals' Views on Parental Participation in the Neonatal Intensive Care Units. J Pediatr Nurs [Internet]. 2017 Sep
38. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Heal Care [Internet]. 2007 Sep 16;19(6):349–57.

Appendix I: Interview guide

Opening question:

How did you experience the implementation of FCC at your ward?

In case of no experience with the implementation: *How do you experience working with the concept FCC?*

- How do you involve parents in the care for their infant?
    - Follow-up: What do you experience as barriers in involving parents in the care and why?
    - Follow up: What facilitates in involving parents in the care?
- How do you experience the involvement of parents in patient/family rounds?
- Do you think that the involvement of parents in patient rounds helps parent to care for their infant? And if so, how does it help?
- In case of experience with standard care and FCC:
    - Has you role as …. changed in FCC, if so how? And how do you experience this 'new' role?
    - Has your relationship with parents changed in FCC? And if so, can you explain what has changed? And how do you experience this relationship?
- In case only experience with FCC:
    - How do you experience your role as … in FCC?
    - How do you experience the relationship with parents in FCC?
- How do you deliver the part of 'caring for parents' in FCC?
- How do you identify the needs from the family/parents?
- If parents already have children:
    - Do you involve siblings in the care for the infant?
    - Makes is differences in practising FCC if parents have other children? And how so?
- Legislation in Sweden/Norway supports parents to be with their infant in the hospital. If the legislation was different and the father has to go to work a couple of days after the infant is born. How can you still practice FCC Of how can you work around the legislation?
- How are resources of influence of practising FCC?
- In your opinion, what resources should be realised to enhance FCC and why?
- How do you experience the workload in FCC?

Appendix II: Table 1 Baseline characteristics

Table 1: Baseline characteristics Healthcare professionals (N=16)

	N	%	Mean (SD)
Age			45,8 (6,28)
Gender:			
- Male	0	0%	
- Female	16	100%	
Profession:			
- Nurse	7	43,8%	
- Assistant Nurse	1	6,3%	
- Neonatologist	5	31,3%	
- Manager	3	18,8%	
Employed:			
- Part-time	4	25%	
- Full-time	12	75%	
Hospital:			
- Sweden	6	37,5%	
- Norway	5	31,25%	
- The Netherlands	5	31,25%	
Work Experience (years)			20,44 (7,17)
Work Experience FCC (years)			7,56 (3,76)