

Peer support in neonatal care: a collaborative approach

This article is designed to summarise our research on parent-to-parent support within the neonatal unit and to describe the value of working with a wide team. Based on our findings, the article aims to give hope, guidance and support on the practical benefits of working with professionals and parents to improve the experience of neonatal care and to develop further research in this area.

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Keywords

parent support; parent-to-parent; neonatal; NICU; preterm; premature; parent peer; staff involvement

Key points

Hunt HA, Prosser S, Collinson A, Boddy K, Thompson Coon J, Whear R. Peer support in neonatal care: a collaborative approach. *Infant* 2021; 17(5): 218-21.

1. Parent-to-parent support services are beneficial.
2. Collaborating with parents in research and practice is valuable.
3. Valuing and involving staff at every stage of research is essential.

Background

The first two years of a baby's life is a critical phase in child development. Equally important is the experience of the parents and, in the event of neonatal difficulties, parents and their baby(s) should have quick referrals and access to world class care.¹

The Better Births national maternity review report published in 2016 emphasised the importance of access for parents, proximity of care to home and active involvement for parents in their baby's care and in key decision making.² The NHS Long Term Plan³ echoes this recommendation, emphasising the need for seamless care for parents and their babies and an improved experience for babies cared for in neonatal units (NNUs) and their families.

Parents of babies admitted to NNUs experience an emotional journey. Feelings of helplessness, fear, sadness, guilt, grief and anger are common and may persist long after leaving the hospital. *The First 1,000 days of life* report published by the House of Commons Health and Social

Care Committee in February 2019⁴ particularly highlighted the value and potential presented in peer-to-peer support for parents and families. The report quoted the Big Lottery Fund, which explained that peer support is useful as: "Some parents may find it easier to relate to a peer who has gone through similar experiences; they may feel that the peer understands what they are going through and won't judge them."⁵

The experience of families in neonatal care has been further complicated by the COVID-19 pandemic with reduced access for visitors (including direct family members), which in turn results in reduced support available for families who find themselves in this environment and perhaps an increased sense of isolation and anxiety. However, this has led to a national positive reinforcement of parents not being visitors but partners in care.^{6,7}

Researchers from the University of Exeter Medical School and Royal Devon and Exeter Foundation Trust, the Royal Cornwall Hospitals NHS Trust and local Devon charity SNUG (Supporting



Investigating the experience and effects of parent-to-parent support.

Neonatal Users and Graduates), wanted to find out:

- if peer support is effective for helping families during neonatal care
- what peer support may look like
- how it is organised
- what the impacts and challenges are to implementing this kind of support.

How we went about this

Please note this research took place in 2018-2019, ie before the COVID-19 pandemic.

This project was put together by a multidisciplinary team of researchers (with methods and topic expertise), clinicians in paediatric and neonatal care, and parents with experience of neonatal care and providing parent-to-parent (P2P) support to ensure that everyone who the research concerned was represented within the project team and equally valued. This team along with a Parent Advisory Group (PAG) steered the project from beginning to end to produce, discuss and inform the research and enable it to be shared with relevant audiences in the most useful and accessible way.

Recognising the importance of engaging NNUs and practitioners, we worked closely with staff throughout the project in a number of ways. At the beginning, we made scoping telephone calls to each of the 12 NNUs in the South West Neonatal Network (**FIGURE 1**).

Phone calls were led by the neonatal nurse on our project team, supported by one of the academic researchers. The aim of the phone calls was to establish what was actually happening in NNUs in the South West region (in terms of parent support). The other important purpose of the calls was to make contact and tell people about the research project and to let them know about opportunities to get involved. Information gathered from these calls helped to scope current P2P support activities within South West NNUs. We used this information to ground our understanding in discussions within the research team and with the PAG.

The PAG was made up of seven parents with relevant and varied experience of having a baby in neonatal care and experience of P2P support in this context. All the parents were actively involved with SNUG, and it was through the charity that we asked for members and recruited volunteers to help. We met at a child-friendly soft play area familiar to the

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 Dyson Neonatal Unit, Royal United Hospital, Bath
 Neonatal Intensive Care Unit, Southmead Hospital, North Bristol NHS Trust
 Regional Neonatal Care Unit, St Michael's Hospital, Bristol
 Neonatal Unit, Royal Devon and Exeter Hospital
 Neonatal Unit, Gloucester Royal Hospital
 Neonatal Intensive Care Unit, Derriford Hospital, Plymouth
 Neonatal Unit, Great Western Hospitals NHS Foundation Trust, Swindon
 Neonatal Unit, Musgrove Park Hospital, Taunton, Somerset
 Special Care Baby Unit, Torbay Hospital, Torquay
 Neonatal Unit, Royal Cornwall Hospital, Truro
 Neonatal Unit, Yeovil District Hospital NHS Foundation Trust

FIGURE 1 The 12 NNUs within the South West Neonatal Network.

parents as the regular location of their SNUG meetings. We scheduled meetings to suit the majority of parents. Four face-to-face PAG workshops took place over the course of the project and between meetings the group was involved in the project via a closed Facebook group.

The main focus of the PaReNt project was to conduct a systematic review⁸ to bring together and summarise all existing research that might help us to answer the question: "What is the experience and effects of P2P support from the perspective of people giving and receiving support, and those involved in implementing P2P support in the context of the provision of neonatal care?"

To do this, we searched the relevant academic literature via bibliographic databases, references of included studies, and relevant reviews and websites. The literature that was identified was then screened against inclusion criteria for the review. Studies were excluded where the support intervention was provided by professionals (instead of parents), where the intervention was for bereaved families or those whose child was receiving palliative care, and where the intervention was about education rather than support. The results of the included studies were brought together and shared with our project team, parents and stakeholders (including neonatal teams, commissioners and charities) at an 'impact conference'. The results were also published in an open access peer reviewed journal.⁹ The whole process took 12 months to complete.

Scoping phone calls

At the beginning of the PaReNt project, we made a number of calls to find out what sort of P2P support activities were

currently happening in NNUs in our region. The PAG and neonatal professionals on the team helped to create a series of topic points and conversation starters, which provided a structured and consistent approach to the calls.

We were able to have meaningful conversations (100% response) with all of the 12 South West NNUs and were pleased at both the range of activities and the active engagement of the staff we spoke to. In many of the phone calls, there was a feeling initially from units that they did not provide much, but as the discussion developed people recognised activities that were relevant to our conversations. Examples included cot-side visiting, coffee mornings on the unit and in the community, parent notice boards (specifically requested by, and for the sole use of parents), Facebook sites, WhatsApp groups and creative gifting from individuals and groups (eg Christmas and Mother's Day gift parcels).

Following the phone calls, we met as a research team and drew the different types of information and links between them on a whiteboard, to help make sense of all the factors that had been mentioned in the calls. The information gathered through the calls was not 'data'; rather, this was an important part of the process to engage neonatal staff with our research and to ensure that the work was grounded in reality. Talking to, listening to, hearing and validating their activities and views was a vital part of building participation in our study and making sure it was relevant to the people it had potential to impact.

We used the material within the research team, with the PAG and in an impact conference to inform discussions alongside the results of our systematic review and decide

on the key messages. Through this, the PAG was able to validate activities and information given by the neonatal staff, which helped us to triangulate the picture we had developed of current neonatal activity with the systematic review findings.

Review findings

P2P support is beneficial

The review found 14 studies (from Canada, USA and Finland) that could help to inform the role of P2P support in the neonatal environment (none were conducted in the UK). The evidence suggests that P2P support can help to reduce feelings of maternal anxiety and perceived stress. Some evidence also suggests P2P support can improve the overall satisfaction of care while in hospital and may improve feelings of self-esteem and confidence in being able to look after the child once discharged home. P2P support can take many forms and we don't yet know what works best for whom and in what context, but flexibility in the timing, location and form of contact may be beneficial. In the research studies, most P2P support was conducted face-to-face in the hospital on an individual basis but it sometimes occurred at home, over the phone, by email or online and sometimes in groups, with varying frequency and duration of contact. P2P supporters were usually mothers who had had their own journey through neonatal care, some were given specific training and support and others were not. Fathers were under-represented in the research both in terms of giving and receiving of P2P support. The qualitative evidence around P2P support in the neonatal context identified four main themes relating to the benefits of giving or receiving P2P support (FIGURE 2).

The research conducted in this area to date is not strong or comprehensive so more research needs to be conducted to understand:

- what works best for who (including fathers)
- the potential for any negative impacts for givers and receivers of support
- the barriers to implementing this type of support in hospital and at home (and how to overcome them).

In our final project team meeting, we were joined by a professional scribe who created a graphic from our results and discussions (FIGURE 3).

Trust: Peer supporters were seen as friends with whom parents could be honest and 'real', who understood their experience and recognised the value of timing of support

Hope: Peer supporters were felt to give parents confidence in their caring skills and helped to 'normalise' their experiences

Information and help: Peer supporters were able to translate technical terms and point out key information

Connecting: Peer support helped to reduce feelings of isolation and was often part of a two-way relationship benefitting hospital staff as well as parents

FIGURE 2 Identified themes on the benefits of giving or receiving P2P support.



FIGURE 3 Visualisation of the key findings from the PaReNt project. If you would like to use this image in your unit, please get in touch: evidsynthteam@exeter.ac.uk

Impact conference

The aim of the impact conference was to discuss what we found, what the really important messages were and how to get these out to where they are most needed. We invited the 12 South West NNUs, local commissioners, neonatal network managers, local maternity system (LMS, now known as Local Maternity and Neonatal System, LMNS) managers, parents and charities to help explore our research findings and talk about implications for practice. On the day (in October 2018), staff from nine NNUs were able to attend, along with representation from the South West Neonatal Network, LMS, British Association of Perinatal Medicine (BAPM), commissioning, parent representatives, members of SNUG and researchers and students from the University of Exeter. We felt this level of attendance was impressive given that people were ostensibly travelling to Exeter simply to hear the results of a systematic review.

The introduction to the impact conference featured a video of a parent who had experienced peer support on an NNU – this set the scene for the ongoing

discussion and was a powerful and engaging start to the day. Round table and group discussion throughout the impact conference was active and engaged, with strong motivation to keep the conversation going. The key messages are summarised in FIGURE 4.

We identified a number of gaps in the evidence; the most prominent where we found limited or no evidence were:

- P2P support targeted towards fathers of babies cared for in NNUs
- Potential negative effects of P2P support and the impact of negative experiences on P2P support (on parents and parent supporters)
- Evaluations of P2P support interventions based in the UK
- Conflicting evidence of the effectiveness of P2P support targeted at increasing breastfeeding rates
- Lack of evidence on the implementation of P2P support.

Other key points discussed and questioned at the impact conference were:

- Do we need evidence if something instinctively feels 'right'?
- Can P2P support cause harm?

- What sort of evidence do we need?
- How do we make it sustainable?

There was a great deal of interest and passion among conference attendees to learn from current peer providers and we are looking to 'keep the conversation going' and build on the findings from the PaReNt project. Through our wide network, we continue to promote our research and contribute to discussions in the field on social media and in person. We have mailed everyone who attended the impact conference and said they would like to be involved in further activity, and we have mailed all NNUs in England.

Valuing and involving staff at every stage of research is essential

As with involving parents, we were keen to include neonatal professionals within the project beyond the members of our research team. We chiefly did this through the scoping calls, the impact conference, and our plans to develop ongoing relationships. By inviting professionals to the impact conference, the invitation to engage was extended to the NNUs, the hospitals and the staff. In turn, this encouraged staff to bring parents from their NNUs, inviting them to be part of the conversation. This felt like a positive cultural shift in our research practice as well as in the family and staff interactions, where everyone could meet and discuss on a level playing field and be meaningfully involved in developing the findings and next steps.

Conclusion/summary points

This project was funded for one year from 1 January 2018 to 31 December 2018. In reality, both the impact and the activity has extended far beyond this rigid timetable and the ripples created by the initial project idea continue to spread. Neonatal staff, commissioners, charities and parents involved in the project continue to help spread the word of our research and the role of P2P support, and continue the discussions sparked by the findings and networks we developed.

In the course of this project, we have experienced a surge of neonatal staff, parents of babies cared for in NNUs, commissioners making decisions on neonatal services, charities supporting parents and babies, and academic researchers interested in improving on what we already know about the benefits of P2P for parents of babies cared for in NNUs. The willing involvement of people,

1. Local knowledge is invaluable; what may work in some units may not work in others
2. P2P support can help by providing emotional support, reducing feelings of isolation and providing a valuable source of information and help in hospital and beyond
3. Multidisciplinary teams can learn from parents providing P2P support
4. Support needs to be individualised

FIGURE 4 Shared practice points on P2P support.

and their readiness to join with others to share experiences and ideas, has led us to reflect on how sustainability and resilience can be built through a network of individuals. This may have greater resonance beyond our research; staff changes and variations in administration can be overcome if the real appetite for change and improvement is not reliant on one individual, but instead comes from the links between people. This desire for joined up thinking, with a diverse group of individuals bringing different skills, experiences and local knowledge, chimes with the drive to build relationships between professionals and families promoted across the Neonatal Critical Care Transformation Review,¹⁰ NHS Long Term Plan³ and the *First 1,000 Days of Life* report.⁴

Planning for and maintaining such services now and beyond the COVID-19 pandemic needs to continue and this project can provide the basis for solid developments in neonatal care and research. Since this research was conducted, the Neonatal Critical Care Transformation Review¹⁰ has been published which, as part of its vision, highlights the need to enhance the experience of families in neonatal care. There is to be a national roll-out of family coordinator roles within the neonatal network, highlighting the importance of support for families as detailed in the recommendations of the Neonatal Critical Care Transformation Review.¹⁰ Our research, and the multidisciplinary team involved in producing it, shows how P2P support can play a substantial role in supporting this vision. We hope to continue research in this area, incorporating the rich diversity of professional and personal experience we have benefitted from within the PaReNt project.

Acknowledgement

The work was funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit Programme (Grant Reference Number PB-PG-0416-20032).

This report is independent research supported by the NIHR Applied Research Collaboration South West Peninsula. The views expressed in this publication are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

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Further details about the project including publications and useful resources can be found at: <http://clahrc-peninsula.nihr.ac.uk/research/parent-to-parent-support>.