Dr. Carolyn Blackburn, Reader in Interdisciplinary Practice and Research with Families, Director Centre for the Study of Practice and Culture in Education and Professor Merryl Harvey, Professor of Nursing and Family Health, Department for Children and Young People's Health / Co-lead Elizabeth Bryan Multiple Births Centre, Birmingham City University

'We weren't prepared for this': Parents experiences of information and support following the premature birth of their infant

Infants and Young Children

Submitted to journal 7th August 2018

Accepted for publication 26th December 2018

Abstract

Having a child born prematurely can plunge parents into an unknown and sometimes frightening situation, where they experience a loss of control over events and reduced decision making capacity. Preterm birth sometimes results in post-traumatic stress disorder for parents and negatively impacts on parent-child interactional patterns, especially if parents were unprepared for this eventuality. The role of information, support and early intervention in parents' coping capacity in this situation has been noted in developmental systems theory to contribute to family interactional patterns. This paper reports on a mixed-methods study that explored the information and support needed by and available to parents following pre-term birth in England and the effect of this on their emotional well-being. The findings suggest that support systems do not always provide timely or helpful emotional or practical support to parents and this has the potential to place additional stress on family interactional patterns, especially where parents were unprepared for the possibility of pre-term birth.

Keywords: Prematurity; Premature Birth; Developmental Systems Theory; Families

Introduction

Premature infants are noted to be at risk for developmental delays (Marlow, 2004; Wolke, Strauss, Johnson, Gilmore, Marlow, & Jaekel). From quantitative research studies, it has been argued that this can be compounded by less than optimal interactions between parents and infants born prematurely due to circumstances surrounding premature birth (Greenberg & Crnic, 1998; Davis, Edwards & Mohay, 2003). Having a child born prematurely can plunge parents into an unknown and sometimes frightening situation, especially if they were not considered at risk for premature birth by professionals and therefore not prepared for the eventuality. Parents of prematurely born infants may experience a sense of loss of personal control over events, particularly those related to the survival of the infant (Meck, Fowler, Caflin, & Rasmussen, 1995; Foster-Cohen, 2017) which can result in anxiety and stress.

Parents may also experience a loss of their role as decision makers and care givers of their child (Campbell & Fleischman, 2001; Foster-Cohen, 2017) that could result from parent-infant separation brought about by hospitalisation (Moehn & Rossetti, 1996). It is not surprising therefore if parents of infants born prematurely are reported to experience prolonged psychological distress (Carson, Redshaw, Gray*, et al.*, 2015). Treyvaid, Lee, Doyle & Anderson (2014) found that very preterm birth influences parental mental health and family outcomes seven years after the birth and argue for more support for parents of children born prematurely to support their emotional well-being.

In a meta-synthesis of studies published between 1990 and 2015 relating to parents experiences of caring for preterm infants after discharge from neonatal intensive care units (NICU), Adama, Bayes & Sundin (2016) found three main themes that were of concern to parents and of potential interest to professionals. Firstly support from others (professionals and family members) improves parents confidence in their ability to care for their infant. Secondly, there were additional challenges for both mothers and fathers in caring for preterm infants over full-term infants, not least parents' concerns over their child's survival and their own ability to provide care away from the safety of NICU. Yet this also provided opportunities for strengthening relationships between parents once challenges were overcome. Thirdly parents experienced their role as one of being over-protective, neglecting their own needs to ensure the infants were met and overwhelming feelings of guilt and responsibility.

Care systems

Professional knowledge about expected developmental milestones and the emotional impact of premature birth on parents has been found to be important, yet in need of improvement (Blackburn & Harvey, 2018; Foster-Cohen, 2017). These issues are acknowledged by the National Institute for Health and Care Excellence (NICE) Quality Standard (2018) for developmental follow-up of children and young people born preterm. As part of the system of care in the UK, NICE (2018) recommend that parents or carers of a preterm baby have an agreed discharge plan with a single point of contract in the community and that children born preterm have developmental surveillance and assessments according to the child's needs. NICE (2018) stipulate that parents should be able to access support and information for both acute and non-acute problems that arise and should know where and how to access such information and support. A key professional contact for new parents comes from Health Visitors (HVs) who hold an assessment and monitoring role for all children and especially those considered at risk for developmental delays as is the case for babies born preterm. However, they are one part of the early years workforce and system of care available to support parents and children in the community. In addition to HVs, there are also a range of other professionals including social workers, Portage workers, specialist neonatal teams, GPs, speech and language therapists, occupational and physiotherapists, developmental care specialists, play therapists, dieticians, child and adolescent mental health services and charities offering community support. All of these services operate independently and often in different locations. This approach differs to New Zealand where an integrated co-ordinated centre-based approach is offered to all parents of children born prematurely in the area by the Champion Centre, Christchurch. Regular assessment and monitoring sessions then take place at 8, 12, 18, 24, 36 and 48 months. At these sessions the child and parents/caregivers are engaged in a positive assessment process which is play-based and child-friendly, to elicit the child's best performance and parents emotional state.

Further to this community/centre-based support, support from peers, family and friends are fundamental to parents' well-being. Information and support and key aspects within the theoretical framework of developmental systems theory as explained in the next section.

Developmental systems theory

Within the context of family systems, the relationships and bonds between parents and infants are the primary influence on child development. Parents use' of responsive interactional styles that encourage children to engage with their parents is partly dependent on their psychological health and positive well-being. Systems theory as conceptualised by Bronfenbrenner (1979) stresses the importance of relationships within a family for optimum child development, but also places emphasis on the family's interactions with systems outside the home. This suggests that information and support provided to families in the event of premature birth can indirectly influence the healthy development of children and is of interest to both researchers and policy makers, since variables within systems can be manipulated to enhance outcomes. These ideas are promoted within the developmental systems approach (Guralnick, 2011) which argues that key components of optimum family interactional patterns are parent's social and peer network, community activities and socio-emotional connectedness between parent and child. Key family resources identified within Guralnick's framework include parents coping style and perceived confidence and competence. These components are not only related to parent's own social and cultural capital, but are also information and resource dependent. This includes information provided prior to the birth of a child, during and after birth and information and early help provided on discharge from hospital.

Premature birth

Premature birth can be defined in terms of gestational age or birth weight. The World Health Organisation defines preterm birth as babies born alive before 37 weeks of pregnancy are completed and defines sub-categories of preterm birth, based on gestational age:

- extremely preterm (less than 28 weeks)
- very preterm (28 to 32 weeks)
- moderate to late preterm (32 to 37 weeks).

For low birth weight, the follow categories are defined:

- Low birthweight - Born weighing less than 2500g (5lbs)
- Very low birthweight - Born weighing less than 1500g (3lbs)
- Extremely low birthweight - Born weighing less than 1000g (2lbs)

Recent research about premature birth from a health and social care perspective focused on the months immediately following the birth (Harvey *et a.l,* 2013; Garfield *et al.,* 2014; Gray *et al.,* 2013). Studies have also focused on parents experiences of having (Lohr, von Gontard & Roth, 2000), caring for (Jackson, Ternestedst & Schollin, 2003) and parenting premature infants (Swarts, 2005). Learning difficulties faced by children born prematurely have been identified from largely quantitative studies (Marlow, 2004; Johnson *et al.,* 2010; Costeloe 2012; Wolke *et al.,* 2015). Qualitative studies have explored mother-child interactions following premature birth (Nicolau, Rosewell, Marlow & Glazebrook, 2009). More recently mixed-methods research has identified the professional knowledge that parents would like early childhood professionals to hold about premature birth (Blackburn and Harvey, 2018). There have also been historical studies relating to the support needs of mothers following premature birth (Davis, Logsdon & Birkmer, 1996; McKim, 1993 for example). This paper explores parents' experiences of information and family / community support provided following premature birth in the current socio-cultural-political UK context.

Aim of research

This paper reports on a mixed-methods study that aimed to explore parents' experiences of premature birth and information and support from professionals, family and community. Research questions included:

1. What are parent's experiences of having a child born prematurely?
2. What information and support would parents find beneficial?
3. What information and support do parents receive?

Methods

An online survey was promoted widely via social media and existing contacts. The survey consisted of 24 questions, included both open and closed questions and was designed to be completed within 20 minutes unless participants wanted to disclose more detailed information for which there were open boxes for this purpose. Questions related to parents' experiences of hospital, early help and community support, family support and early childhood intervention and education. The survey questions were derived from an earlier study conducted by Imperial College London (ePrime: Evaluation of MR imaging to predict long-term outcome in preterm infants, Edwards, Redshaw, Kennea *et al.,* (2017). However, they were adapted to reduce the number of early postnatal questions and include further questions relating to community support and early care and education not included in the ePrime study). Further to this, advice and guidance was sought from the Director of the Champion Centre in New Zealand who offer a relationship based early intervention service for children and families and an assessment and monitoring programme for babies born prematurely. The survey questions were piloted with three parents prior to launch. This paper reports only on the early postnatal and community support and intervention data as the early care and education data has been reported elsewhere (Blackburn and Harvey, 2018). The link to the survey was placed on the University website and the survey was promoted widely through existing links and social media. The survey was promoted by BLISS charity for babies born premature or sick. A total of 209 parents responded to this. Of the 209, 200 (96%) were mothers and 9 (4%) were fathers. The majority of participants were married (68%) with remainder either living together (21%), single (10%) or in a civil partnership (1%). In terms of education 61% of parents had either an undergraduate or postgraduate degree, with the remainder having at least high school/secondary school level qualifications. The largest age band was 31-40 (58%) followed by 21-30 (21%) and 41-50 (20%) with the remainder being 51 or over. Parents were invited to leave their contact details if they wished to participate in an interview. A total of 25 parents provided contact details and indicated interest in participation in an interview. However, of these only 13 responded positively to a email/telephone invitation from the researchers to arrange a suitable date and time for interview. The intention had originally been to select an interview sample to provide a maximal variation sample of ages and other social demographics. However, in practice as already explained this was not possible and in the end, twelve mothers and one father were included in the sample. Interviews took place by telephone at a time and date convenient to the parents and a structured interview schedule guided the discussion to ensure that all parents were asked the same questions in order to reduce bias. The data was collected in 2016/2017 prior to the publication of the NICE guidelines. Further ethical considerations are discussed below.

Ethical considerations

Ethical considerations related the power relationships between researchers and participants and the sensitive nature of research questions. All interviews were conducted at a time convenient for the participant. The guidelines from the British Education Research Association were followed at all times. The researcher monitored participants' speech and vocal expressions at all times for signs of distress and discomfort. Participants were informed of their right to informed consent, right to withdraw from the research at any time and to confidentiality and anonymity.

Data analysis

Data were analysed to answer the research questions at the first level allowing common and discrepant themes to emerge subsequently. Research questions identified *a priori* themes and thereafter emerging themes were identified. Qualitative content analysis provided the opportunity to organise, condense and categorise data through a process of interpretation of and inference from participants' original expressions. This was an inductive process rather than being theory guided and deductive. A process of reducing and clustering to form initial codes or sub-categories that described followed. The unit of textual analysis was an extract from a transcription with factual connection to an idea and issue. For example parents commented on the eventually of a premature birth being something strange and unknown to them, had not been discussed or even mentioned and this gave rise to the issue of feeling unprepared. After initial codes had been identified in data of two or three transcripts, codes were compared with each other according to similarities and differences to determine which data ‘look alike’ and ‘feel alike’ as suggested by Lincoln & Guba (1985, 347). The data analysis was informed by processes of thematic analysis – a foundational analytical method designed to identify, represent and report thematic patterns that occur within the data (Braun & Clarke 2006).

Findings

Findings are discussed under the research questions identified above.

The first question asked about parent’s experiences of having a child born prematurely. Under this question two main themes emerged; need to be prepared and the role of professionals in parents’ hospital experience.

Need to be prepared

Although this did not arise from analysis of survey data, from interviews parents described the shock of having a preterm baby and mentioned that they would have liked the risk of prematurity to have been discussed with them prior to the birth. They felt unprepared for the eventuality and this contributed to emotional distress:

> *I don’t know. It’s very hard, isn’t it, because you think…it is such a scary time when it happens? I knew nothing about premature babies beforehand. No-one had…like none of the midwives had even mentioned it. You’re not even given inkling that it might be a possibility. You really are just thrown into this world or things that just seem so farfetched. It is a real shock to the system.* (Survey respondent)

One of these parents also said that she would like more research into the reasons for prematurity, as no-one had explained to her why her children had been born prematurely.

The role of professionals in parents' hospital experience

From the survey, many parents said that they felt supported by staff and that their hospital stay had been a positive experience:

> *It was very hard emotionally but all of the nurses were lovely and gave my husband and me lots of advice in the early days of how to look after our baby. Being able to stay in the hospital for the first few days was so important as I could go and see her at any time of day/night.* (Survey respondent)

However, a similar number of parents described their hospital experience in negative terms as emphasised in the comments below:

> *It was incredibly stressful and the most traumatic experience I have ever had. I have been diagnosed with PTSD.* (Survey respondent)

Some parents acknowledged that although it was a stressful time, support from staff reduced stress and anxiety and increased positive aspects of care:

> *At the time it was scary and emotionally it was a roller coaster, but looking back there were benefits to the supportive community within the hospital, as I learnt a great deal about prematurity, newborn care and even about myself.* (Survey respondent)

For some parents there was a different experience between being on the neonatal ward and the maternity ward in terms of their experience. The lack of support from staff had a detrimental effect on parent / child bonding and maternal well-being for a number of parents:

> *I will be forever grateful to the hospitals that cared for my son and helped him live and thrive; I could not fault his care. However, as a mother, I felt completely let down in many ways. I feel in hindsight that I probably suffered mild depression and some form of stress/trauma during the whole experience, which has left me fearful of having more children.* (Survey respondent)

The second question and third questions related to information and support needed and received by parents. As these two questions are closely intertwined and parents reported their responses in relation to these aims in an inter-related manner, findings that link to these questions will be reported together.

Findings are discussed under the themes of ‘‘Need for information’ ‘Need for support’. Each of these themes has sub-themes as shown below:

Need for information: information sought, received and given in hospital; the role of professionals; information provided on discharge

Needing and finding support in the community: family support; professional support family; support from charities; peer support

Need for information - information sought, received and given in hospital

Parents were asked about how much information they were given about their baby during their stay in hospital and who provided the information. As can be seen from Figure 1, more than half of survey parents (57%) were given lots of information about practical aspects such as ‘feeding’ and their role in their baby’s care. More than half (51%) were given some information on prematurity. As far as the long-term developmental outcomes for their baby, nearly half (47%) were given little or no information, less than half (38%) were given some information and only 18% were given lots of information on long term outcomes for their baby. The majority of parents received information from doctors and nurses although some also received information from a range of other professionals and many searched on the internet for information.

PLACE FIGURE 1 ABOUT HERE

Parents commented that hospital staff had focused on practical and immediate aspects of neonatal care which left them concerned about their babies long term outcomes with 14% parents commenting on the lack of information about this:

> *I was very concerned about the impact it would have on his development, but the focus in the hospital seemed to be just about immediate survival and getting him well enough to go home.* (Survey respondent)

> *Day by day we didn't really know what the ultimate outcome would be. In hindsight I know that we had relatively straightforward cases. Had we known this at the time we would have been more relaxed.* (Survey respondent)

Other parents reported that they were not provided with information on even basic aspects of how they could provide care for their baby and this impacted upon their confidence as a parent. Important aspects such as Kangaroo care, breastfeeding, and whether or not the baby would survive were not communicated to parents:

> *I would like to have known more about how I as a mother could help my baby. Kangaroo care for example was mentioned, but I wasn't given much information on when I could hold my baby, how long to hold him for, how to hold him. All of these things meant I didn't like to do it too much because I was scared it would be detrimental to his well-being.* (Survey respondent)

From interviews, whilst three parents said that they had received enough information about their child's long term developmental outcomes, the remaining ten parents felt there was an absence of information given to them in hospital. Information given to them focused on their child's immediate survival and health care needs reinforcing comments from survey parents. One father described the choices he and his wife were faced with when the rupture of her membranes (waters breaking) at 23 weeks and 2 days:

> *We then had the chat with them where they talk you through the likely outcomes which are under 24 weeks you've got two choices, you can either cuddle them as they pass away when they're born or they can give them a very quick medical assessment, but then it may be that they die before that so you don't get to cuddle them while they're alive. But you have to choose one of those two things which is quite a conversation.* (Interview participant)

On balance he felt that the amount of information provided was appropriate but admitted that this depends on individual circumstances and timing. He suggested that his wife probably could not have embraced any more information and was content to monitor her daughter's progress by observation, whereas he needed more information so that he could react. He valued the honesty at the beginning of his daughter's journey regarding the choices available to him. However, he spent considerable amounts of time researching premature birth on the internet. Another parent reported that the timing of information provided was crucial in determining parent's ability to absorb the details and ensuring that the information was useful:

> *I think it would have been useful to know more when he was out of danger, when they were preparing to move him, when he was more stable and they were moving him to the next ward. So when you've gone from NICU which is*

> *obviously really intense and you can’t really focus on anything because it’s just such a horrible experience.* (Interview participant)

For the three parents who reported having ample information, their child had been at risk of not surviving. One parent expanded on this aspect by explaining that her child had experienced ‘bleeds on the brain’ so they were advised about the possibility of developmental delays. However, she also stated that she felt that they were ‘steered away from wanting answers’ in relation to specific examples or details of developmental delays.

Another parent said she was provided with sufficient information about the possible consequences such as cerebral palsy and developmental delays. This had enabled her to prepare and accommodate such as using sign language from a very early age. Information was also useful in terms of knowing how to relate to and bond with a prematurely born infant as explained by one mother:

> *They gave me the BLISS packs and there was a leaflet and there was a section about if the child doesn’t make it, I remember he was five days old and he’d kind of hit a wall and things were going rapidly downhill and they said, you know, now might be the time to read that. I did actually find that quite helpful because it expressed other parents’ views that when their child didn’t make it, you kind of had two viewpoints. One was the viewpoint of parents who had kind of held back from developing a bond because they didn’t want to get close to a baby that wasn’t going to make it. But the experiences in the booklet showed that in cases where the baby didn’t survive, the ones who didn’t develop the bond felt guilty because they wondered if maybe that had an impact on the baby, but the ones that did develop the bond said that there was*

> *kind of a sense of satisfaction that they knew that the baby knew he was loved and that sort of thing.* (Interview participant)

Information provided on discharge

There seemed to be a paucity of information provided for parents about support for themselves and / or their baby after discharge. From the survey, 38% of parents reported little or no information; the same number reported some information and only 28% reported receiving lots of information on this aspect.

28% of parents had residual questions on leaving the neonatal unit. Most parents wanted to know more about their baby's long term developmental outcomes, but a number also wanted to know about basic aspects such as feeding, basic care and whether their baby would survive:

> *I didn't actually know if my baby was likely to live, I was scared to ask. We went about a week thinking she could die from the infection ... had until I finally asked a doctor who told me she would definitely fight it.* (Survey respondent)

> *Discharge plan was non-existent and felt rushed; I didn't understand what follow-up we should expect or how to get help with issues. We live rurally and were out of reach of the post-discharge outreach team so only had our health visitor to rely on - who was good but not specialist in prem issues.* (Survey respondent)

From interviews parents said that follow up information (who to contact should there be any concerns on leaving hospital) was reported as being extremely important by all parents and yet reported as being absent from their discharge plan. One parent commented on the lack of understanding by GPs about the developmental delays that can result from premature birth:

> *I don't understand why they think because he spent four months in an incubator, basically, which should have been four months in my womb, why they think those four months…they're just going to catch up.* (Interview participant)

Needing and finding support in the community

From the survey and interviews after leaving hospital, parents had a wide range and varying levels of support networks available to them.

Family support

The majority of survey participants (77%) said that their partner had been very helpful or extremely helpful and not surprisingly this was the highest source of support reported for support networks. It is concerning that nearly half (46.9%) or parents felt that their relatives were either; not available, not helpful at all or only sometimes helpful and for 70% of parents partners relatives were also not available, not helpful or only sometimes helpful.

From interviews for eight interview parents, there was ample family support in terms of practical and emotional support for the parents. For example, providing pre-cooked meals and visiting as often as possible. However, four parents had family who lived too far away to provide any practical support and others felt that wider family members had little understanding of what kind of support might be needed in the circumstances or were hesitant to offer for example baby-sitting services as they were nervous about caring for a premature infant and / or multiples:

> *We were in hospital for such a long time, and they weren't allowed to visit. Even my mum and dad were only allowed to visit at certain times. Then we came home and we were obviously really paranoid about germs, so we didn't*

> *want anyone to come and visit. And then you get really isolated as well, because I didn't go out when I came home. The health visitor came to my house, because I refused to go to the clinic. I don't think we went out for a year, for the six months at home.* (Interview participant)

By contrast, one interview parent mentioned that as a family they just wanted to be left in peace following intensive intervention during their hospital stay, saying that they just wanted to *"kind of hideaway and it just be the two of us or three of us when my husband was around."*

Professional support

In terms of professional support, survey parents reported either lack of availability of many early help and intervention services or that services provided were minimally helpful. For example, the majority of parents (61%) said that their GP was not available, not helpful at all or only sometimes helpful whilst 92% of parents reported that a portage worker had not been available to them, 64% that a speech and language therapist had not been available and 62% that a developmental care specialist had not been available. Moreover over 90% of parents reported no access to child and adolescent mental health services or early support services and over 70% reported no access to an occupational therapist.

Eighteen survey parents said that they had excellent support from a range of professionals including health visitors, physiotherapists, occupational therapists, SCBU, midwifes, NICU nurses, outreach nurses, portage workers, Home Start workers. By contrast 22 parents reported negative comments about health visitors, speech and language therapists and community support teams.

Parents particularly commented that any help given was often too late, for example some parents said they had not seen a health visitor until two weeks after coming home with their baby. Twenty four survey parents commented on a fragmented early help system upon discharge from hospital as shown above in the section on comments about leaving hospital and shown emphasised in the comments below:

> *My baby struggled with his development and I was worried. Limited to no support offered. I feel that my baby needed more support with access to free specialised groups to help with his development and to support and give me ideas. We feel very alone and trying our best to help him. We use the Internet a lot.* (Survey respondent)

> *J was 645g at birth; she is now 8 years old and academically at the top of her class. She has problems with severe reflux/poor weight gain and asthma. She has attended speech and language, physio, gastroenterology and ear nose & throat. In her first year of life we had in excess of 150 appointments with professionals and yet; most of these appointments were unhelpful. . I myself have suffered from PTSD from her birth and the year/s that followed. I had no support for my own physical or mental health and it still affects me to this day.* (Survey respondent)

However, one parent commented that when early intervention is provided, the benefits and outcomes can be quite significant:

> *Our son has had specialist child psychotherapy for children 'at risk of autism'. He doesn't now have autism and I believe the early intervention he received has led to this. He was the surviving twin. His sister died at birth.* (Survey respondent)

The role of HVs emerged as a significant theme from both survey and interview parents. Thirty per cent of survey parents report that they only saw their HV for a short period of time and nearly fourteen percent that they saw them infrequently for a longer period of time. Nineteen survey parents said that HVs had insufficient knowledge about premature birth

> *Health visitors came and only once asked how I was coping. I burst into tears and said I was struggling as nothing had gone how I expected and it was hard having a baby who needed oxygen and a ton of medication. She told me it was "probably just baby blues" and that it would pass.* (Survey respondent)

> *The health visitor made me very stressed about my daughter's poor weight gain. In all my interactions with health visitors I feel they lack basic understanding of prematurity - e.g. not knowing how long to correct premature babies' ages. Almost every parent of a premature baby I've spoken to say the same thing.* (Survey respondent)

From interviews, two parents mentioned that communication between the Hospital and the HV was poor. Nine out of thirteen parents reported negative experiences of the health visiting service, with two parents expressing concerns that that the service focus on the child rather than the whole family / parents.

> *Health visitors were the least helpful. They were the worst. They just say stupid things to you like can he hold his head up, can he sit up yet, and I'm like, well, he shouldn't have been born yet. That's a really stupid thing to say, things like that. I found them really unhelpful.* (Interview participant)

> *The health visitor was awful, hadn't got a clue what advice to give us and everything like that at all, frankly was about to retire and I think had just*

> *switched off completely. But then the next one who she passed on to wasn't much better as well.* (Interview participant)

By contrast four parents from interview expressed positive experiences of the HV service as exemplified from the following comment:

> *She was good at telling me when would be the right time to take G out for some fresh air in the pram and things like that, like keep him in for another few weeks yet because he's not due yet so don't take him out in the fresh air just yet and things like that. When I used to take him to the baby clinic when it was weaning time she gave me a BLISS weaning leaflet because that was for premature babies essentially, so just to give me some extra guidance. She was totally tuned in with having a premature baby, and it was an amazing experience, I could ask her anything, I could ask all of my concerns. I had a brilliant experience with the health visitor.* (Interview participant)

Support from Charities

A number of parents from the survey and a couple from interviews mentioned the important role played by Charities in both hospital and home support including psychological support for parents. This included BLISS charity for children born sick or premature, Tommy's and Homestart.

Peer support

A number of parents (three) stressed the role of parent to parent support in that other parents who had shared similar experiences provided a degree of 'comfort'. By contrast parents who didn't have similar experiences could be a source of stress as they were more likely to judge children's development unfairly.

Discussion

Parents involved in this mixed-methods study were keen to talk about their experiences of premature birth and contribute to improved parental knowledge and support as evidenced by the high number of responses to the survey. 209 parents responded to an online survey and 13 of these participated in a semi-structured interview. Whilst the sample is limited in terms of the gender bias towards mothers, the sample includes some fathers and mothers from sufficiently varied age categories. The limitations of the study are discussed below.

The study aimed to explore parents' experiences of having a child born prematurely and parents' information and support needs in relation to information and support provided.

The data were analysed thematically and the themes of parents needing to be prepared, needing information and support in hospital and in the community were identified with sub-themes under each. These themes are linked to the research questions within the findings section.

It is acknowledged that children born prematurely are at risk for developmental delays (Marlow, 2004; Wolke *et al.*, 2015) and that a mitigating factor in reducing this is healthy and responsive parent-infant interactions (Greenberg & Crnic, 1998; Davis, Edwards & Mohay, 2013). The early social experiences of infants are contextualised within a family unit. Therefore parent reports of their experiences of premature birth are indicative of infants experiences.

In relation to parents' experiences of premature birth, parents in this study reported feeling unprepared for the eventuality of premature birth and that both this and the paucity of information provided to them in hospital had the potential to affect parents' emotional state and their relationship with their infant. Preparing all parents for the possibility of premature birth might help to reduce some of the stress and prolonged psychological distress created by an unknown reality that parents felt ill-prepared for as noted by previous research (Blackburn and Harvey, 2018; Meck *et al.*, 1995; Carson *et al.,* 2015; Treyvaid *et al.,* 2014). In addition, some parents reported their hospital experience in negative terms contributing to the overall traumatic experience of having a child born prematurely.

Following this, information provided to parents once in hospital does not necessarily reassure them about their child's survival or ability to thrive in the long-term. Parents experiences of information and support during their hospital stay varied widely with some parent given lots of information about practical aspects of caring for them baby whilst others receiving little information about significant aspects of care such as survival of their baby. Whilst it was acknowledged by parents that their capacity to absorb information in the immediate postnatal period might be limited, it was also stressed that parents requests for further information was not always responded to in respectful ways which increased stress and disempowered parents. Where parents were provided with information they were able to develop positive strategies such taking time to bond with their child, even if there was a serious risk to the infant's survival, they appreciated being provided with the necessary information to make the choice. This also included being given information later on so they had felt better prepared and had introduced strategies such as the use of sign language with their child to mitigate and reduce the likelihood of developmental language delays. This in turn had improved their relationship with their child and improved their confidence as noted by Adama, Bayes & Sundin (2016).

Furthermore information provided on discharge from hospital was equally disappointing for more than a third of parents with many having residual questions regarding both basic care and long term development for their baby.

Family and community support after leaving hospital is acknowledged as an important resource for families (Guralnick, 2011) which impacts on family interactional patterns. Findings from this study suggest that whilst partners are a helpful resource for the majority of survey parents, wider family members are not for many parents as nearly half of all parents said that their own relatives were not available, not helpful or only sometimes helpful and three quarters that their partners relatives were similarly not available, not helpful or only sometimes so. However, this contrasts with interview findings where eight of the thirteen parents had help such as pre-cooked meals and frequent visits.

Support from professionals was a particular area of concern from survey and interview findings. Although some parents report positive experiences, many report difficulties with a number of professionals including their GP and most significantly HVs. Late visits, lack of expertise and sometimes lack of empathy for parents' emotional state were among the complaints from parents about the health visiting service. This is of particular concern given that health visiting is universal service. In this study, it has been highlighted that when health visitors are knowledgeable about premature birth and attuned to the emotional and information/support needs of parents, this can contribute positively to parents' emotional state and relationship with their infant. Most significantly is the late availability of services and lack of co-ordination between services mentioned by parents. Consideration could be given to developing an integrated early assessment and monitoring programme similar to that provided by the Champion Centre in New Zealand that adopts a proactive stance to information and support.

Charities can play an important role in the support and information provision to parents but not all parents are made aware of these services as only a few parents from the survey mentioned this and even fewer in interview despite their services including psychological support for parents.

Guidelines are available from NICE (2018) to support professionals in their work with families, however the focus on children's survival and development minimises the emotional impact on parents and the subsequent influence on family interactional patterns. Data collection for this study was undertaken in 2015/2016 prior to the NICE quality standard publication. Therefore further research to identify changes to professional practice following the publication of the NICE quality standard in providing adequate information and support for families would be useful.

The findings from this study suggest that a number of variables within the external systems available and intended to support families need to be modified, including those related to prenatal information, postnatal information and community support such as GP and HV practices, not to mention family support. Where HVs have been helpful and sensitive to parents emotional and practical needs, parents coping behaviour has been reported by parents in this study to be improved. Urgent attention needs to be paid to the emotional needs of parents following preterm birth to ensure optimum parent- child interactions and child/family well-being.

Strengths and limitations

This study represents in-depth qualitative data and rich descriptions of parents' experiences. This is triangulated by the use of both an online survey and semi-structured interviews. Trustworthiness was ensured by the use of a well-established and appropriate analytical method for qualitative research and the findings have been shared with parents and professionals (member checking) to improve accuracy.

This broadly qualitative study is contextualised within UK policy and practice which limits the possibility of generalising some of the findings internationally. For example, prenatal, postnatal neonatal care and family support differs across countries, cultures and time. In addition, although responses to the survey were reasonably high (2019), only thirteen qualitative interviews were undertaken and only one of these was with a father. This further limits the potential for generalisability. However, this was not the aim of the study and parent's experiences of professional support, and information receiving are subjective and valid in their own right in qualitative studies.

The participants were recruited through the use of social media which in all likelihood suggests that participants have regular access to a computer and are likely to be proactive in seeking information and support. The experiences and information and support needs of parents who do not use information technology and/or have limited or no access computers and the internet may not necessarily be reflected in these findings.

It is also true that in qualitative studies, it is unusual to quantify the data as has been the case in this study in relation to the specific occurrence of each theme out of the total number of participants. However, providing the sample size is not too small thematic analysis is possible (Braun & Clarke, 2006; Boyatzis 1998) and doing so allowed the researcher to identify dominant themes.

Implications

This study is contextualised by the ecological dimensions which bound it (country, time, and policy factors). There are a number of implications arising from the findings discussed in this paper related to this. Firstly, the timing and amount of information shared with parents is an important factor in their experience of having a child born prematurely at particular points. This includes being prepared for the eventuality that premature birth is a risk or a possibility at least; having sufficient information regarding their child's survival and immediate care needs in hospital whilst at the same time some indication of potential long-term developmental outcomes to enable them to plan; a comprehensive and integrated discharge plan. Secondly, on discharge into the community, parents had hoped to meet appropriately trained and empathetic early years professionals such as HVs, yet this wasn't always the case. Families were also not always helpful and consideration might be given to developing family information packs about premature birth to ensure that families understand the emotional and practical support needs of parents experiencing premature birth. Finally the study has highlighted the need for the development of an integrated and co-ordinated assessment and monitoring system for parents of premature babies to support parents on their emotional journey and ensure children's optimal development.

References

Adama, A., Bayes, S. and Sundin, D. (2016) Parents' experiences of caring for preterm infants after discharge from Neonatal Intensive Care unit: A meta-synthesis of the literature. Journal of Neonatal Nursing 22, 27-51.

Blackburn, C. & Harvey, M. (2018): 'A different kind of normal': parents' experiences of early care and education for young children born prematurely, *Early Child Development and Care* https://doi.org/10.1080/03004430.2018.1471074

Carson C, Redshaw M, Gray R*, et al* (2015) Risk of psychological distress in parents of preterm children in the first year: evidence from the UK Millennium Cohort Study BMJ Open 2015;5 :e007942. doi: 10.1136/bmjopen-2015-007942

Foster-Cohen, S. (2017) *The Impacts of Prematurity* Keynote for Interdisciplinary Perspectives on Premature Birth, Birmingham City University, Birmingham 14th July 2017

Treyvaud, K. Lee, K.J., Doyle, L.W., and Anderson, P.J (2014) Very Preterm Birth Influences Parental Mental Health and Family Outcomes Seven Years after Birth *Journal of Pediatrics* March 2014Volume 164, Issue 3, Pages 515–521 DOI: https://doi.org/10.1016/j.jpeds.2013.11.001

Braun, V., & V. Clarke. 2006. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology* 3 (2): 77–101.

Bronfenbrenner, U. (1979) The Ecology of Human Development. Cambridge: Harvard University Press

Campbell, D. Premature babies more likely to end up in lower- paid jobs. The Guardian 1st September 2015

Davis. L., Edwards, H. & Mohay, H. (2003) Mother-infant interaction in premature infants at three months after nursery discharge. *International Journal of Nursing Practice,* 9, 374-381

Drewett, R., Blair, P., Emmett, P., & Emond, A. (2004). Failure to thrive in the term and preterm infants of mothers depressed in the postnatal period: A population-based birth control study. *Journal of Child Psychology and Psychiatry*, 45, 359–366.

Edwards AD, Redshaw ME, Kennea N,et al. (2017) Effect of MRI on preterm infants and their families: a randomised trial with nested diagnostic and economic evaluation *Arch Dis Child Fetal Neonatal Ed* Published Online First: [October 2017]. doi:10.1136/ archdischild-2017-313102

Garfield CF, Lee Y, Kim HN (2014) Paternal and maternal concerns for their very low-birth-weight infants transitioning from NICU to home. *Journal of Perinatal and Neonatal Nursing*; 28 4 305-312

Gray PH, Edwards DM, O'Callaghan MJ, Cuskelly M, Gibbons K. (2013) Parenting stress in mothers of very preterm infants – influence of development, temperament and maternal depression. *Early Human Development*; 89 9 6250629

Guralnick, M.J. (2011) Why Early Intervention Works: A Systems Perspective *Infants and Young Children,* 24 pp 6-28

Greenberg, M.T. & Crnic, K.A. (1988) Longitudinal predictors of developmental status and social interaction in premature and full-term infants at age 2. *Child Development*, 59, 554-570

Harvey, M.E. Nongena, P. Gonzalez-Cinca, N. Edwards, A.D. and Redshaw, M.E. (2013) Parents' experiences of information and communication in the neonatal unit about brain imaging and neurological prognosis: a qualitative study, *Acta Paediatrica,* 102(4): 360-365.

Jackson, K. Ternestedt, B.M. & Schollin, J. (2003) From alienation to familiarity: Experiences of moths and fathers of preterm infants. *Journal of Advanced Nursing, 43(2),* 120-29.

Lincoln, Y & Guba, E (1985) Naturalistic Enquiry. Newbury Park, CA: Sage

Liu L, Oza S, Hogan D, Chu Y, Perin J, Zhu J, et al. Global, regional, and national causes of under-5 mortality in 2000-15 (2016) an updated systematic analysis with implications for the Sustainable Development Goals. *Lancet*. 2016;388(10063):3027-35.

Lohr, T., von Gontard, A., & Roth, B. (2000). Perception of premature birth by fathers and mothers. *Archives of Women's Mental Health* 3(2) 41-46

Marlow N. Neurocognitive outcome after very preterm birth. *Arch Dis Child Fetal Neonatal Ed* 2004; 89:F224-8

Meck, N.E., Fowler, S.A., Claflin, K., & Rasmussen, L.B. (1995). Mothers' perceptions of their NICU experience 1 and 7 months after discharge. *Journal of Early Intervention*, 19, 288–301.

National Institute for Health and Care Excellence (2018) Developmental follow-up of children and young people born preterm ISBN: 978-1-4731-2949-8

Moehn, D.G. & Rossetti, L. (1996). The effects of neonatal intensive care on parental emotions and attachment. Infant-Toddler Intervention: *The Transdisciplinary Journal*, 6, 229–246.

Swartz, M. K. (2005) Parenting preterm infants: A meta-systhesis *MCN: American Journal of Maternal Child Nursing 20(2),* 115-120

Wolke, D., Strauss, V. Y.-C., Johnson, S., Gilmore, C., Marlow, N., & Jaekel, J. (2015). Universal Gestational Age Effects on Cognitive and Basic Mathematic Processing: 2 Cohorts in 2 Countries. *The Journal of Pediatrics, 166*(6), 1410-1416.e1412. doi:10.1016/j.jpeds.2015.02.065