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EMPIRICAL RESEARCH QUALITATIVE

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Living with unsettled baby behaviours: Qualitative interview study exploring parental perceptions and experiences of help-seeking

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Abstract

Aim: To explore parents' perceptions/experiences of help-seeking for unsettled baby behaviours, including views and experiences of obtaining advice from primary healthcare professionals.

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Design: Semi-structured qualitative interviews.

Methods: Recruitment occurred via social media, general practice and health visiting teams. Remote semi-structured interviews were conducted with parents of babies. Babies were under 12 months old at time of interview, and parents had perceived unsettled baby behaviours in their first 4 months of life. Interviews were transcribed and data analysed using reflexive thematic analysis.

Results: Based on interviews with 25 mothers, four main themes were developed. 'The need for answers' highlighted parental uncertainty about what constitutes normal baby behaviour, leading to help-seeking from multiple sources. 'The importance of health professionals' and 'Experiencing health professional support' identified perceptions about limited access, communication, mixed advice and how these influenced parental perception/management of behaviours. 'Foundations to help-seeking' highlighted important roles of social support and online help for valued shared experiences, emotional and practical support.

Conclusion: Health professional access and advice are important to parents, despite the increasing role of online help and importance of social support. More support and improved access to reliable sources of information is needed for parents.

Implications for the Profession and/or Patient Care: Findings will inform future research and clinical practice to address parental uncertainties. Qualitative research with front-line health professionals is necessary.

Impact: Findings can inform the development of resources to support professionals/ families managing unsettled babies.

Reporting Method: Standards for Reporting Qualitative Research.

Public Involvement: A public contributor was involved throughout all stages of the research. Emerging findings were discussed at a parent group.

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What does this paper contribute to the wider global clinical community?

- Addressing parental uncertainties is important; about what is normal, nonpharmacological approaches and when pharmacological intervention is required.
- A digital information/self-management intervention may be useful for parents/ clinicians.

KEYWORDS

advice, baby, crying, general practitioner, health visitor, help-seeking, parent, qualitative research, symptoms, unsettled, vomiting

1 | INTRODUCTION

Parents commonly report unsettled behaviours in babies under 1 year, such as excessive crying and posseting (Douglas & Hill, 2011; Pérez-Escamilla et al., 2023; Vilar-Compte et al., 2022). These symptoms occur along a continuum and are usually part of normal baby behaviour but are often interpreted as problematic by parents (Vilar-Compte et al., 2022). This influences how parents manage behaviours and how they feed their babies.

Unsettled baby behaviours are associated with potential negative outcomes such as parental mental health problems and unwanted cessation of breastfeeding (Pérez-Escamilla et al., 2023; Vilar-Compte et al., 2022) and in some cases risk of injury (Barr, 2014). It is suggested that unsettled babies are also often over-labelled or mis-diagnosed with a medical cause (The Lancet, 2023). This can lead to unnecessary medication use, and significant resource use and health service costs (Mehta et al., 2022; Van Tulleken, 2018). For example, cow's milk allergy (CMA) is labelled in up to 40% of babies (Chalmers et al., 2020) and 73.6% of babies have two or more guideline-defined CMA symptoms by 12 months of age (Vincent et al., 2022). However, cohort studies estimate the prevalence of CMA as <1% (Schoemaker et al., 2015). National Health Service (NHS) prescription costs in England for specialist formula increased from £4.6 million to nearly £60 million between 2007 and 2018, without any apparent increase in disease prevalence (Mehta et al., 2022). Similarly, gastro-oesophageal reflux is very common in babies; 78.1% of a sample of 1225 babies at 3 months of age were vomiting (Vincent et al., 2022). It can generally be managed with feeding advice, yet often parents receive a prescription (Scherer et al., 2013). Recent research suggests that prescribing for reflux has also increased significantly in recent years. Between 2010 and 2016, prescribing rates increased for alginate (15.7% to 24.7%), ranitidine (2.3% to 9.7%) and omeprazole (0.9% to 3.2%) (Cowie et al., 2018).

2 | BACKGROUND

It is important for health professionals to be alert to the possibility of CMA, and 'over-labelling' or 'misdiagnosing' also has negative consequences for many parents, babies and families (Vilar-Compte et al., 2022). For example, there is limited evidence for the transfer of allergens through breastmilk (Allen & Boyle, 2022; Munblit et al., 2020). However, parent concern about CMA can lead to changes in feeding such as dietary exclusion (mother and baby), early cessation of breastfeeding or introduction of combination feeding (Allen & Boyle, 2022; Ghio et al., 2022). These changes have been linked to poor parental self-efficacy and poorer parental mental health (Allen & Boyle, 2022; Brown, 2018), and there are links between use of specialist formula and risk of tooth decay and obesity (Mehta et al., 2022). Medications for reflux, particularly acid suppressants, are often found to be ineffective, to cause additional problems and place babies at risk of serious illness. For example, in a randomized controlled trial of medications and a prospective cohort study, there were significantly more adverse events in babies receiving medication. These included lower respiratory tract infections (RCT, placebo comparator) and gastroenteritis (cohort study, compared to no medication) (Hudson et al., 2012).

A recent systematic review of qualitative research about parental experiences of excessive infant crying identified 22 papers that mainly focussed on the emotional impact of crying on the family and parental management and coping strategies (Muller et al., 2023). The review revealed an evidence gap for how parents assess, make sense of or 'label' unsettled baby behaviours, and about parental information seeking and help-seeking. Since this review, a qualitative analysis of parents' discussions in online forums has been completed (Ghio et al., 2022), highlighting that uncertainties about 'normal' baby crying may lead parents to seek a medical diagnosis or label. There was also a perceived importance of showcasing credibility by sharing detailed experiences online.

Further research with parents is needed to explore their helpseeking. For example, who they turn to for support and advice, when and why they seek support, and the support and advice they take away from these interactions. This would then help to inform future research to better support families managing unsettled baby behaviours.

3 | THE STUDY

3.1 | Aim(s), objective(s) and research question

This study aimed to explore parents and carers' views and experiences of help-seeking for unsettled baby behaviours such as crying and posseting/vomiting. Although parents and carers were invited, all participants were parents, so only 'parents' are referred to hereon. Research questions were as follows:

- 1. When and where do parents seek advice and support for their baby's behaviours?
- 2. What advice do they take away from these interactions?
- 3. What are parents' views and experiences of obtaining advice from healthcare professionals working in primary care?

4 | METHODS/METHODOLOGY

4.1 | Design

A qualitative semi-structured interview study with parents of babies with unsettled behaviours such as excessive crying and vomiting.

4.2 | Theoretical framework

Using a generic qualitative approach (Kahlke, 2014), this study was conducted by a team of academics and clinicians who pragmatically explored how and when parents seek help for their babies' symptoms, and the advice they take away from these interactions.

No specific theoretical framework was used for analysis. Although an inductive analysis was performed, findings were interpreted through a theoretical lens of the common sense model of illness self-regulation (Leventhal & Brisette, 2012).

4.3 | Study setting and recruitment

The study was advertised to parents in the community (social media). It was also advertised via primary/community healthcare in England; GP practices (the primary place of contact for families with primary care doctors (GPs) and nurses), and via health visitors who provide universal community care for children under 5 years old. Facilitated by the National Institute for Health and Care Research clinical research network, four GP practices (1 from the Wessex region and 3 from Thames Valley and South Midlands) completed a database search and invited up to 100 parents with babies aged up to 12 months, and opportunistically invited parents in consultation. Two health visiting teams within one NHS Trust opportunistically invited parents in each of their clinics and advertised with posters. Interested parents informed the research team directly by completing a reply form with their contact details (via Microsoft Forms online or in a freepost envelope) or by contacting the researcher. Social media advertising involved social media posts and targeted advertising, linking to the reply form online.

The online reply form linked to the participant information sheet, which defined excessive crying as 'not stopping crying for hours without being settled'. The form also asked questions to confirm eligibility for inclusion. Optional questions were included to enable purposive sampling to ensure a maximum diversity sample, including ethnic background, parent and baby age, unsettled baby behaviours and when they started, and whether the baby had any diagnostic labels. If paper reply slips were returned, these questions were instead asked when the researcher contacted the potential participant.

Over 100 potential participants expressed an interest. It was not possible to record the number of participants who were invited but did not express an interest (nor their reasons for not participating). The researchers did not know who had been invited until parents contacted the research team directly to express an interest in taking part. Some who expressed an interest in taking part were not selected for interview, due to purposively sampling others or because they were ineligible. Some were selected but did not continue because of time constraints or participant non-response. We tried to purposively sample two fathers who expressed an interest. However, no father interviews took place, due to time constraints or because the mother was interviewed instead.

4.4 | Sample size

As Braun and Clarke discuss (Virginia Braun & Victoria Clarke, 2021), the meaning of data is interpreted by the researcher, rather than the data itself. Therefore, there was no anticipation of a required sample size for 'data saturation' ahead of data collection. Pragmatically, an approximate target sample of 20 to 25 participants was instead estimated before data collection. This was anticipated to provide sufficient information power (Malterud et al., 2016) for researcher interpretation of the data. The maximum number was met with 25 interviews conducted. At this point, new main themes were no longer being developed.

4.5 | Inclusion and/or exclusion criteria

Parents of babies aged up to 12 months were included if they had experienced common symptoms in their first 4 months of life, or if they had considered CMA, reflux or colic (regardless of whether a diagnosis had been given). In study invitation materials, we described common baby symptoms as excessive crying, vomiting, fussing unless being held, rash, changes in stool consistency/colour, gas/wind or nasal congestion.

Parents of babies with serious or life-limiting conditions were excluded to try to ensure that the unsettled behaviours discussed by parents were the primary concern.

4.6 | Data collection

Twenty-five semi-structured interviews were conducted between March and August 2022. Twenty-four were conducted by SH (a female postdoctoral researcher with experience in child health research and with qualitative research methods), and one by AD (a PhD student and health visitor). Neither of the interviewers knew the participants prior to the interviews, nor were they involved in their care. Participants were not informed that AD is a health visitor (a UK health professional who supports families with children under 5 years old) in case this would influence interview responses.

The interviews took place remotely to facilitate recruitment of busy parents across a wide range of locations across the country. They were via video call or telephone, based on participant preference and lasted up to an hour. No one else contributed to the interview, although some of the parents had their babies with them.

A semi-structured topic guide (Data S1) was developed iteratively within the research team (based on academic, clinical and personal knowledge from researchers, public contributors and clinicians) and used to guide the interviews. Interesting areas for exploration arising from earlier interviews were added as probes as data collection progressed. Questions asked about perceptions of baby behaviours, feelings and experiences about this, help-seeking (with healthcare professionals, online and in the community) and about feeding practices. Field notes were kept by the interviewer after each interview. All but one of the interviews were audio or video recorded (via Microsoft Teams) and transcribed verbatim. A professional transcriber was used. Transcripts were checked by SH for accuracy before coding. The interview that was not audio/video recorded was due to participant preference, and detailed notes were taken instead. Unfortunately, it was not within this study's capacity to return transcripts to participants for checking.

4.7 | Data analysis

Alongside data collection, interview transcripts were analysed inductively using Braun and Clarke's reflexive thematic analysis (Braun & Clarke, 2006, 2019, 2022). Braun and Clarke's reflexive thematic analysis (Braun & Clarke, 2006, 2019, 2022) was used to allow for an inductive latent approach working within the paradigmatic framework of interpretivism and constructivism. This enabled us to be flexible and responsive to the data during the analytical process (Braun & Clarke, 2019).

All transcripts were coded by SH (bottom-up approach), and a coding framework was developed to facilitate sharing and contribution of ideas through team discussion. As new concepts were drawn from the data, this was developed iteratively throughout the analysis in discussion with SH, IM, MS, AD, KHS, DG, LL and SA. NVivo software was used to handle data, and themes were developed with the use of thematic maps. See Figure 1 for the final thematic map and Figure S1 for an example of the thematic map during the development of themes and subthemes. For the interview that was not recorded/transcribed, the interview notes were nearly finalized.

4.8 | Ethical considerations

This study was reviewed and approved by the University Research Governance office and the Health Research Authority (with a proportionate review from the North East–Tyne and Wear South Research Ethics Committee). IRAS reference 309678.

Participants were given a participant information sheet prior to agreeing to take part in the study and gave informed consent prior to taking part in the interview. Participants were given a debrief statement at the end of the interview, which had details of resources for support in case they experienced any concerns or distress by discussing this topic. Participant confidentiality was maintained with the use of unique participant identification numbers. Any potentially identifying information in the interview recordings was removed from the transcripts.

4.9 | Rigour and reflexivity

Steps were taken to ensure rigour for our inductive approach within a multidisciplinary team. Notes about the participants' data and researcher thoughts were written after each interview. An audit trail of researcher thoughts and development of codes/themes was facilitated by researcher notes and thematic maps. To ensure multiple perspectives shaped the analysis, analysis included 2GPs, 2 psychologists, 1 HV and a public contributor. Wider team discussions about interviews/findings were regular throughout both data collection and analysis. Discussions reflected on team members' prior and lived experiences (e.g., clinician's experience and parental experiences) and how these related to the findings. The Standards for Reporting Qualitative Research (O'Brien et al., 2014) was used for the reporting of this study.

4.10 | Public and patient involvement and engagement

Public contributor and co-applicant KHS were involved throughout all stages of the project and attended regular research team meetings. KHS gave input into how to conduct this study in the most meaningful ways to parents. This helped with wording participant facing materials (adverts, reply form, information sheet, consent form and topic guide) and effective ways to recruit parents. KHS was also involved in the development of coding manual, data interpretation and writing the paper. The development of themes was also discussed with a local group of eight parents (with unsettled babies from an area of relative social deprivation) as part of a 'listening café' engagement project with a children's centre. The parents agreed with the study findings, expressing similar thoughts and feelings.

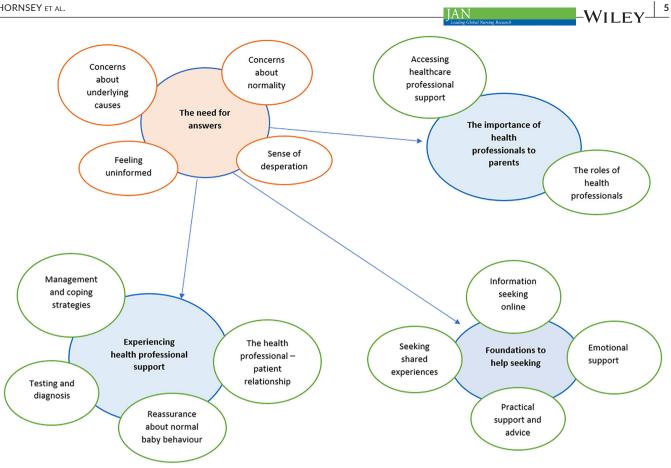


FIGURE 1 Final thematic map.

5 **FINDINGS**

5.1 **Characteristics of participants**

The 25 participants were all female, and their age ranged from 24 to 39 years. 52% were white British, and for 60% of participants, this was their first child (see Table 1). Baby age ranged from 6 weeks to 11 months, and parents perceived a range of unsettled behaviours, mainly excessive crying (88%), vomiting (48%) and perceived pain (48%). Some parents reported a HCP-diagnosed label of colic (16%), reflux (36%) or allergy (28%). Many parents had labelled the behaviours as one or more of these labels.

5.2 Themes and subthemes

Figure 1 highlights the themes and subthemes.

5.2.1 Theme 1: The need for answers

Many participants spoke about seeking advice and support whilst looking for answers regarding their baby's unsettled behaviour. Participants often questioned potential underlying causes of baby behaviours and whether behaviours were 'normal' or not. Parents also often reported feeling uninformed and were desperate for answers and support. These all seemed to be important triggers for support seeking (from health professionals or elsewhere).

Concerns about underlying causes

Often participants described concerns about underlying causes of their babies' symptoms, for example underlying possible medical label or diagnosis, such as allergy or reflux or other illness. This often led to seeking assessment and a label/diagnosis. Sometimes parents suspected that the underlying causes were something that they were doing wrong.

I wanted answers. Because when I didn't know it was silent reflux it was, what is happening to my baby? Am I doing something wrong? Is it something I'm doing? Is there something wrong with her digestive system? ... I just always felt in my gut, something isn't right. So, when I went to the GP I just wanted to know what the heck was going on, really. P15

I was really worried that he was, he did have an allergy or intolerance...but then when we ruled out an intolerance or an allergy, I felt better and I just thought, this is just the way he is. P13

TABLE 1 Participant characteristics.

Demographics		Ν	%	Range	Mean	
Baby	Age (at date of interview)	6 weeks to 11 months				
	Age (at onset of unsettled	behaviours)			0–1.5 months	
	Issues identified by	Crying	22	88		
	parents (quoted by parents)	Wind	13	52		
		Perceived pain	12	48		
		Being sick	12	48		
		Fussiness	9	36		
		Short sleep duration	8	32		
		Moody	6	24		
		Will not be put down	6	24		
		Putting knees up	6	24		
		Snotty nose	5	20		
		Diarrhoea	4	16		
		Explosive nappies	4	16		
		Clingy to mother	3	12		
		Not wanting to feed	3	12		
		Back arching	3	12		
		Green poo	2	8		
		Weight issues	2	8		
		Unsettled	2	8		
		Crying after a feed	2	8		
		Tummy sounds (gurgling)	2	8		
		Wriggling around	2	8		
		Clenched fists	2	8		
		Constipation	1	4		
		Blood in poo	1	4		
		Nappy rash	1	4		
		Mucous in poo	1	4		
		Not wanting to be held	1	4		
		Stiff body	1	4		
		Lethargic	1	4		
		Cough	1	4		
	Parent label (diagnosis	Allergy	15	60		
	or explanation of symptoms)	Colic	13	52		
		Reflux	13	52		
		Intolerance	10	40		
		Tongue Tie	5	20		
		Silent reflux	2	8		
		Under/overstimulation	2	8		
		Developmental leaps	2	8		
		Eczema	1	4		
		Constipation	1	4		
		Asthma	1	4		
		Overtired	1	4		
		Immature digestive system	1	4		
		Foremilk/hindmilk imbalance	1	4		
		Cranial misalignment	1	4		
		High needs baby	1	4		

Demographics			Ν	%	Range	Mean
	HCP label (reported by parent)	Reflux	9	36		
		Allergy	7	28		
		Colic	4	16		
		Silent reflux	2	8		
Parent	Age				24-39 years	29.68
	Gender	Female	25	100		
	Ethnic background	White British	13	52		
		Indian	3	12		
		Black African	2	8		
		British Pakistani	2	8		
		Black British	1	4		
		Black Caribbean	1	4		
		White and Black Caribbean	1	4		
		White Mixed	1	4		
		Asian	1	4		
	Number of children	One	15	60		
		Тwo	6	24		
		Three	3	12		
	Occupation (grouped	Professional	9	36		
	from free text responses)	Clerical and intermediate occupations	5	20		
		Routine, semi-routine manual and service occupations	2	8		
		Technical and craft occupations	2	8		
		Unemployed	1	4		
		Missing	6	24		

Concerns about normality

Many participants spoke about being concerned around not knowing whether or not their baby's behaviours could be considered as 'normal'. Others confidently interpreted that the behaviours were not 'normal'. Reasons were often related to previous experience (a different experience to previous children, or being a first-time parent), parental instinct or a mismatch of experience and expectations.

> I'm a first-time mum, um, and so I wasn't really sure if it was normal to be sick the amount that he was being. P13

Concerns seemed to lead to help-seeking for reassurance from various sources, often health professionals;

I just felt like for my own emotional well-being, I was like, I, I need somebody else to tell me, somebody who's medically trained to tell me that it's okay, that this is normal, because in that moment it just never felt normal. P12 Some parents seemed confident to interpret their baby's behaviours as normal, interpreting them as due to early stages in baby development. This seemed to be due to initial parental thoughts of similar experience with having other children, from working in healthcare or from hearing from peers about 'normal' baby behaviour. They either sought medical help alongside a consultation for something else, or did not seek help from a health professional;

> I put it down to normal baby digestive issues with it being so immature. I hadn't really considered the fact that it could be something more. P1

> because I've got other children... I firstly knew it wasn't going to last forever... her digestive system will catch up with itself and she will be able to work it out. P5

Other situations varied whereby parents changed their minds about interpreting baby behaviours as normal or remained uncertain, sometimes related to the baby's behaviour on that day or how long the behaviours had been happening; I was considering speaking to a health visitor this week actually...I've learnt now that [baby] has good days and has bad days, um, I've kind of just come to terms with the fact that he's just generally quite a cranky baby. I don't actually think there's anything wrong, 'cause even like, sometimes now I'm even like, oh, is it reflux, is it, you know? I'm, I'm kind of just, I don't know, never, I'm still thinking that there might be something wrong when I really don't think there is'. P20

It was probably about two months in... that's when I started thinking, oh, she should have stopped by now... up until then you kind of think, oh, it's just 'cause their tummies are just growing, or have they just come out, it's all kind of uncurling or whatever. So, about two months was when I raised it with the health visitor more'. P21

Feeling uninformed

Often participants described the feeling of being uninformed about various factors such as explanations for behaviours and awareness of management strategies. This seemed to lead to help-seeking from various sources:

> ...just constantly feeling frustrated and just, erm, not knowing what to do, where to get help from and getting more information, and what could make it better, and what was causing it to be honest. P24

This feeling of being uninformed was also influenced by various situations, for example lack of personal experience (either through not having had other children or through having had other children without these symptoms). Some said that they felt uninformed as a result of negative experiences with professional support or a lack of anticipatory advice during prenatal and perinatal care on what baby behaviours to expect.

> I never really had anybody to talk me through and say look, there's a potential this could happen. It is hard, you know what I mean? P12

On the other hand, some participants felt more informed after attending parent groups or parenting classes like antenatal or post-natal breastfeeding classes/sessions, or parent-led baby massage classes.

Sense of desperation

Often parents described feeling desperate for answers and support. Some described that they had struggled with their mental health and often parental mental health seemed entwined with their perceptions of baby's behaviour. They wanted to 'fix' the symptoms to help their babies but also to relieve their own stress, which was sometimes described as leading them to 'breaking point'. Parents often said they had tried everything they could and this desperation led them to seek support from multiple sources or anywhere they could for answers about their uncertainties, but also for help to resolve their baby's symptoms:

> I just was willing to kind of take anything and everything because I just felt like I was at breaking point. I didn't know what would help us, I just knew something needed to change. P14

> I think baby blues just hit me like a freight train... I did talk to the GP about it because I tried using the sort of-it sounds awful, but I tried using the sort of route of it's affecting me to get in to see them so that they would talk about her. Then they're, 'Well, do you need more antidepressants?' 'No, I need you to fix her, because if you fix her it'll fix me'. P15

On the other hand, some participants did not appear desperate about symptoms and instead discussed them in a routine health professional consultation. It seemed that parents who experienced less distress had either not yet considered a diagnostic label or described an acceptance of the behaviours as normal and something they just needed to get through.

5.2.2 | Theme 2: The importance of health professionals to parents

Consulting with health professionals played an important role in many participants' accounts, and seemed to influence their perceptions and management of symptoms. A variety of health professional roles were mentioned, for example primary care and community professionals (health visitors, general practice GPs and nurses, midwives, pharmacists), urgent care health professionals and services (e.g. 111 the UK phone number for urgent healthcare advice, visiting a hospital emergency department, calling an ambulance), secondary care professionals (e.g. dieticians, consultants, paediatricians) and in few cases non-NHS private healthcare professionals (e.g. midwife, chiropractor, private treatment for tongue tie). One participant mentioned thinking about seeing an osteopath but had not done so. Sometimes other healthcare professionals (e.g. counsellors, mental health nurses) were mentioned in relation to managing parental mental health. Participants commented on different professional types, and their perceptions of accessing health professional support.

Some participants did not seek help from a health professional, although reasons for this differed and included wanting to (or feeling they should) manage the symptoms themselves, and waiting it out.

I just wanted to wait and see how she gets on before doing that. P24

The roles of health professionals

Participants had different experiences and perceptions of different health professional types. Parents most often described seeking help in primary care either specifically for their baby's symptoms or in a routine visit. This was usually in relation to parental uncertainty and to receive an assessment (for a label/diagnosis or for potential underlying causes) or management advice. Pharmacists were mentioned, but this was in relation to collecting a prescription for specialist formula rather than for advice.

> I felt like I was on the phone to the GP every other day for about two weeks, just, this isn't normal, this isn't right. And she was constipated as well. We started getting that coming in too. So, I was like, I don't know if this is air. I don't know if this is constipation. I don't know if this is—who knows what it is? It's a guessing game all the time at the best of times. P15

Many health professional types were consulted to address parental uncertainty or provide reassurance. Although less common than consulting a GP/health visitor (or mentioning it in passing during a scheduled appointment), some parents said they had sought help via emergency services. This was mainly due to a desperation for answers, worrying that their baby was critically ill, or because it was out of GP opening hours, or due to a perceived lack of support from previous non-emergency consulting.

> If I'd get frustrated I'll call 111 or even the emergency line, because I'm frustrated and I need help, and when no one is there to help I'll just literally try all the numbers. P23

Some participants were uncertain of which health professionals to seek support from and how, leading to confusion about navigating services. For example, they were unsure because they had tried one type of health professional and perceived this as unsuccessful or they were advised to see another type of health professional, or they were initially not sure of who would be most appropriate to ask:

> I'd phone the health visitor number, and they'd say, 'Oh, that's not us, that's the GP,' or the GP would say, 'That's not us, that's the health visitor, or it's kind of tricky to work out who you are meant to listen to, or go to.' P21

Accessing healthcare professional support

Participants often commented on trying to access health professional support. This was often perceived negatively, with feelings of being unable to book an appointment at their GP practice, limited accessibility to health visitors or a feeling of being dismissed or ignored by health professionals in consultations. This often led to participants feeling frustrated or that they had been left alone to manage symptoms, without a label/diagnosis or reassurance. For some, this was also a reason for participants seeking support from urgent care services.

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So then obviously I was like, I said to the doctor again, 'I think she's got reflux as well.' Again I was ignored. They didn't say to me, like oh they didn't even want to see her. P10

I had to ring 111 because my doctors were just fobbing... Well, the receptionists were just fobbing me off with, 'Oh, babies cry. I'll see if I can get a doctor to have a word with you,' and I'd just never hear anything back... P8

These perceptions appeared to be heightened due to the COVID-19 pandemic;

the health visitors, with COVID, they don't come round now. They see you at like six days and then leave you to it. It's terrifying. P4

Some positive experiences with accessing health professionals were also discussed. This seemed to be when participants perceived them to be more accessible. They felt they were listening to them and taking them more seriously by making time for them.

> the health visitor gave me her phone number, so if I ever had any problems I could just text her and she would reply...she was wonderful. P21

> I feel there were two types of experiences for me, because when I was in [location A] the health visitor experience wasn't as great... I literally felt like I was just a number...they're just ticking me off. ...whereas when I shifted to [location B]... she took literally twice the time to sit and talk to me, and understand you know what issues or whatever I'm going through, and it made me feel like, you know what? You're there to listen to me, and I really like it because you care about me... P23

5.2.3 | Theme 3: Experiencing health professional support

Participants' descriptions of advice they received from health professionals differed widely, and this seemed to influence their perception and management of behaviours. For example, some parents' accounts focussed more on the management and coping strategies they were recommended, or medication they were prescribed. Others focussed more on assessment or physical examination and testing, with the view towards obtaining a label/diagnosis. <u>10 |</u>W

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Participants also commented on normalization (where health professionals advise that the behaviours are a 'normal' part of baby behaviour that will improve with time) and reassurance from health professionals, perceiving this both positively and negatively which impacted their perception of health professionals. All these experiences were perceived with mixed opinions and seemed to be impacted by the communication from health professionals.

Management and coping strategies

Parents described being advised about multiple different management and coping strategies from health professionals. These included practical non-pharmacological management strategies (massage, cycling of legs, changes to milk/formula, positioning and winding changes), over the counter treatments (colic drops, saline drops), or prescriptions for specialist formula milk or medication such as omeprazole for reflux. Some were advised a combination of these, whereas others focussed more on one of them and at different points in the help-seeking process. Some described focussing more on the management of parental mental health.

> I had a telephone consultation with the GP first... he said that it sounds like reflux, silent reflux...so he prescribed us [brand] over the phone and then said, if it wasn't working, to ring back up. erm So we tried [brand] for, I'd probably say, five or six days, erm but then the side effects of the [brand] were a lot worse for her than... Because they make her extremely constipated. P29

Perceptions of advice were taken described differently by participants with both positive and negative views about the advice they had received and about how successful they were for management. For example, some participants said that they had wanted a prescription for medication, related to a desperate wish to resolve the symptoms and perceiving medication to be the best/fastest solution, or because of lack of success with non-pharmacological approaches. Others had wanted to avoid or stop medication because they felt non-pharmacological methods or tests should be tried first (and that prescribing was the easiest response for the health professional). Other reasons for not wanting medication were because they had used medication previously and perceived it as either impractical to give to their baby, unsuccessful or to give side effects. Some wanted it but only because they felt nothing else had worked.

we lost a lot of faith in them, with the fact that the GP was just prescribing us medicine, prescribing us medicine, and then the hospital was just prescribing us medicine instead of running any tests or whatever. P29

They said, 'I think we're going to try omeprazole now.' I was like, 'Okay. Whatever. I will try anything. I just want my daughter to be able to have a bottle without screaming at me'. P15 Non-pharmacological advice was generally described as helpful, even if not always successful and felt like 'trial and error'. However, non-pharmacological advice was sometimes perceived as generic or vague and participants described a wish for more individualized or detailed advice. One participant talked about the need for more breastfeeding advice:

> in the UK, there is not enough emphasis on breastfeeding and I wish there was. I wish there was more support... It's not difficult just to add a bit of further training for GPs, add a bit of further training for nurses and midwives. Even midwives don't have enough training. They don't recognise tongue tie, and they don't recognise allergies. There's got to be more help and support out there for breastfeeding. P9

Testing and diagnosis

Many parents described the assessments, testing, labelling or diagnosis they received from health professionals. The discussions about these between parent and professionals were described by participants as initiated by the parents or the professionals. Tests for milk allergies were most often done by changing formula following negotiation with a health professional (such as a GP or consultant), a meeting between experts with the professional acting as the gatekeeper.

> I remember speaking to my GP and saying to them, maybe, maybe it's, it's the actual formula she's allergic to. Maybe that's what's upsetting her, and I remember asking them and saying please can we, like, I know that there's a dairy-free formula but it's a prescription only, and I remember saying to them, please can we try that, and then the doctor saying, no, she's fine. P12

Labels for colic or reflux were usually given after parents described their baby's symptoms to a health professional. However, some parents described already knowing or suspecting it was an allergy (from experience with their own formula changes or diet changes, or due to recommendations from others) and wanted a health professional to confirm this on their record. Signposting between health professionals was also noted by some.

Reassurance about normal baby behaviour

Participants also discussed the reassurance that they had received from health professionals that their babies' behaviour was a normal part of baby behaviour or development. Although it was clear that many parents wanted reassurance or advice about any potential underlying causes, reassurance about 'normal' baby behaviour was often received differently. For example, some described the usefulness and positivity resulting from this:

> you kind of feel, you feel a bit more reassured, you feel a bit more calmer after speaking to somebody, and you realise that it's not kind of an emergency

as such, it's not something that you need to be so worked up about. P6

Other parents perceived this as being inaccurate, dismissing or that they had been 'fobbed off'. Whilst some parents said advice about normal behaviour was helpful, knowing that they had to 'ride out' unsettled baby behaviour did not give them comfort in the short term when they were struggling:

> they say the good thing is that they'll grow out of it by three months, and as I said before, that is definitely not reassuring. That is actually very scary because each day going by is difficult. You want something to help your child now. P22

The health professional-patient relationship

Parents' perceptions of their relationship with their health professional seemed linked to how they perceived the baby behaviours, how they perceived the health professional advice (such as reassurance that their baby's behaviour is normal), how they sought further help and how they managed behaviours. For example, many parents described a feeling of being 'fobbed off' or dismissed by health professionals when parents felt they were the experts in knowing their baby.

> It just felt very much like every time you saw someone it was very, 'Oh, paranoid first-time mum, here we go.' No, something's wrong! P15

Others were sceptical of their health professionals' training or advice. Many of these factors led to frustration, distress and further helpseeking from health professionals or elsewhere.

> when the doctor said to me, it was okay, I was like, I don't know, something in my head just said, it's not okay, you need to find somebody else that's going to help. So then I phoned like I text my health visitor. P10

Some felt their health professionals' advice was not personalized enough or that they were misunderstood, for example not understanding the financial strain of buying different bottles.

> ...for the health visitor to just go, 'Just go buy some bottles.' I was like, 'Well, I haven't really got the money to go and just constantly keep buying new things'. P10

Although there were many negative perceptions, some parents perceived a positive relationship and communication with their health professional and highlighted that this helped their situation.

...so we went to the GP and then their advice was really helpful. And they tried everything that I think

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could be tried, to help ease the reflux, but unfortunately nothing that we tried did help... they explored the avenues so, so we saw a few different doctors... and each of them was, was really nice, and took it seriously. P13

5.2.4 | Theme 4: Foundations to help-seeking

Regardless of whether participants described seeking and receiving support from health professionals, it seemed their initial or main source of help-seeking were often social support and/or online helpseeking. These provided a sense of shared experience, a source of information (assessment of symptoms and management strategies), practical support/advice and emotional support.

Participants discussed social support being a lifeline, providing reassurance, practical support and advice. Various forms of social support were discussed by parents, ranging from online parenting forums to family and friends. Parenting support groups were important (online or in person):

> thank God for this—for the [parent group] in [city], because I just go onto [messaging app] and I'm like, 'Hey, my child has got this funny rash on her face. Is it normal? Has, has anyone else experienced this?' P23

Although it was clear that social support was important to participants, there were mixed positive and negative perceptions about the social support received. For example, many were positive:

I've always had a brilliant support network around me, so really lucky with that. P13

Some were negative or discussed limited support. For example, the following parent discussed limitations of social support in relation to their cultural norms:

culturally, it's a little bit different. You don't really ask for help. People just, or advice, people just offer advice...having a baby in the kind of family dynamic that I live in...there's so much advice given to you about formula, breastfeeding, all of that, often in a very critical way, um, I just ignored most of it, to be honest, just filtered through, for my own sanity, for making sure that I could, I could manage. I think too much advice sometimes is a bad thing, you know. It's contradictory... what I've learned is that every child is different. What might work for one child will not work for another child. P12

Online information seeking also played a large role for parents in seeking support and managing their babies' symptoms. Various

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online resources were mentioned, including search engines, parenting forums, NHS websites, social media pages, other websites and apps. This was usually to seek information but also included validating their feelings and situation. A small number of participants seemed to avoid looking online in certain situations or all together.

Seeking shared experiences

Participants clearly described the importance of seeking support from other parents with similar experience, either through family and friends or through parenting groups online. This was usually to know that they were not alone, to be validated or understood, but also to know about management strategies, which had worked or not worked for others in their situation.

> To have made a friend who's got a child exactly the same age and is also going through a similar sort of journey, it was like, 'Oh my God, I feel heard. Somebody hears me and gets it.' P15

Often, if participants described a negative perception of social support, it was because they felt that the person providing the support did not understand; either they had not experienced this problem, or that they did not have children.

> And friends and family, if I'm honest, allergies isn't, unless they've experienced it, they have no idea. P9

Emotional support

Often participants described the importance of emotional social support. They often used the internet to seek emotional and peer support for their babies' behaviours, usually via online parenting forums where they could seek validation of their feelings and reassurance:

> other mums would just, you know, say, 'You know what? You're not all, all alone. We're in this. We're in it together.' And it made me feel like, you know what? I'm not alone. It's fine. It's okay to not be okay. P23

> parents are genuinely just pouring their hearts out online, um, so I was just, just reading that, trying to find some comfort in knowing that it wasn't just me. P12

Practical support and advice

Participants often described the usefulness of practical support and advice. For example, the usefulness of family and friends taking the baby to give the parent some rest:

my mum was a bit of a saviour in that moment... she came down for five days and helped out a lot. Like, she would have [baby] after a feed so I could have a bit of a nap, and reminded me to eat and hydrate and like looked after me so I could look after [baby]. P14 Practical advice referred to many different types of management strategies for which the participants had mixed opinions:

> one of my friends, you know, suggested swaddling, white noise. White noise is actually really quite helpful, he likes white noise. P20

Other practical forms of advice described from social support referred to the advice to see a health professional, or advice as to what they thought was the explanation.

Information seeking online

All but one participant sought information online. Often this was to assess the behaviours, but parents also explored suspected labels/diagnosis and searched for management strategies. For example,

Just Googling, 'Why is my baby screaming? Why is she arching her back?' and things like that. P8.

we did actually look initially for like any tricks to try and help with silent reflux...So we were looking for people that had tried the medicine, it hadn't worked, what else did they do... P29

Usually, online information seeking occurred regardless of other help-seeking factors such as seeking help from professionals, but the timing of seeking information online varied. For example, some sought information as a result of perceiving a lack of health professional support, some sought it prior to health professionals, others described searching online about behaviours before their baby was born, and others described trying multiple avenues at the same time.

> ...I've learnt a lot just generally about health, erm, and being fobbed off by doctors, er, quite a few times in the past for my own health, for my children's health. Erm, so I've, maybe the past five years, I've kinda took things in my own hands and did my own research online. P22

Participants appeared to have mixed perceptions of online resources. Whilst the usefulness of the internet for information seeking was evident, often participants described that it carries risks due to the large quantity and variety of information, including information which could be inaccurate or non-specific to their situation:

[search engine] can be your best friend or your worst enemy. P6

6 | DISCUSSION

Parents in this study had often seemed desperate for answers to their uncertainties about their baby's unsettled behaviours, mainly

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about what range of behaviours to interpret as normal and concern about potential underlying causes. They sought empathy, explanations and solutions from healthcare professionals but had mixed experiences and perceptions of health professional support. Experiences included limited access to support, assessment and labelling of reflux or allergy, reassurance of 'normal' baby behaviour, and both pharmacological and non-pharmacological management. As their foundation to help-seeking, they also commonly sought advice, information or support and validation of experiences from social networks or online.

The concerns about underlying causes influencing help-seeking is in line with recent online discussion forum research about excessive infant crying; parental suggestions/thoughts about various diagnoses and underlying causes influence parents to search for a diagnosis (Ghio et al., 2022). This highlights the need to inform parents about when symptoms are a normal part of baby behaviour and when a label/diagnosis or medical intervention is required.

Whilst there were mentions of non-pharmacological recommendations in this study, the findings about diagnoses/labelling of reflux or allergy and prescriptions (for specialist formula or reflux medication) are similar to findings from other research about labelling and prescribing (Chalmers et al., 2020; Mehta et al., 2022; Scherer et al., 2013; Schoemaker et al., 2015; Vincent et al., 2022). Although it is important to diagnose and treat these conditions when they occur, research suggesting over-labelling (Chalmers et al., 2020; Schoemaker et al., 2015; Vincent et al., 2022) and inappropriate prescribing (Mehta et al., 2022; Scherer et al., 2013) further highlights the need to distinguish between when diagnoses and prescriptions are necessary. The search for a diagnostic label or underlying cause also aligns with core assumptions in Leventhal's (2012) Common Sense Model of self-regulation (Leventhal & Brisette, 2012), which finds identity and cause to be core domains of illness representations.

Parents in this study sought validation, empathy and understanding in their help-seeking. They often felt this was missing from health professionals, feeling 'fobbed off' or dismissed, resulting in negative perceptions of their support or reassurance of 'normal' baby behaviour. This is echoed in recent survey research of parents with unsettled babies in the Netherlands (van der Veek & van Rosmalen, 2023) and similar to other paediatric conditions in primary care/community health such as eczema and sleep (Cook et al., 2020; Santer et al., 2012). It is therefore important to ensure that parents feel understood and that reassurance about normal behaviour (or a lack of label/diagnosis) does not mean that patients will not be supported.

The current study highlights that often parents perceive limited access to health professionals and a varied health professional/patient relationship, which impacts their perceptions and management of their babies' behaviours. Parent frustration surrounding access to health professionals is understandable; however, this study was conducted at a time of increasing strain and scarcity of health visitors (UK community child health nurses) and GP workforce, which possibly contributed to frustrations with access. For example, for health visitors, the primary contact of babies in this age range in the UK (Public Health England. Health visiting and school nursing service delivery model, 2021), the recommended caseload is 250 children. However, only 6% have this recommended amount or less and 28% currently manage over 3 times more. It is estimated that the UK is short of 5000 health visitors currently with a reduction of 40% since 2015 (Institute of Health Visiting, 2023). This study was also conducted whilst COVID-19 was still active and remote consultations were more frequent with GPs. Therefore, whilst it is important to improve on ways to help patients, which ease the pressure on the NHS, the way that new support is accessed, communicated and tailored will be an important factor for ensuring parents accept and trust the support.

The role of online help-seeking and social support (online and in person) is also important. These findings are similar to studies of online help-seeking whereby parents/patients value the use of finding convenient and credible information online but acknowledge risks such as finding overwhelming, inaccurate or distressing information (Treadgold et al., 2020; Ziebland & Wyke, 2012). The current study also echoes research, which highlights the use of sharing experiences online whereby people can develop a feeling of connectedness and being understood from accounts of shared experiences (Treadgold et al., 2020; Ziebland & Wyke, 2012). Indeed, the current study findings are in line with previous excessive baby crying research whereby parents shared experiences in online discussion forums, which influenced their perceived credibility (Ghio et al., 2022) and whereby parents emphasize the importance of social support (Brown, 2018). Parents in this study also had positive perceptions of parent groups both online and in person, suggesting that increasing access to remote or face-toface parent groups may also provide an alternative to individual consultations.

It would therefore be beneficial to provide families with a tool such as an online support guide that provides the evidence-based information and tailored advice, which would reduce their uncertainties and facilitate self-management. This tool could be accessed prior to consulting with health professionals and include patient stories, which may ease parental anxieties and reduce the number of consultations needed. Similarly, a tool could be used to facilitate consultations whereby health professionals can effectively signpost for further information.

6.1 | Strengths and limitations of the work

This study had a sample size of 25 mothers with sufficient information power for developing main themes. It included a diverse sample of baby age, baby symptoms and parental ethnic background. However, it would have been useful to include fathers and other parents/carers to explore any potential differences. Future research should incorporate other ways to include fathers and partners in this research, for example specifically targeting fathers only (e.g. more targeted social media advertising) and comparing to findings of studies with mothers. Many parents in this study were first-time parents, which may have been relevant to perceptions of unsettled behaviours. Furthermore, some of the babies had been born prematurely and this may have impacted the advice they sought and received. Full analyses on these aspects were outside the scope of this study and need exploration in further research.

Most of the expressions of interest were from social media; eventual participants were from social media (n=19) and via GP practices (n=6). This may have led to bias whereby the sample included were more likely to search online for help. Parental experiences may have been different if more had been recruited via GP practices and health visiting teams. Due to participant self-selection by responding to adverts, some participants with more extreme experiences (e.g. highly negative) may have been more likely to take part. Parent accounts were also mostly retrospective, rather than about current experience. Nevertheless, parents often appeared to remember these difficulties clearly.

Parental labels for colic and reflux, and variations of these terms such as 'colicky' babies were often interchangeably used as symptoms and labels. Due to parental report, the exact diagnosis, label or advice given to parents by health professionals was not confirmed nor was it always certain which exact combination of behaviours parents were referring to. However, the interchangeable use of these terms by parents and in the advice that parents perceived or retained is interesting and supports previous research (Ghio et al., 2022). Future analysis on parental understanding and labelling of baby behaviours is required.

6.2 | Recommendations for further research

The perceived role of healthcare professionals in facilitating parents' understanding and management of baby behaviours suggests that it would be beneficial to conduct qualitative research with front-line healthcare professionals. It would be beneficial to interview health visitors and GPs because they are the first point of call for parents in the UK and they were often mentioned by participants in this study.

Future research to develop and better sign postresources such as self-help interventions, with evidence-based advice and explanation, would be useful. Currently, there are websites available with some information about a range of child health issues such as Wessex Healthier Together (Healthier Together, 2023). An intervention specific to unsettled babies would provide more detailed and individualized information specific to this issue, which may be more meaningful to parents. Parents could then access this for support, providing them reassurance whilst also easing pressure and resources needed from time-constrained and resource-limited consultations.

6.3 | Implications for policy and practice

It is important to address parental concerns and uncertainties, ensuring that they feel understood and that they will still be supported. Distinguishing between when diagnoses and prescriptions are necessary could be facilitated by educating parents and professionals. Increasing detailed information about non-pharmacological strategies could help with this. This could ultimately reduce unnecessary NHS costs and side effects of medication.

Any interventions developed may be signposted by current websites such as Healthier Together (Healthier Together, 2023), or by health professionals in consultations. Health professionals may also be able to use similar interventions in clinical practice as a guide for evidence-based advice and to reduce over-medicalization and over-prescribing.

An online tool could be used in conjunction with strong healthcare professional communication skills. This study suggests that for the tool to be effective, the consultation with a healthcare professional recommending it will need to be experienced as empathic and validating for the parent. Patient voices may also be useful for an online intervention increasing perceived credibility of information for parents; this technique has been used successfully in other digital self-management interventions (Sivyer et al., 2022).

7 | CONCLUSION

Parents often feel uncertain and desperate about their baby's behaviours, with questions surrounding normality and suspected underlying causes. Consulting in healthcare is important to validate the parent experience and provide them with the support they need. Parental perceptions of limited accessibility, communication and mixed perceptions of advice given in consultation impact their perceptions/management of behaviours, and their parental mental health. Parents value shared experiences from other parents for their experiences to feel valid and for them to trust information.

There is need for more support and improved access to support for parents. Due to increasing constraints on NHS resources and funds, it would be beneficial to develop a digital self-help intervention as a step between symptom onset and seeking advice in healthcare. This could target parental education around normality and when/where to seek help within the NHS, and it could incorporate patient stories from other parents. Digital interventions for health professionals could similarly be developed to help them advise about symptoms in consultation, with the target of reducing over-labelling of colic/reflux and inappropriate prescribing whilst still supporting families who are struggling with these symptoms. Ultimately, interventions such as this could help to alleviate parental distress and reduce harm through over-medicalization. Further research with primary care professionals (such as health visitors who are often the first point of access for parents) is necessary to inform the development of these interventions.

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None.

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