



'You've Just Got to Crack on with it': A Qualitative Study of Parents' Perceptions One Year after Very Preterm Birth

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Abstract

Background: Qualitative studies have explored parents' experiences of having a preterm baby; however these commonly focused on parent's recent experiences of neonatal unit care and the early months immediately following discharge home.

Objectives: To describe parents' experiences and perceptions of their very preterm child's development, adaptation to family life during the first year and the impact of early information-giving about their child's prognosis.

Methods, setting, participant: This study was part of a program of research that included a trial and follow-up of babies born before 33 weeks gestation and their parents. Using purposive sampling methods, telephone interviews were conducted with 30 parents one year after preterm birth. A topic guide ensured a consistent approach. With parental consent, the interviews were audio-recorded enabling verbatim transcription. Qualitative analysis using NVivo 10 identified emerging themes and associated sub-themes.

Results: Two over-arching themes were identified; 'facing the future' which focused on current perceptions of the prognostic information parents had received early on, with three key themes: 'anticipating the scan result', 'hearing the prognoses' and 'relief and concern'. The second over-arching theme 'looking back from now' focused on parental perceptions one year on, with four key themes: 'Being in the neonatal unit', 'how it affected us', 'Needing information and support', and 'The child we have now'.

Conclusion: The one year interviews provided insights about the impact of preterm birth and the ways in which families of infants born at 26 to 32 weeks gestation adjust, cope with a child's developmental and specific needs and in the process, adapt to the baby they now have. They also show just how early prognostic information-giving can have a lasting and profound effect on parents.

Keywords: Parents; Preterm; MRI; Ultrasound; Developmental prognosis; Information-giving

Background

Qualitative studies have explored parents' experiences of having a preterm baby. However, these have commonly focused on care in the neonatal unit care and shortly after discharge home [1-6]. During the early weeks of their child's life, the main focus for parents is on their child's likely survival, on-going problems and becoming familiar with caring for a child who was born prematurely [7-9].

Studies exploring the longer term impact on parents of preterm birth have generally been quantitative in approach [10-13]. These have shown the consequences of preterm birth for parental stress and distress [11-15], with the time immediately following the birth usually being the most stressful [13,16], though some effects were evident later in the first year. Parents of infants born at lower gestational ages and lower birth weights report more stress and some differences in the stress responses of mothers and fathers have been described [17]. A longer term quantitative study has shown a correlation between parental stress and their child's cognitive outcome, though this was not associated with prematurity, but rather with disability [18]. Few studies have explored perceptions and parenting experiences qualitatively beyond the early months following preterm birth [19], and no studies have been identified which have reflected on parents experiences of the impact of earlier

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prognostic information given during the neonatal period.

The objective with this study was to better understand the impact of early preterm birth, of the prognostic information arising from ultrasound and magnetic resonance imaging about possible developmental outcomes and to describe their experience during the first year. The timing of the interviews just over a year after the birth enabled parents to reflect back on the experience of getting to know their preterm baby, the information received and their own adaptation to family life following preterm birth.

Method

This study was a component of a larger program of research that included a trial in which parents of babies born at less than 33 weeks gestation were randomized to receive prognostic information at term based upon either MRI or ultrasound brain imaging (ePrime study) [20]. Following randomization parents received information based upon their individual baby's scan [21]. Parents and babies were recruited to the ePrime study whilst being cared for in one of 13 neonatal units in the London area. Families were followed up with standard measures at four time points and a full developmental assessment at 20 to 24 months corrected age.

When consenting to the main study parents were also invited to consent to being contacted and possibly taking part in a one year telephone interview. It was recognized and planned that both qualitative data on parents own perspectives should be collected, a total of 350 of the 434 'family units' (mothers and fathers or single parents) in the ePrime program consented (80%). Parental consent for interview was reaffirmed by research nurses during the contact maintained through the first year. Initially a random table of all parents who had given their consent to the interview was used in selecting the parents to contact. Towards the end of interview data collection, purposive sampling was used to ensure diversity within the sample of 30 parents [22].

In this qualitative component of the program, thirty audio-recorded telephone interviews were conducted with parents around the time of their child's first birthday. The topic guide was informed by data collection in earlier components of the main program and earlier studies of parental experiences of preterm birth [1,2,7,23], and ensured key issues were discussed. In line with qualitative methods, the structure of each interview was determined by participant responses. Whilst all interviews were slightly different, the same broad topics were addressed: What parents remembered of information-giving, the child's health and development over the first year, sources of support and impact on family life and parental health. Audio-recordings enabled full verbatim transcription. The sample size was chosen for practical reasons in planning the whole work program [24].

Recruitment, data collection and preliminary analysis were undertaken concurrently. Initial analysis was undertaken using 'NVivo 10' by one researcher. The text was coded and themes identified. No attempt was made to reach saturation [25]. Following analysis of a subset of transcribed interviews by a second researcher the coding was reviewed and amended in an iterative manner by both researchers until the final themes were agreed [26,27].

Results

A total of 30 individual interviews were carried out with parents one year after the birth. Attempts were made to contact 44 parents:

Table 1: Participant characteristics.

Participant characteristics		
Gender n=30	Mothers	25
	Fathers	5
Parents age (years) n=30	Median	34
	Range	21-52
Previous children n=30	Yes	14
	No	16
Partnership status n=30	Lives with partner	28
	Does not live with partner	2
Ethnicity n=28	White	22
	Black and Minority Ethnic	6
Left education n=29	Age 16 years or less	6
	Age over 16 years	23
Employment n=30	Paid work	18
	Looking after family	10
	In education	2

One parent declined participation and unsuccessful attempts were made to set up interviews with 9 mothers and 4 fathers. A total of 25 mothers and 5 fathers were interviewed (Table 1). They were between 21 and 52 years of age and were from a range of ethnic backgrounds. The interviews concerned 35 babies (16 boys, 19 girls) including four sets of twins and one of triplets (both the mother and father of one set of twins were interviewed). The babies were born between 26+1 and 32+5 weeks gestation. At the time of the interview the babies were 11 to 17 months corrected age (median 13 months). The interview sample consisted of equal numbers of parents who had received either US or MRI based information. Interviews ranged between 14 min and 39 min (median 25 min) in duration and were arranged at time convenient to the participants including evenings.

Three parents of singletons who received MRI results were given abnormal results. Two had anticipated this and for one the result was unexpected. All parents given US results were received normal results. The overarching and key themes identified are listed (Table 2) and verbatim extracts from the interviews used for illustration. Interview extracts indicate participant number and Father (F) or Mother (M) giving response.

Facing the future

From the perspective of the early days, most parents felt being given information early on, following the birth of their preterm baby was likely to be beneficial. Three key themes were identified within this over-arching theme, based on what parents had hoped at the time, hearing the details of the prognosis and how they felt following the information received.

Anticipating the scan result

Prior to the scanning appointment at term age most parents had hoped to receive the MRI result, however, some had been concerned that the detail provided by this type of scan could reveal unanticipated problems. Overall, they had hoped that the scan, MRI or US, would be normal.

M1515/1521: '...they'd done various tests while the kids were in hospital, I think I would have been surprised if they'd told us they'd picked up something at that point.'

Table 2: Themes identified in parent interviews at one year.

Over-arching themes	Key themes	Illustrative quotations
Facing the future	Anticipating scan results	'we thought let's see what comes back.... so there might be a little bit of something wrong'
	Hearing the prognosis	'I found it really difficult to comprehend because (of) the parameters of what they gave us'
	Relief and concern	'I was obviously shocked and upset at what was said....I think that's quite difficult to digest.'
Looking back from now	Being in the neonatal unit	'They're fantastic. We can't complain, both my husband and I, we're so impressed with what they do'
	How it affected us	'I think it was the feeling of, is she actually going to wake up in the morning?'
		'But then my husband rightly said we've got our little boy, we've got to crack on otherwise you won't get this time again'
		'It's full-on. He was a rubbish sleeper for about the first 8 months and he slept in with me... I've been... much more protective of him. It probably sounds awful, but I just didn't want to let him go. I think I was really worried about us not having a bond'
	Needing Information and support	'He was the consultant we saw when he was in hospital. I feel like I know him and I trust his opinion'
		'The GP [Family doctor] has experience in special care babies. So certainly in the early stages of seeing, of him being home... I felt very comfortable.'
The child we have now	'At the beginning yes, we looked on the Internet... but after that, we were just looking at her and she was fine and I don't want to be worried about the information'	
	'He's scrumptious ((laughs)). He's fine.'	
	'We don't really think about them being preterm babies any more. We do just really consider them to be normal, healthy little boys.'	
		'We had no expectation that we'd have a child who could sit, talk, feed himself or learn to walk; or doing anything. And he's so normal; it's just an absolute, absolute delight.'

A few had been aware from their time in the neonatal unit that their baby had experienced a cerebral bleed and therefore had thought they might be given an abnormal result. The possible findings were now framed in terms of the developing relationship with their baby.

F2035: 'Well, we don't know, we thought, let's see what comes back.... so there might be a little bit of something wrong but we thought, let's see what happens, you know. It isn't going to make us love him any less.'

Hearing the prognosis

The parents talked about the scan findings and predicted outcome they had been given for their baby twelve months earlier. They remembered which result they were given, most were able to summarize the findings and remember the kind of images they were shown and how the risk information was given:

F1358: 'Oh yes, we were given the ultrasound and we were told that it was fine and we were told of the fact that it reduced the risk of anything concerning development-wise from, I can't remember what the figures were, but it reduced it.'

M1554: '...She explained everything in quite a lot of detail about what she'd found and the implications of that for our child and then also the long-term implications, what could still arise despite what the scan showed.... We came away feeling like we'd got useful information.'

Some had found the information confusing and difficult to relate to their baby at the time. Specific comments were made about complex terminology, alarming statistics and superfluous information:

M1017: 'I found it really difficult to comprehend because the parameters of what they gave us, I think it was between about 19 and 80% chances of having significant problems. That's such a HUGE parameter and the problems varying so much between like, you know clumsiness and cerebral palsy.'

One concerned mother described how she had looked up information on the internet on the journey home to better understand what she had just been told:

M2345: 'One thing I do remember quite vividly is sitting in the taxi going away from the hospital and actually googling cerebral palsy because I didn't actually really understand what it was. I wanted to see what it actually meant.'

Relief and concern

Parents talked at length about the immediate impact of information they were given at the scanning appointment. The majority, who had received a normal result following MRI, talked of a 'massive relief, being pleased, happy, reassured and encouraged. Those with a normal US result, whilst similarly pleased, in some instances referenced earlier neonatal cerebral scans:

M1156: 'I think to be honest, again, because we'd had ultrasound results explained to us before, it was, you know, it was kind of, there was nothing new that came out of the result. It was just all very, I hate to use the word 'standard', but it was something that we'd been introduced to before, so it wasn't unfamiliar to us.'

For a few parents, the scan presented an abnormal result and one mother questioned whether it would have been better not to have known.

M2345: '... I think the feeling that I came away with was I don't know what to do with this information. I don't know where to go with this, what are we supposed to do? And it was a bit of a shock really.... When we left there, I felt happy with participating It was very thorough but I think afterwards we just came away kind of regretting doing it.'

Another felt it colored her experience of being a parent and how she saw her child's development:

M2345: '... many times I've thought I wish I didn't have that information, it's best not to know, because I'm always on the look-out for something and basically I've been told from a lot of people that there isn't actually anything you can do if she has cerebral palsy. All you can do is trying and support her... I have thought, because there were times, when there weren't any physical, any visible signs, that we could have maybe had a less stressful time. I know that's a bit burying you're head in the sands but it would have been nice not to have had

it always in my head.’

For another mother the abnormal result had been quite unexpected:

M1017: ‘I was obviously shocked and upset at what was said..... I think that’s quite difficult to digest... like the actual little bit of brain damage, that absolutely freaked me out completely... like obviously he was my baby, but he was this tiny, teeny thing that I hadn’t known very long. And then now, you know, he’s my little boy. But at the time it was really difficult to get my head round...’

The difficulty of making sense of the information given and of coming to terms with what had been learned had been hard for some. The immediate impact of what parents were told early on and the realities of then caring for their small preterm infant and their now older growing baby were emphasized.

Looking back from now

The second overarching theme ‘Looking back from now’ with four key themes arises from parents considering their baby’s initial care, what had happened in the intervening time period and how they now felt about it.

Being in the neonatal unit

Reflections on the first year with their child often involved starting with parents’ experience of the Neonatal Unit (NNU). They had no difficulty remembering their baby’s stay and care, recalling their worries, concerns and fears at the time, particularly about their child’s survival.

F1130: ‘She had a very rough start. For the first four or five months, you know, she was quite poorly. So yeah, we were very worried. We were very worried about what the future would hold for her’.

Many parents said they had received exceptional care and some remembered being given general information about the possibility of long term health and neurodevelopmental problems. However, none could recall being given precise information predicting outcomes specifically applied to their child:

M1365: ‘At the very, very beginning when she was born. The consultant at X ((hospital)) went through the risks of premature babies, so we knew there was a chance of it, but nobody said she’s got it or she hasn’t’.

Some were grateful for the way in which neonatal staff had focused on the present rather than the future:

M3475: ‘They didn’t talk about it at all in the neonatal unit. They’re very positive there. They don’t like to focus on anything that may go wrong later on. They like to focus on what’s happening now and I think that really did help because I think when you’re in there you really have enough to worry about. You don’t want to be thinking about in two years, three years’ time, what’s going to happen.’

How it affected us

During the interviews, parents described the impact of having a preterm baby on themselves and the wider family and of the information received. They also described becoming a parent and the challenges that were complicated by preterm birth. Some were experienced parents and although their other children had been born at term, felt the earlier parenting experiences had helped them to cope with preterm parenthood. Some were parents of twins or triplets and the difficulties they faced were felt to be even greater if they were also

first time parents.

Parents talked about developing an attachment with and learning to care for their child, adapting to changes of roles and responsibilities, trying to be a ‘good’ parent, avoiding being over-protective and rebuilding their self-worth. Whilst a few said it had been easier than they had anticipated, most talked about the hard work, exhaustion, coping with their own emotions and getting through the ‘ups and downs’. The first few months following discharge from the NNU were felt to be the most difficult.

M1619: ‘It’s full-on. He was a rubbish sleeper for about the first 8 months and he slept in with me. So I definitely found I’ve been... much more protective of him. It probably sounds awful, but I just didn’t want to let him go. I think I was really worried about us not having a bond or as strong a bond, because obviously I couldn’t hold him when he was in intensive care, which was only for 5 days, but I was really paranoid about that.’

F2047-2059: ‘I think for me, it’s the lack of me-time. Because we don’t have support here, it’s just the two of us. So for the most part, that’s been the difficult part. It’s like you can never go anywhere, you’re bound to them always.’

For many new parents the vulnerability of their baby and the responsibilities they felt was almost overwhelming:

F1358: ‘I think the fact that when she came home...she was a vulnerable patient rather than a baby... she had to be kept away from other children so we couldn’t really do very much. Her temperature had to be 36.5; I still remember the figures ((laughs))..., that was the most difficult bit. Not being able to turn your back for a second really. I think without having previous children, it was really difficult to work out what’s normal... It takes quite a long time for that to settle down... with 1358, if the neonatal unit hadn’t put so much effort into looking after her and keeping her alive and they’d done such a good job and suddenly the responsibility was on us and that felt quite enormous at times. But we’ve done it.’

However, looking back over the first year there was clearly satisfaction and enjoyment:

M2047-2059: ‘I’ve thoroughly enjoyed it, although there’s been time when we’ve been absolutely exhausted and there have been a few times when I’ve been on my own and it’s all got a bit much.’

M1017 ‘I’ve always wanted to have children and I think that I’m good at it ((laughs)). I really enjoy spending time with him, especially now, he’s hilarious. I really enjoy being with him and I’m really lucky that I work three days a week so that I can spend extra time with him.’

M2094: ‘I think she was quite an easy baby looking back... As long as I’ve got a regular routine I’ve managed it quite well. I don’t think there’s anything that’s been difficult with her.’

In addition to coping with preterm birth and the care of their child over the preceding year, many parents had also coped with their own health problems and other major life events affecting the family. For some mothers health problems were associated with at-risk pregnancy and childbirth. Other major life events included family bereavements, problems at work and moving home.

In talking about the impact on the family of having a preterm baby and their child’s first year of life many parents described the positive emotional impact.

M1017: 'He's the first one in both sides of the family, first grandchild, so he is like a big deal and it has brought both sides of the family together.'

In some families parents reported that their experiences of preterm birth had caused their relatives and close friends to worry more during their own pregnancies. Those with other children spoke specifically about the effects, with some siblings becoming involved in the child's care and others receiving less attention as the focus had shifted.

M2583: 'They're absolutely fantastic with him. Yes, brilliant. I mean from the minute 1, obviously he was premature, I was in hospital for quite a while and my older girl who is now 12, said 'Mummy I just can't go and see him because he's just far too little.' So I said, well that's fine, wait until he comes home'... you should see them now, it's like they're the mummy and he's the baby, they can't do enough for him.'

M1619: 'I think that did temporarily affect my relationship with my daughter ((sibling)). She always has been, but very much became a daddy's girl. Which I think I will always feel a bit guilty about.'

Parents also talked about the longer term impact of early information and how they had felt. Those who received a normal result found it reassuring, saying it enabled them to accept that their child was well and to plan for the future. Parents who had received a more problematic report now indicated that coping had become easier over time and that to them, the baby's survival was the most important thing. These parents talked about having found a way of moving forward:

M1017: 'I think for a little while, for the first couple of weeks, I had probably one of the worst weeks of my life when I had that information because I just completely freaked out.... But then my husband rightly said we've got our little boy, we've got to crack on otherwise you won't get this time again, you know, we'll never have a 7 week old baby again. You've just got to crack on with it. And I think that really helped..... having a young baby is probably the best thing in the world to make you not think about things like that, because you've got them there and they're little and demanding.... You can't sit and wonder and worry because you've just got to get on with things and look after him and make things good for him.'

Needing information and support

A large proportion of the one year interviews were spent discussing the information and support parents had accessed over the preceding year. This included input from health care professionals, family, friends, support and service user groups and using the internet. Overall they felt neonatologists gave them the most useful and detailed information at follow-up appointments, trusting their judgment and feeling able to ask questions. In their discussions with parents, these clinicians were felt to be positive and upbeat, irrespective of situations where longer term problems were becoming apparent.

M1017: 'I see Dr X ((neonatologist)) every, it used to be every three months, now it's every six months. He was the consultant we saw when he was in hospital. I feel like I know him and I trust his opinion...'

By the time of the one year interviews some babies had been discharged from neonatal follow-up, and in seeing different clinicians a few parents felt the information they received was less helpful,

possibly because the individual they then saw did not seem to know about the baby.

M1515/1521: I don't know how far back they actually look when you see them. I don't get the impression that them always seem to know what's happened to them.

Some babies had been referred for on-going care to other health care professionals such as physiotherapists, audiologists and developmental specialists. Parents were overwhelmingly positive about these specialists the diversity of which reflected their child's needs, saying they gave them guidance and detailed, open and honest information about their baby and his or her problems.

F2035: '...we've got a string of doctors for everything because of the prematurity and the hearing. You know, we're all over the place really. We've got a full schedule. The diary is full up to the brim' ((laughs)).

M1554: 'And there's also physiotherapy they've been wonderful and his movement is ok and he's keeping up with his milestones. There's a few little things and so she's helping us to do exercises for that.'

M2345: '...we have a fortnightly visit from the Portage nurse. Although she really comes to support 2345 with her development... she is very supportive to me as well, and I'm finding that really helpful in a practical sense.'

Parents had more mixed views about the routine community follow-up provided by general practitioners (family doctors), community neonatal nurses and health visitors (community and public health nurses). Several mentioned a lack of support from health visitors and described their poor understanding of the needs of families following preterm birth.

M1554: Our health visitor's been wonderful, she's come to the house and stuff but the information she's offered me, has been limited. My general knowledge exceeds that and my common sense had worked it out, long before someone had told me.

General practitioners were generally regarded positively and families particularly valued the continuity of care, particularly from those who had insight to the problems associated with prematurity.

M1156: 'the person I mainly see, is actually, the GP, has experience in special care babies. So certainly in the early stages of seeing, of him being home... I felt very comfortable and she understood the overall thing and not just seeing this baby who was you know, one month old or two months old or whatever... she's seen him from teeny tiny.'

Parents with a child requiring support from a range of specialists spoke about facing a number of challenges. In some instances, different specialists gave contradictory information; however, in other cases seeing a range of health care professionals enabled parents to fill the gaps in their own knowledge. Some families had moved in the interim, a few experiencing a delay in the transfer of medical notes and difficulty in accessing support in the new setting. Conversely one mother felt the family was receiving better support in the new location.

M2345: All of this support has happened since we moved... now that we're out of London it feels as though there's not so much pressure on the professionals. We're getting appointments very quickly, so we're actually quite inclined to stay here for a while. We don't want to rock the boat really.'

Most parents talked positively about the support that they received from friends and family during this year. Sharing common experiences with friends and family was beneficial emotionally and the help received, which sometimes included supporting the child's specific needs, was valued.

M1435: 'My friend gave birth in the February, she had twins. One of which she lost, he had a hole in the heart. But they were very small and I spoke to her a lot. We sort of cried on each other's shoulders So I've shared my experiences with her, talked to her.'

Family and friends who were health care professionals were able to clarify information parents had previously been given:

M1017: 'A couple of my friends, well one of them is a nurse at X ((hospital)) and one of them's a doctor and I was talking to them about it... My friend who's a doctor, I've known her all my life and for her to go through it all with me, it's easier.'

However, some parents felt relatives and friends did not fully understand the challenges and difficulties associated with prematurity and felt very protective of their child.

M3475: 'Friends and family don't know. And it's so frustrating. Oh goodness me. My mum says; why isn't he walking yet? Why's he not getting any teeth yet? You were walking at 10 months, mum, he's not actually 10 months yet. He's only been out of hospital for a few months Give him a chance. It's so annoying, and you have to keep on pulling people up.'

Mixed views were held about the usefulness of information obtained online. Some parents found it helpful and accessed information *via* specialist websites and chat-forums. Others parents felt they needed to filter the information on the Internet, with some feeling that information obtained had escalated their worries and concerns.

M2268: 'At the beginning yes, we looked on the Internet. I tried to look for some information, but after that, we were just looking at her and she was fine and I don't want to be worried about the information. Sometimes it's only people unfortunately with very bad stories or it's not truthful.'

M3505: 'I did at the beginning, you know, when she was still in hospital and when maybe she had first come out. I did quite a lot of 'Googling' but in a way, I didn't find it that useful and I could almost just see myself getting really worked up.'

Sharing experiences with other families who understood their situation and accessing specific information and advice was thought to be helpful. However, it was difficult to locate groups specifically for children who had been born preterm. Conversely, other parents had deliberately avoided accessing such groups, wanting 'to move on' and focus on the future.

M3088: 'I see some mothers at the clinic but it was such an awful period in my life I don't really want to be reminded of that by being with other mothers of preterm babies or reading stuff on the Internet. And also 3088 was one of the kind of success stories whereas other people have had problems....You don't want to parade your very healthy baby.'

The child we have now

Parents talked specifically about their child, reflecting on their experience as a parent, their child's personality and health and

development over the previous year.

Almost all the children had experienced some sort of health problem including a need for surgery, chronic lung disease, reflux and developmental delay. Parents often commented on the impact of these problems on their baby, themselves and the family more generally. Although it was clear that several children had a range of serious problems, parents were generally positive about their progress and were optimistic about the future.

M1017: 'It feels like I'm at X ((hospital)) a lot and I think like I felt, because he was in there 3 weeks when he came, that I begrudge having to be at the hospital now. I'd just rather not ((laughs)).'

M2268: 'In the beginning she was suffering from bad reflux. So the first three months, she was crying day and night. It was long time before we finally found what it was.'

M3475: 'He's absolutely wonderful. He's had one or two little hiccups when he's had to go back into hospital... So he's had to have things like an inhaler... But he's doing really well now. He's off all of the medication and he hasn't had to go back to the hospital for the last four months or so.'

Parents were asked to describe their child now in a few words. The phrases and adjectives they used included: 'scrumptious', 'delightful', 'great', 'fantastic', 'wonderful', 'relaxed', 'happy', 'calm', 'sociable', 'strong', 'perfect', 'normal', 'healthy', 'outgoing', 'active', 'easy', and 'a fighter'. A few parental responses were not quite so unequivocally positive and included: 'attention-seeking', 'small', 'cautious' and 'loud'.

M1156: 'You know, he's a little charmer to be honest ((laughs)). I know I'm biased.'

M2106-2144-2131: 'They've been very good actually. I must say they were really quite content kids and they are very good.'

M1447-1459: 'They kind of keep swapping really, to start with, one was kind of much more out-going and less timid and that was 1447 the bigger one; whereas now, he's much more cautious and 1459 is absolutely fearless and you can't turn your back with him.'

Parents had differing views on the extent to which they continued to focus on the fact that their child was born preterm. Some still thought of their child as an ex-preterm baby and to some extent this was reiterated by health care professionals who continued to distinguish between actual and corrected age. There was a lack of clarity for some, though not all parents, about when adjustment for prematurity should stop:

M1105: I was told once he passes the first year, he's no more considered as premature.

F1358: Yes, everything's done on her corrected age other than her vaccines ... that's taken into account and that's slightly odd because her contemporaries are born after her but are in fact two months ahead of her developmentally

M1515/1521: We went to see the health visitor the other day and she said that they will keep adjusting until they're about aged 2.'

In talking about their child now, many parents focused on development. For some it was a sensitive issue and apparent delay was associated with a need to correct for prematurity:

M3505: 'I said to my husband I've got to stop saying it. Whenever

anyone asks me how old she is, I always caveat it with oh, she was early, so she's actually. No, I'd hate anyone to judge her and think, oh, she's not walking or whatever. No, I'm always a bit protective and quite defensive which I probably shouldn't be. But I mean certainly my parents will always comment on, oh, she's doing well given that she's not really one yet.'

Most parents felt their child was either progressing as they should be or was slightly behind and almost all felt their child would soon 'catch up.' One parent for whom developmental delay was predicted at the scanning appointment commented on the extent of their child's current delay and was philosophical about the future and others, despite extensive delay nevertheless tried to be optimistic about the future.

M2345: Well I think generally in herself, she a very, very happy, a contented baby. Her physical development seems to be where the delay is and the pediatrician suspects that she has increased muscle tone in her legs and in her arms At the moment, she's not fully sitting independently yet. We're working on building up her strength around her stomach area. She's on the verge of crawling..., as for her walking; I have no idea when or if that's going to happen.

M107: 'He's just so relaxed, that's his problem ((laughs)). He's like his dad; he'll do it in his own time. He's just really happy doing whatever he's doing.'

Although parents tried not compare their child with those of friends and family or older siblings, this was often inevitable, particularly when comments were made by other people.

M1554: 'I do watch what other children are doing developmentally just to see if he's kind of doing similar things but I'm also not losing sleep if he's not. This is something we're just going to have to wait for...whereas other parents whose children were born at term, there's more, not in a horrible sense, competition, but are we in the right place? We're never going to be quite there so that's that.'

When asked what had been the most challenging or worrying aspect of the previous year, many parents spoke about coping with specific health problems that were related to their baby's preterm birth. They also talked about difficulties commonly associated with caring for any baby or toddler such as weaning and coping with tantrums. Parents with twins and triplets talked about trying to establish a routine and coping day-to-day with one parent describing this as 'fire-fighting.' For some returning to work or trying to run a business presented additional challenges. However, worries primarily focused on coping with their child's health problems and long term neurodevelopmental outcomes.

M3475: '... we were so scared for the first nine months. We just thought when we put him down to sleep is he going to die on us? So we had no sleep and when we were, we were sleeping in shifts so one of us stayed up and watched him. That was very difficult.'

M2345: 'It's actually been the unknown, not knowing exactly how she's going to be. Because at the end of the day the difficulties that she's got, you know, not crawling.... But really the main challenge has just been that feeling of is she going to be delayed walking? Is she going to walk at all? We've had to prepare ourselves for the fact that she might not be walking for years. Because you worry, but there's nothing that you can do. You've can only wait.'

Parents were also asked what had been the best aspect of

the previous year. All talked extensively and warmly about their experiences, often mentioning significant events such as bringing their child home from hospital or developmental milestones such as sitting, crawling or walking. Parents commented on family events such as christenings, birthdays and Christmas and getting responses from their child such as a smile, a kiss or a cuddle. They also talked about seeing their child's personality develop and the social interaction with siblings. Almost all of the best things focused on the child and many parents used the phrase 'just having him'. However, a few spoke more profoundly saying the best thing was that their child was alive and one mother said it was simply letting go of some of that fear' M3370.

M1365: 'Bringing her home. Bringing her home from special care was the best thing. Walking in with the car seat and thinking, it's our turn now; definitely bringing her home.'

F1358: 'Now she's just, you know, all over the place, into everything, communicating and all the rest of it and she's great fun. She's very rarely upset. She smiles at everyone and she's very playful and I think that's been the best bit really.'

M1554: 'The fact that my child's alive. The fact that I've got a child who is alive is the most important thing, but the fact that he's even vaguely normal. I mean, wow. We had no expectation that we'd have a child who could sit, talk, feed him or learn to walk; or doing anything. And he's so normal; it's just an absolute, absolute delight. I have to say, I wake up and I am grateful every day.'

Discussion

The one year interviews provided an opportunity to hear directly from parents in their own words about what was important to them following the very preterm birth of their baby or babies. The retrospective reports and reflections go beyond parents' initial reactions to the early birth and immediate needs and care of their baby. Thus the interview data provide insights on the longer term impact of having a baby or babies born at less than 33 weeks gestation and the ways in which parents and families adjusted over this first year and dealt with their children's specific needs.

The data collected and analyzed reflect the stories of their babies in the language and phrasing used and the themes identified, presenting individual perspectives and key issues more broadly. Parents had no difficulty recalling their experiences over the previous year and clearly enjoyed talking about their child. Overall, the most emotionally challenging times for parents had been when the baby was cared for in the NNU and during the first few months after taking the baby home. This finding concurs with that of other studies [6-9]. These challenges were intensified for some parents by having twins, triplets or subsequent bereavement. That their early feelings and reactions were so well remembered is indicative of the power and marked impact of this aspect of their experience [4], is in accord with other studies [1,9,13].

Parents described the experience of how they faced up to the possible future, projecting forward. At the same time the focus of the immediate months following their baby's discharge home was on getting to know and learning to care for their baby. Whilst they enjoyed this period of time, the impact on themselves and the wider family is evident. Nevertheless, in looking back parents were mostly positive about the first year, enjoying interactions with their babies and developmental progression, even when recalling difficult situations. The fatigue and exhaustion experienced by parents following preterm

birth and care of infants with health problems is more common, but in nature is similar to that of parents of term infants [28].

For the study parents being given a 'normal' US or MRI result of term age scans was reassuring. However, their interpretation of the information received appears relatively simplistic, as has been described in studies of information-giving in other aspects of perinatal care [21,29,30]. On reflection for some parents, they felt that while they were provided with additional information, following the term scans, this did not always feel beneficial to them in their new parental role.

Strengths and Limitations

Interviewing parents one year after their baby's preterm birth enabled recording of reflections on their earlier experience and the impact over the preceding year. Few studies have followed up parents of preterm in this way and almost all of the mothers and fathers who were contacted directly agreed to be interviewed, including some whose babies had been found to have an abnormal scan or had ongoing complex physical and developmental problems.

Telephone rather than face-to-face interviews were conducted and while this can present some logistical challenges such as overlapping speech or lack of information about non-verbal cues speech [31,32], this method proved to be an effective and practical way of collecting data causing minimal disruption to the participants. This is an increasingly utilized method of data collection [33,34], which has been successfully employed in studies of challenging and sensitive topics [35-37]. The method also precluded the need for the parent or researcher travel, enabled flexibility and convenience on timing, and was potentially less intrusive for participants [31,32].

The participant group was relatively diverse, though it is acknowledged that fathers were less well represented in this group than was intended, though some mothers felt they were speaking for both parents. Efforts were made to address this imbalance with the later two year interviews.

Conclusion

This study adds to the body of knowledge about parents' experiences beyond the early months following preterm birth. The data from the one year interviews provide a more individual perspective, than survey based data. The evidence presented suggests that at this time parents are adapting to the baby they have, largely focusing on the present. The findings also show the differing sources of information and support parents accessed over the first year and emphasize that early prognostic information-giving can have a lasting and profound effect on families. The parents' reflections on their experiences highlight the challenges that clinicians face when endeavoring to give parents accurate information in a way that can be understood. Use of the themes identified and parents own words may influence clinicians in their practice and could potentially contribute to effective dissemination of the wider program findings in the NHS context.

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