FAMILY-CENTRED CARE IN THE NEONATAL INTENSIVE CARE UNIT: AN ACTION RESEARCH STUDY

(THE ARRCC STUDY – ACTION RESEARCH ON RELATIONSHIP CENTRED CARE)

EXECUTIVE SUMMARY: FEBRUARY 2017

INTRODUCTION

This executive report presents the main findings of the Action Research on Relationship Centred Care (ARRCC) study, which we carried out in the Jessop Wing Neonatal Intensive Care Unit (NICU), Sheffield between January 2015 and June 2016. The research was funded for 12 months through a grant from the General Nursing Council Trust (GNCT) and additional funding was received from the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Yorkshire and Humber, to extend the project for a further 6 months. The research was classified as an NIHR Portfolio study, which helped to secure the additional support of a research nurse from the NIHR Clinical Research Facility Sheffield to help with recruitment.

The ARRCC study evolved out of our concern over the mismatch between research evidence and clinical practice relating to Family Centred Care (FCC) in the Neonatal Intensive Care Unit (NICU). Despite a plethora of research highlighting the benefits of parental involvement in the care of their infants, the implementation of family-centred care in the Neonatal Intensive Care Unit (NICU) remains inconsistent. The purpose of this study therefore was to develop, implement and evaluate evidence-based family-centred interventions to support the parent-infant relationship in the NICU.

BACKGROUND

Preterm birth is associated with increased neonatal mortality and morbidity (Costeloe et al 2012) and it is generally believed that early stressful environmental influences on the brain during critically sensitive developmental periods contribute to these adverse outcomes. One of the most profound stressors for the preterm infant is early maternal separation and a growing body of evidence suggests that the quality of mother-infant interaction in early postnatal life can influence an infant's emotional and cognitive development, with long-term health consequences (Trevyvaud et al 2009, Montirosso et al 2012).

Although when parents become anxious and stressed, their ability to bond and attach to their baby may be affected, helping parents to observe and interpret their infant's behaviour is associated with improved long-term development (Nordhov et al 2010). A number of programmes exploring the impact of combining various strategies to facilitate parental-infant interaction in the NICU have reported positive findings such as decreased parental stress and reduced length of stay (Melynk et al 2008, 2006), improved cognitive outcomes for infants at 5 years (Nordhov et al 2010), improvements in the quality of maternal caregiving behavior (Welch, Firestein et al 2015), reduced length of stay (Örtenstrand et al 2010), increase in neonatal weight gain and increased breast-feeding at discharge (O'Brien et al 2013).

As it was not possible to directly implement any of the existing FCC programmes in our unit, we aimed to combine findings from the wider research with local data to identify interventions that would be achievable and meaningful to families in our NICU. To achieve this objective, we brought together researchers, nurses, doctors, AHPs and parents, to explore issues around FCC and identify specific obstacles and enablers. We then co-developed and implemented evidence-based family-centred interventions and evaluated their impact on parents, infants and staff in our unit.

AIMS AND APPROACH

The study utilised a participatory action research approach to enable researchers, neonatal staff and parents to co-develop, implement and evaluate evidence-based family-centred strategies in a 50-cot tertiary NICU in the UK. The specific research questions were:-

1. What factors (obstacles and enablers) influence the implementation of family-centred interventions?
2. What impact do family centred interventions have on staff satisfaction and confidence in providing family-centred care?
3. What impact do family-centred interventions have on parental stress, satisfaction and confidence in providing care?
4. What impact do family-centred interventions have on breast-feeding rates and parent/infant skin-to-skin contact?

STUDY DESIGN

The study comprised of three phases:-

1. **The exploratory phase**, in which focus groups, interviews, surveys and diaries from staff and parents were used to describe the current context and perceived barriers of parental involvement and help develop evidence-based interventions.
   A large number of staff were involved in individual projects which included:-
   - An initiative to promote skin-to-skin care including training, new guidelines and a 'kangaroo care awareness month'.
   - A change in practice to accommodate 24 hour parental presence in the NICU, including ward rounds, nursing handovers and procedures.
   - The development of specific staff education sessions focusing on the parent-infant relationship and increased support for existing programmes e.g. 'Family and Infant Neuro-developmental Education (FINE)'.
   - A review of facilities for parents to stay close the their baby e.g. reclining chairs to facilitate skin-to-skin care and enable parents to sit comfortably next to their baby for long periods of time.
   - Parent-held interactive diaries designed to encourage communication between parents and staff.
   - Regular coffee mornings for parents to facilitate peer support.
2. **The Intervention phase,** in which three action research cycles tested and further refined the interventions, informed by on-going data collection from parents and staff.
3. **The evaluation phase,** in which baseline measures were repeated, in order to identify any changes and evaluate the impact of the interventions. Focus groups and interviews with staff and parents provided insight into the process of change and the perceived success of the initiative.

KEY FINDINGS AND RECOMMENDATIONS

Data from parent questionnaires, diaries and focus groups collected during Phase 1 were used to gain insight into parents' perceptions of their relationship with their baby and identify factors influencing their involvement in care. This information was used to help shape the development of family centred care interventions, which were implemented in Phase 2. Further data were collected in Phase 3 to identify any changes and explore the success of the interventions. Findings suggested a higher level of satisfaction, reduced levels of stress and increased involvement for parents in Phase 3.

Similarly, data from staff questionnaires, focus groups and interviews were used to gain insight into staff perceptions of family centred care, identify factors influencing parental involvement in care, inform the interventions and explore the success of the changes. Staff also presented a more positive perception of family centred care in phase 3. Findings generally concur with the existing research literature but also add new insights into FCC and highlight a number of implications for future practice, education and research, which are introduced below.

The parent-infant relationship

When asked to describe their relationship with their baby in the NICU, parents discussed expectations of a unique bond, characterised by physical closeness, connectedness and an acknowledgement of parental responsibility. In other words, they expected to be 'doing for' and 'being with' their baby. When constraining factors within the NICU meant that their expectations were unfulfilled they felt anxious and

distressed. When they received support to adjust their expectations so that they could be achieved within the NICU environment, they experienced greater fulfilment.

Our findings suggest that progression from an unfulfilled to a fulfilled parent-infant relationship in the NICU is not a linear process and can be affected by a number of issues. For example, complex professional, cultural and parental factors can increase parental stress and reduce fulfilment. Alternatively the same issues, if managed differently, can reduce stress and increase fulfilment. An understanding of this process can help staff to develop strategies, which enable parents to fulfil their parenting role within the challenging NICU environment.

The parent-staff relationship

Parents described how the quality of their relationship with their baby is significantly influenced by the quality of their relationship with the staff. Parents strive to establish their parental role within the NICU and rely on staff to help them achieve their expectations of parenting. Unfortunately, not all staff have the necessary skills to provide adequate support and parents described insensitive conversations and inconsistencies in practice which led to increased anxiety. Staff in phase 1 of the study also acknowledged variations in the quality of parental support and highlighted the need for further education and training.

Following the implementation of FCC interventions, which included staff workshops and education sessions, staff reported increased confidence in supporting parents to become involved in specific areas of caregiving. Similarly, parents' perception of staff support was slightly improved in phase 3. Courses such as The Family and Infant Neuro-developmental Education (FINE) (Warren 2015, 2015a), which was utilized by participants in our study, provide a pathway for all levels of staff to gain a comprehensive understanding of the theory, scope and evidence for family centred developmental care. Our findings suggest that such training should be mandatory for all neonatal staff.

Impact of the interventions on families

In the questionnaires used to measure satisfaction and stress, parents generally reported greater satisfaction and less stress following the introduction of the interventions. Although sample sizes were too small to examine for statistically significant differences between the 2 sets of data, some small differences were observed particularly in relation to the parental role, for example feeling more able to help and protect their baby.

Diary data suggested that following the interventions; there was a greater duration of parental time at the cot side, more active involvement in caregiving and an increase in both the duration and frequency of skin-to-skin contact. Each of these measures is known to have further short and long-term benefits such improved breast-feeding and reduced length of stay. Parents discussed their relationship with their baby more in terms of what they actually did rather than what they would like to do and problems such as staff inconsistencies, the environment, and their own lack of confidence, which were discussed during the exploration phase, were not mentioned. Overall, it appeared that as parents were enabled to focus more on their infant, they became less aware of and concerned by the unfamiliar and potentially stressful NICU environment.

Although our study helped us to gain important insights into the experiences of some families in the NICU, we focused on families who were with their baby for long periods of time, but are aware that little is known about the experiences of families with restricted or reduced time in the NICU. Further research in this area is needed and one of our research team is currently designing a study to test the use of a mobile phone application to help us explore the experiences of families who find it difficult to visit the NICU to care for their baby.

Impact of the interventions on staff

In the exploratory phase of the study, staff described how everyday practice was governed by unspoken rules and traditions embedded in the culture of the NNU, which sometimes prevented rather than supported FCC. They identified the need for a new philosophy of care to inform guidelines, education, policies and practice and improve the quality of care for families. Following the introduction of the interventions, which

included an agreed family centred philosophy statement, staff reported a positive change in attitude towards parents and increased confidence in their own ability to provide meaningful support.

There was also an awareness that the changes brought about by a family centred philosophy of care would require the nursing role to change from 'active caretaker' to 'facilitator of parents in infant care' and that this would be challenging for some staff. Little is known about the impact of FCC on staff and further research is needed to explore ways to support the nurses who support the parents.

Impact of the interventions on workload

Workload and staffing levels were highlighted as obstacles to FCC during the exploratory phase of the study. Both staff and parents identified occasions when interventions such as skin to skin care were not possible because nurses were too busy to provide appropriate support. During the evaluation phase, these issues were not highlighted as obstacles and staff described how increased parental presence could at times reduce the demands on staff time. For example when parents were present during ward rounds, care times and procedures, communication was enhanced and the need for further meetings to repeat information was reduced. Furthermore, when parents were involved in care giving and present during procedures, there was less need for a second nurse to provide comfort and support for the baby. This suggests a positive link between parental involvement and workload, highlighting the need for further research to explore this important issue.

The process of change

Although programmes to facilitate FCC are already established in a number of neonatal units we were unable to directly implement any of them in our setting because of differences in staffing levels, specialist roles, resources or local culture. However, action research enabled us to combine the evidence from previous research with data collected from our own staff and parents, to develop interventions pertinent to our setting and achievable within our resources. By involving parents, staff and researchers in every stage of the process we were able to explore the issues in depth, implement and refine a number of multifaceted interventions and influence the culture of the unit as well as practice.

During regular and on-going reflection we identified a number of factors that contributed to the success of the interventions for example staff involvement, the utilisation of existing areas of good practice and the acknowledgement of the current drivers for change. We also became aware of the need for continued planning, reflecting, observing and acting on our practice to ensure support for FCC strategies beyond the duration of our research study. Tools such as The Bliss Baby Charter Audit (Bliss 2015), which is currently being used in our unit, can help to highlight areas in need of change, justify the need for on-going resources and identify specific areas for further research.

CONCLUSION

This study has contributed new knowledge and informed a discussion regarding the parent-infant relationship in the NICU. Facilitating this complex process requires a personalised and multidimensional approach. It must be underpinned by a philosophy of neonatal care, which acknowledges not only the intrinsic need of parents to 'be with' and 'do for' their baby within the restraints of the NICU, but also the responsibility of staff to enable them to do so.

Although the insights gained during this study have emerged from work undertaken in one NICU, they may be of use to staff in other units who wish to introduce similar initiatives. However, they should be viewed merely as a starting point for a continuous move towards a more family centred approach to neonatal care.

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REFERENCES

Bliss the Premature Baby Charity (2015) *Bliss Family Friendly Accreditation Scheme*. BLISS, London.

Costeloe K, Hennessy E, Haider S, et al (2012) Short term outcomes after extreme preterm birth in England : comparison of two birth cohorts in 1995 and 2006 (the EPICure studies). *British Medical Journal*, 345, 7976.

Melnyk B, Crean H, Feinstein N, et al (2008). Maternal anxiety and depression after a premature infant's discharge from the neonatal intensive care unit: explanatory effects of the creating opportunities for parent empowerment program. *Nursing Research*, 57(6), 383–94.

Melnyk B, Feinstein N, Alpert-Gillis L, et al (2006) Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. *Pediatrics*, 118(5), 1414–27.

Montirosso R, Del Prete A, Bellù R, et al (2012) Neonatal Adequate Care for Quality of Life (NEO-ACQUA) Study Group. Level of NICU quality of developmental care and neurobehavioral performance in very preterm infants. *Paediatrics*, *129*(5), 2011-0813.

Nordhov S, Rønning J, Dahl L, et al (2010) Early intervention improves cognitive outcomes for preterm infants: randomized controlled trial. *Paediatrics*, 126(5), 1088–94.

O'Brien K, Bracht M, Macdonell K, et al (2013) A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. *BMC Pregnancy and Childbirth*, 13 (Suppl 1), S12.

Treyvaud K, Anderson V, Howard K, et al (2009) Parenting Behavior Is Associated With the Early Neurobehavioral Development of Very Preterm Children. *Paediatrics*, *123*(2), 555 – 561.

Warren I. (2015) *Family and Infant Neurodevelopmental Education, Level 1: Foundation Toolkit for Family Centred Developmental Care*. Course material. Erasmus BV, Rotterdam.

Warren I, Oudereimer M, Conneman N, et al (2015a) *Family and Infant Neurodevelopmental Education, Level 2: Practical Skills for Family Centred Developmental Care.* Course material. Erasmus BV, Rotterdam.

Welch M, Firestein M, Austin J, et al (2015) Family Nurture Intervention in the Neonatal Intensive Care Unit improves social-relatedness, attention, and neurodevelopment of preterm infants at 18 months in a randomized controlled trial. *Journal* of Child *Psychology and Psychiatry*, 56(11), 1202-1211.

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