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# Qualitative interview with mothers of moderately or late preterm infants in the UK: where are the care gaps?

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## ABSTRACT

**Introduction** Preterm birth (<37 gestational weeks) accounts for an increasing proportion of global births each year, with moderately or late preterm birth (MLPT) ($32^{+0/7}$–$36^{+6/7}$ gestational weeks) comprising over 80% of all preterm births. Despite the frequency, MLPT births represent only a small fraction of prematurity research, with research exploring the parental experiences of having a child born MLPT particularly neglected. It is vital this perspective is considered to provide appropriate grounding for future research and service provision.

**Methods** Six mothers from the UK of infants (aged between 18 and 36 months) born MLPT were invited to take part in a semistructured qualitative interview study. Reflexive thematic analysis was employed to explore the data and codes were then conceptualised through a process of inductive reasoning to identify patterns of meaning.

**Results** Five themes are presented that are conceptualised from the data: (1) the moderate or later preterm 'label—does it matter?, (2) vulnerability within a new role, (3) coming home and wanting to start 'normal' life, (4) comparisons to provide a reference to experiences and (5) experience of professionals throughout the pregnancy, newborn and early years journey.

**Conclusions** Findings offer in-depth evidence surrounding mothers' experiences of healthcare throughout pregnancy and immediately after birth, perceptions of the 'preterm' label and thoughts on how mothers reflect on their experiences. Future research should show an awareness of the broader family context when interpreting findings and providing suggestions for future research avenues or service provision.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Semistructured interviews allowed for an in-depth consideration of mothers' perspectives on pregnancy, birth and parenthood.
- ⇒ Participants were from a range of geographical locations across the UK, and therefore, able to comment on individual experiences across a range of healthcare facilities.
- ⇒ The remote context of the current study may have excluded participants without the technological facilities to participate.
- ⇒ Participants were asked to recall details over an extensive period of time which may have impacted the accuracy of their experiences.
- ⇒ Conclusions from the current study are representative of mothers' experiences only, further research considering fathers' perspectives is necessary.

## INTRODUCTION

Preterm birth is defined as birth at a gestational age of less than 37 weeks[1] and accounts for 15 million births worldwide each year.[2] Prematurity presents unique medical risks to both mother and baby, being the leading cause of childhood mortality worldwide, with heightened risk of poorer outcomes in less economically developed countries.[3] Despite this, little is known about the experiences and perspectives on mothers*[4] who have a child born preterm, both immediately after birth and over the first few years of life. (*This manuscript acknowledges the widening debate around the correct use of language in the maternity context and the importance of adopting terminology that is representative of all family contexts. Given the infancy of these discussions the terms 'mother' and 'woman' are used throughout in line with current maternal and health carehealthcare policy.[4] We recognise the need for future research to consider wider parental perspectives to expand on those solely of mothers presented here.)

Babies born between $32^{+0/7}$ and $36^{+6/7}$ weeks gestation are classified as moderately or late preterm (MLPT) and comprise 84% of all preterm births.[5] Within the UK, current governing bodies detail extensive guidance on the degree and depth of medical information that should be offered to those at greatest risk of preterm birth.[6] Guidance details the prevalence and subsequent likelihood of various outcomes and specifies those for whom enhanced developmental surveillance and support are necessary (primarily those born <30 weeks). Though the majority of preterm births are MLPT, immediate medical need is often considerably less compared with those born at earlier gestations and those born MLPT are not likely to receive any additional medical or neurodevelopmental follow-up as a result of preterm birth, either in the immediate or long term. The historic prevailing narrative has, therefore, been that being born MLPT was commensurate to being born at term.[7] However, research over the past decade has highlighted that although immediate medical risk may be less pronounced, there are downstream neurodevelopmental differences in those born MLPT compared with their term peers.[8]

The consideration of parents' experiences is vital to ensure that research findings are relevant to the lives of families with a child born MLPT.[9] Research highlights a misalignment in knowledge of preterm birth between parents and clinicians; despite many parents noting a desire to have had prior conversations about preterm birth, clinicians disclose the outcomes of preterm birth only selectively, citing fear of negative reaction as one of numerous reasons to withhold information.[10] It is vital that more is understood about both maternal experiences of preterm birth and maternal understanding about outcomes following preterm birth. Given the intertwined nature of preterm birth and parental experience, further understanding is not only warranted but vital when considering suggestions to improve outcomes.

The potential disruption to the process of bonding with a newborn is one putative downstream consequence of preterm birth that it is important to consider.[11] Given the bonding process between a mother and baby is suggested to begin in the first trimester and extend past the baby's birth,[12] it is unsurprising that this is impacted as a result of early birth. Concomitant with the process of bonding is the consideration of self-efficacy, defined as the perception of one's ability to execute behaviours, noted to heavily affect the process of bonding.[13] Within the context of development, self-efficacy may reflect a parent's ability to facilitate a child's development through control of their environment[14] and is influenced by infant characteristics, educational status and maternal depression.[15] Spending periods of time away from a newborn infant for reasons such as an extended stay in neonatal care facilities[16] or restrictions on parental visiting in hospital settings as seen during the COVID-19 pandemic[17] can impact self-efficacy and the development of bonding. Systems that support the development of self-efficacy and in turn the process of bonding may be necessary as standard practice in postnatal clinical care and warrant exploration in mothers of MLPT infants.

There is an emerging body of research that employs qualitative interviews with parents of preterm born children to detail descriptions of satisfaction of care,[18] first moments with a preterm newborn[19] and feeding behaviours.[20] Yet, these studies have focused solely on those born extremely or very preterm, often excluding those born MLPT. The small pool of MLPT qualitative research that exists highlights that parents of late preterm infants feel unprepared to take their newborns home and liken their medical treatment to that of term-born babies.[21] Wider exploration of research priorities for parents of preterm children highlights the requirement for additional information throughout pregnancy[22] and regarding later cognitive and developmental outcomes.[23] Similarly, when collating interviews with parents of individuals born extremely and moderately preterm, research highlights some broad similarities in parental experiences, yet clinical differences in treatment as staff fail to recognise the need for support among those born closer to term.[24] A clear documentation of the context of MLPT birth and the experiences of parents is vital to allow for the provision of adequate support.

Further understanding of parental experiences and opinions regarding MLPT birth is necessary to ensure that the needs of the majority of preterm infants and their parents are being met. Alongside this, early intervention and surveillance programmes are also targeted towards those born at the earliest gestations, despite the emerging need of those born MLPT.

The current study, therefore, aims to:

1. Describe the experiences of mothers of children born MLPT.
2. Explore support experiences and consider whether these are adequate in relation to mothers' perceived needs.

## METHODS

### Design, setting and participants

This qualitative study was conducted remotely between April 2021 and November 2021. Participants were eligible for the current study if they (1) were living in the UK, (2) were the parent or main caregiver of an infant born MPLT who was (3) aged between 18 and 36 months at the time of interview. The volunteer community sample was recruited via social media and research databases comprised of eligible families that had either expressed an interest to participate in research or had previously participated in research and consented to future contact.

### Interview and data collection

All interviews were conducted remotely using Zoom video conference software by the first author (CL). Personal reflexivity of CL can be found in online supplemental materials 1. Using an interpretivist approach, interviews lasted 30–60 min and followed a semistructured schedule (see online supplemental materials 2), with participants encouraged to include any information that they felt relevant given the exploratory nature of the research. The schedule was generated from inspection of qualitative research conducted with parents of children born at earlier gestations, and consideration of aspects of national policy guidelines.[25] Field notes were taken throughout the interviews and considered when collating data across interviews to assist understanding. Automatic zoom transcripts were generated and then corrected for any errors

**Table 1** Maternal and infant characteristics

| | Child age range at interview | Maternal age at birth (years) | Gestational age (weeks) | Siblings | Neonatal Intensive Care Unit stay | Delivery type |
|---|---|---|---|---|---|---|
| 1 | >28 to <30 months | >38 to <40 years | 33.6 | 2 (older) | No | Vaginal |
| 2 | >22 to <24 months | >34 to <36 years | 34.4 | 0 | Yes | Caesarean |
| 3 | >20 to <22 months | Withheld | 34.4 | 0 | Yes | Vaginal |
| 4 | >34 to <36 months | >26 to <28 years | 34.7 | 0 | Yes | Caesarean |
| 5 | >22 to <24 months | >28 to <30 years | 32 | 0 | Yes | Caesarean |
| 6 | >20 to <22 months | >30 to <32 years | 36.3 | 1 (older) | Yes | Vaginal |

before being anonymised. An independent researcher (DS) who was not present during the interviews listened to half of the recorded interviews and checked the anonymised transcripts for accuracy. Data collection and recruitment were concluded when data saturation had been reached.

### Data analysis

Reflexive thematic analysis was employed to explore the data.[26] Anonymised interview transcripts were first coded by hand using NVivo software. Codes captured both the context and the content of the data and were combined at intervals to help begin to identify preliminary themes. These themes were then conceptualised through a process of inductive reasoning to identify patterns of meaning. The final framework of themes and subthemes was discussed and evaluated with independent researchers (AS and CR).

## RESULTS

### Participants

Participants were six mothers of infants born MLPT living in the UK. Table 1 details the characteristics of participants and their infants. The mean age of mothers at the birth of their child was 32.4 years (SD 4.8).

### Themes

Five themes were conceptualised from the data: (1) the moderate or later preterm 'label'—does it matter?, (2) vulnerability within a new role, (3) coming home and wanting to start 'normal' life, (4) comparisons to provide a reference to experiences and (5) experience of professionals throughout the pregnancy, newborn and early years journey.

Subthemes provide further insight into specific elements of broader themes and are presented below.

### The MLPT: does it matter?

#### *A milestone focused first year*

Mothers reflected on their first experiences of considering the 'preterm label' in reference to developmental milestones 'I was a little bit more anxious about him in the sense of milestones and things' (6). Some parents had been given prior warning of the potential impact preterm birth could have on milestones 'You're also waiting for milestones to hit later, so we were told 'oh a baby smiles anywhere from let's say six to eight weeks, [child name] is looking at let's say 10 to 12 weeks' or what have you' (3). These milestones were used as a reference point to seek comfort 'he seems to me to be developing really well and you know, along a kind of normal trajectory of milestones' (1), 'for the first year waiting to see is he meeting milestones we expect? Is he developing okay? Yes he is, okay fine that's fine….He was meeting all the targets and so I thought well….yeah it doesn't really affect me much anymore' (6).

#### *Growing out of the preterm label*

After a milestone focused first year many felt the preterm label began to diminish with time 'I think it's only really important in that first year but that's my understanding' (2). Mothers note a gradual dissolving of the preterm label with no specific end date 'I feel like he'll get to a certain age, maybe four or five, where it won't matter so much' (5). Participant 6 summarised this idea;

> My experience is that it was fairly front loaded in terms of awareness of him being prematurely born in the sense that certainly the first week and first year I was more aware of it because obviously the hospital are very aware of it.… I don't really think of him as being prematurely born anymore in the sense it doesn't really make a difference to who he is and what he does not that that's the only reason you should think about it but you know it doesn't really affect me much anymore.

#### *The relevance of the preterm label within the context of educational settings*

Looking ahead towards educational settings that participants' preterm children would attend, mothers considered the relevance of the 'preterm' label. One mother whose child currently attended nursery noted she was 'pleased they [nursery] asked' within initial enrolment 'because I think it's really important' (1).

Contrastingly, other mothers presented alternative opinions on the relevance of such information 'I don't think it would be necessary for a primary school to know that she was premature… It shouldn't really put her at any disadvantage so they've no reason to know other than out of interest.' (2). Mothers were not surprised when 'they [nursery] didn't ask on their application forms or anything like that' (4) perhaps related to the perceived lack of relevance regarding the 'preterm' label discussed earlier 'I don't think it occurred to me to mention it, or for anyone to ask about it' (6).

## Vulnerability within a new role

### *Initial moments after birth*

Mothers reflected on the initial moments after birth as being incredibly lonely, particularly when separated from their newborn 'I was left completely on my own, probably for about an hour which was really distressing actually. Probably because if you've been pregnant for that long and then suddenly you're all on your own it's very lonely' (1). This was echoed by other mothers, who noted a sudden shift in staff's perception of mothers immediately after birth 'I felt as though I was kind of like a vessel and I was looked after while I was pregnant until he was out' (5). These early moments, often heavily described when preparing for the birth of a child, look characteristically different for some mothers who are then left to process their situation 'A big thing they talk about in neonatal things is the importance of skin to skin and then I was like 'oh yeah that didn't really happen' (6).

### *The Neonatal Intensive Care Unit (NICU)*

The neonatal intensive care environment was described as a place that led many to question their role as a mother to a newborn. Having medical professionals be the primary source of care was challenging 'I often felt that the nursing team having to do their thing made me redundant and just sort of I didn't need to do anything' (5), 'My overall feeling was not knowing what I was allowed to do and not to do' (6). Although the memory of mothers' time in the NICU was raw and vivid, the emotions associated with this context did not appear to persist 'I feel really happy and secure now, whereas when he was younger and particularly this time in hospital I felt quite insecure about my role' (5). Provision of care was not the only situation that appeared to cause feelings of vulnerability and uncertainty, practical barriers unique to parents with children in NICU had lasting effects.

> You know not being able to decide what he wore every day, I wasn't able to do that because I wasn't there every morning when he got up or there every time he was sick or his nappy needed changing. Other people were making these decisions and I found that really hard and kind of disempowering… for four months of my baby's life I had to ring a doorbell to see him (5).

### *Breast feeding*

The experience of breastfeeding a newborn was continuously described as a tool to both bond with a newborn and remain necessary within their newborns care.

> I desperately wanted to breastfeed and it wasn't because of the actual breastfeeding process…it was just feeling like I had a purpose, that was the only thing I could give him….he's got all of these nurses looking after him and it doesn't matter if I'm at home or if I go at eight in the morning he's been looked after. And that was quite difficult because that's my job as a mum, and so I desperately wanted to breastfeed (4).

The desire to take responsibility for a decision within their newborn's care, such as feeding, was described by one mother to be detrimental to their discharge 'She was being tube fed and I had expressed my desire to breastfeed and I think that probably put me in there [hospital] for another week more than I needed to be in if truth be told' (2). Nevertheless, another mother describes how this desire persisted beyond her family's time in the NICU 'I kept going [breastfeeding] for months because it gave me purpose' (5).

## Coming home and beginning a 'normal' life

### *Something to strive for*

Being discharged from hospital and returning home was a milestone all mothers spoke about regardless of their individual experiences and variation in immediate medical or health concerns. Going home was commonly positioned as the beginning of 'normal' life and subsequently something to strive for 'I was just desperate to go home and start normal life with her' (2). For mothers whose newborns had higher levels of immediate medical need, this was a particularly difficult expectation to manage, 'I had to wait until he was well enough to come home obviously, and that was kind of the goalpost but it just kept moving because he got jaundice and then got better and then got jaundice again!' (1). One mother who reported an extended and particularly challenging time in NICU presented mixed feelings about the gravity of finally being able to take their newborn home 'It was quite obviously a monumental occasion but also just wasn't it was just normal right, he was just here' (6).

### *Perception of normality*

The societal perception of bringing a newborn home and 'normal' life beginning from this point was present in all mothers' responses. Marking this moment was important to mothers. One mother reflected on their experiences, noting an unspoken pressure to wait until their baby was home to share pictures with other people; 'I've got a photo of both partner and I separately holding her little car seat outside the front door like waving, I'll never forget that day' (2).

> I wouldn't share sort of any pictures from when he was really little until you know he came out and he didn't have the nasal tube and all that

> kind of stuff. And I realized actually that's part of his story that's really important… the pictures that you have of your child in an incubator are no less incredible and beautiful than the really cute wrapped up ones in your arms at home, that's still the start of their life. It's almost as though we want to as a society want to kind of erase that part of their existence yeah and then them coming home is normality and that was where that sort of life began (5).

## Comparisons to provide reference to experiences

### Comparisons to those born at earlier gestations

When reflecting on early birth experiences, mothers frequently compared their own personal journeys to those of mothers with babies born at earlier gestations as a frame of reference, 'But again, the whole time is like this positioning against people having it worse' (1). These comparisons were in relation to both immediate contextual experiences such as the NICU, 'I was very very aware that there were lots of mums around me who had been there for a lot longer that sort of kept me in check a bit that come on actually… in comparison this is nothing' (2) and longer term contexts such as nursery 'Like if I had a 25-weeker going to nursery that you know, was a lot smaller than other children and maybe a lot behind developmentally like I'd be really feeling like I had to justify myself all the time' (4).

### The 'magical full-term baby'

As well as comparing to babies born at earlier gestations, mothers also made comparisons to babies born at full term. For some mothers, this provided a benchmark of 'normality' 'I mean he came home, he wasn't on any kind of medication, he didn't need any extra stuff or have his NG [Nasogastric tube] tube. I think really it was quite comparable to having a full-term baby I think' (1), 'I still got the whole coming home experience and it was still all brand new for me just like it would be for a full-term baby…I think it's just the initial after birth that's different personally' (3).

Participant 5 presented this comparison through a negative lens 'I felt quite resentful when I saw heavily pregnant women, because I never was….I felt envious of the little things…having to have that relationship [with a new-born] in public'. They further note the experiences they missed out on, 'It felt more out of control…other parents whose pregnancies go to full term, they can have those meltdowns in private like we all do.'

Other mothers reflected on being unable to consider the experiences of a full-term parent 'yeah I think it was comparable. But then I don't know I've never had a full-term baby so this magical full-term baby, I don't know!' (1).

## Experience of professionals throughout the pregnancy, newborn and early years journey

### Throughout pregnancy

The lack of prior information regarding preterm birth throughout pregnancy was voiced by all mothers, 'I definitely didn't contemplate that [being born preterm] being something that might happen without any prior warning…it certainly wasn't a conversation that was ever had that it might be a possibility' (2). One mother noted that even after a medical procedure, preterm birth was not discussed by healthcare professionals, 'They did the steroid injections but never said to me 'right you're having these and this means we are anticipating he's going to come in a week'. (4).

Some mothers contemplated why information was not shared throughout pregnancy, 'No one really talked about that [NICU] in our sort of journey so far, I don't know if it's not wanting to scare people and wanting to present the best case scenarios, there's a lot of talk in like NCT and stuff about avoiding fear' (6), with others reflecting that it would be been helpful 'They kind of want to tell you enough but they don't want to overcomplicate things…. but I feel like it would have been reassuring to know more in advance' (4). One mother who was aware her baby may be born earlier because of medical concerns spoke about seeking her own information as a result of a lack of communication from healthcare professionals and the challenges this posed, 'Towards the end of pregnancy I was still reading these books that have got the typical journey and thinking right I don't know at what point this is going to stop applying to me' (5).

### Early years professionals

Mothers also reflected on their experiences of professionals throughout their newborn's first years of life, with particular reference to health visitors and general practitioners. There appeared to be some discrepancies in relation to how informed health visitors were on preterm birth 'It depends who's weighing them, but sometimes if you've got a prem baby they'll be like 'Oh, you know I'm not sure if I'm supposed to fill the charts with their current or actual age' or whatever it's called…that can be a bit disconcerting if you're like well if you don't know I'm not sure I know kind of thing' (1). Notably, one mother sought to bridge the knowledge gap outside of health visitors all together; 'The health visitor is just a broad person to give you little snippets of advice…maybe there needs to be more support groups like independent ones that you can go to' (2). This need for bespoke support was carefully summarised by one mother;

> We got sent home and at no point has anyone ever said we're going to do a follow up…no one's really checked his growth other than a health visitor with a tape measure…I feel like you need a bit of an MOT* for preterm babies to have a bit of reassurance that everything's developing as it should be…I felt like I needed a debrief, you need someone to run through

with you and say 'oh right so because of all this everything's fine now, and this is what you want to look out for going forward and if you've got any concerns' (4). (*MOT refers to routine testing of motor vehicles to ensure their safety and roadworthiness that takes place yearly in the United Kingdom.)

## DISCUSSION

This is the first qualitative interview study to explore in detail the experiences of mothers of MLPT born infants. Findings offer in-depth evidence surrounding mothers' experiences of healthcare throughout pregnancy and immediately after birth, perceptions of the 'preterm' label, and an exploration of how mothers reflect on their experiences.

Mothers of MLPT born children described a loose affiliation with the 'preterm' label, explaining this is something that diminished as their child grew older. This is in contrast to qualitative research with parents of children born at earlier gestations who describe a stronger affinity with the preterm label.[27] Social identity theory states that to be a member of a group, one's self-concept must align with others' experiences, knowledge, values and emotional significance.[28] Mothers of MLPT newborns share a biological context that their baby was born before 37 gestational weeks, but experiences from this point onwards can differ dramatically. Families of preterm newborns are less likely to access routine postnatal services and support than parents of full-term newborns,[29] suggesting that those in need of timely support for their preterm newborn may not readily seek support. While socially the identification as a member of a 'preterm' group is an inherently personal preference, there may be some clinical utility in preserving the preterm label for those with newborns born MLPT.

Related to uncertainty about a preterm identity, mothers made comparisons to both those born at earlier and later gestations throughout their reflections. Comparison strategies such as this are commonly used to provide clarity, understanding and reference.[30] This method of self-evaluation is noted to be particularly common where concrete information is lacking[31] and is suggested to play a key role within the cognitive vulnerability model of depression.[32] The use of both upwards (to parents of 'full term' newborns) and downwards (to parents of those born at earlier gestations) comparisons throughout the early birth context indicates mothers of MLPT newborns could be at an increased risk for feelings of low self-concepts and low self-esteem.[33] A recent meta-synthesis highlighted the continued importance of maternal care in the postnatal period,[34] which is even more pertinent for mothers whose birth is earlier than expected. To reduce downstream emotional consequences of early social comparisons, bespoke, concrete information for those born MLPT should be provided to reduce the drive for comparison. Additionally, conversations that validate the experiences of parents of MLPT born babies could reduce any negative impacts from comparisons.

All mothers interviewed within the current study spoke in detail about bringing their newborn home, irrespective of differences within the postnatal experience. This transitional period has been associated with regaining control through returning to a familiar environment, with an explicit need for professional reassurance during this transition period highlighted for parents of preterm children.[35] For families whose newborns experience an extended period of time within NICU, going home is a monumental occasion often accompanied with extensive parent focused information around continuation of care.[36] However, only one of the five mothers in the current study whose newborns were admitted to the NICU highlighted information provided by healthcare professionals as being relevant to their transition home. This suggests healthcare professionals, both at the point of discharge and in the immediate aftermath of the newborn coming home, should be aware of the nuanced needs of families of MLPT born infants and how their experiences may differ from 'normal', equipping professionals to provide more bespoke support throughout this transition.

Despite the vulnerability noted by mothers in reference to the transition to motherhood and early postnatal experiences (theme 2), interactions with professionals appeared to be a rare and targeted occurrence. The National Institute for Health and Care Excellence (NICE) guidelines are commonly used within the UK to detail to service providers the extent to which parents of children born preterm should receive information and support after the birth of their child; surrounding immediate postnatal care, at discharge home and across the early years.[25] However, within the UK, there are currently no guidelines surrounding information provided throughout pregnancy, despite 15 million births worldwide being before 37 weeks completed gestation each year.[37] Recent exploration of parental priorities of preterm children aligns with ideas highlighted within the current study, suggesting presenting parents with literature that they can read and discuss in their own time might be helpful.[38] Further evidence suggests a more directed midwife-led model of antenatal care as another solution to bridge the gap.[39] These two putative solutions directly address 1 of the 15 research priorities related to preterm birth, regarding what should be included in packages of support given to families.[40] Future research and service provision should explore how best to address this need for information throughout pregnancy as well as postnatally in a timely manner.

All mothers within the current study described their interactions with health visitors, with differing levels of perceived support regarding their child's prematurity. This discrepancy is in line with evidence highlighting a particular knowledge gap and training need for health visitor professionals with regard to preterm birth.[37] A survey of health visitors within the UK documented that redeployment, staff shortages and an increase in caseload during the COVID-19 pandemic led to considerable pressure on health visitors and the service they were able to provide.[41] Taking into consideration, the overwhelming pressure noted throughout the context of the global pandemic that persists today, a timely solution to issues raised within the current study may be the creation of information pamphlets detailing the unique experiences and challenges for parents of MLPT born children that could be distributed with no additional resource need for health visitors.

Given the age of infants within the current study (20–36 months), opinions around school and other educational settings were purely speculative. Despite this, the overarching opinion was that a child being MLPT was not something parents would automatically share with a school as it was considered to be unrelated to their wider growth and development. This opinion contradicts research highlighting the specific needs of preterm pupils within the classroom and highlights the need to consider the opinions of parents of MLPT as a distinct, majority subgroup of those born preterm.[42–45] The paucity of information regarding the potential downstream effects of MLPT birth (theme 5), combined with educational professionals feeling ill equipped to support preterm children within the educational context,[46] indicates a concerning environment in which the needs of those born MLPT are not being recognised. The creation of training resources (such as those previously mentioned) and awards such as the ‘Prem Aware’ programme[47] to assist schools in providing support is incredibly encouraging. Greater awareness and information provided to parents would further bridge this gap as without this, schools-based programmes may have little effect. Providing a system that offers an all-round model of support for those who need it must be the priority for those born MLPT.

Although the current study is the first to consider the unique perspective of mothers of MLPT born infants in the UK, there are important limitations to be noted alongside the conclusions. First, the study sample was composed of solely of mothers of MLPT born children in the UK, with no paternal or wider caregiver’s perspectives included. Larger samples that are inclusive of alternate geographical perspectives on a wider scale and paternal or other caregivers’ perspectives would benefit the understanding of MLPT parent experiences across cultures and settings. Additionally, the time frame in which the current data were collected should also be considered. The COVID-19 pandemic had a considerable lasting impact on the provision of antenatal and postnatal services within the UK. Notable constraints include the transition of antenatal workshops from group settings to remote delivery, visitation restrictions within hospital settings and the availability of health visitors to provide in-person appointments to new parents. Any lasting restrictions will have undoubtedly impacted parental opinions shared across interviews regarding personal experiences and professional support. Future research should assess the extent to which contextual restrictions impact parental experiences and assess the generalisability of conclusions within the current study conducted within the context of the COVID-19 pandemic.

In conclusion, the current study detailed the experiences of mothers of MLPT born infants. The findings offer unique insights into the ways in which parents of moderate or late newborns classify themselves as having a ‘preterm’ child, and how this appears to diminish with age. A paucity of information provided by healthcare professionals both throughout pregnancy and postnatal care provides some explanation as to why parents believe the implications of preterm birth are no longer relevant past the period of health visitor follow-up. Future research should explore to what extent prior knowledge and discussion of preterm birth during pregnancy is helpful. Being mindful of the current circumstances health visitors are operating in and in the interest of more timely change in support, clinical services should explore the use of educational information that can be distributed alongside current developmental follow ups. Arguments made around ‘early intervention’ by the research community should perhaps shift to discussions around more timely support for those identified as being most vulnerable to the effects of MLPT birth.

**Contributors** CL: conceptualisation, methodology, formal analyses, investigation, data curation, writing (original draft and review/editing), project administration. AS: conceptualisation, resources, writing (review/editing), supervision, funding acquisition. DS: investigation, data curation, writing (review/editing). CR: conceptualisation, resources, writing (review/editing), supervision, funding acquisition. CL and CR are the guarantors.

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