Received: 1 December 2023 | Revised: 9 February 2024 | Accepted: 11 March 2024

DOI: 10.1111/jan.16166

SYSTEMATIC REVIEW

JAN Leading Global Nursing Research WILEY

'Either something's wrong, or I'm a terrible parent': A systematic review of parent experiences of illness-related interpretations for unsettled babies

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Funding information
School for Public Health Research, Grant/Award Number: C008

Abstract

Aims: To explore parents' experiences of unsettled babies and medical labels.

Design: Qualitative systematic review, thematic synthesis and development of a conceptual model.

Review Methods: Systematic review and thematic synthesis of primary, qualitative research into parents' experiences of unsettled babies <12 months of age. 'Unsettled' was defined as perception of excessive crying with additional feature(s) such as vomiting, skin or stool problems. The Critical Appraisal Skills Programme (CASP) checklist was used to assess trustworthiness.

Data Sources: Structured searches completed in CINAHL, Medline, Embase, PsychINFO and CochraneCT on 23 March 2022 and rerun on 14 April 2023.

Results: Ten eligible studies were included across eight countries contributing data from 103 mothers and 24 fathers. Two analytical themes and eight descriptive themes were developed.

Firstly, parents expressed fearing judgement, feeling guilty and out of control as a result of babies' unsettled symptoms and seeking strategies to construct an *'Identity as a "Good Parent"'*.

This desire for positive parenting identity underpinned the second analytical theme *'Searching for an explanation'* which included seeking external (medical) causes for babies' unsettled behaviours.

Conclusion: Parents can become trapped in a cycle of 'searching for an explanation' for their baby's unsettled behaviours, experiencing considerable distress which is exacerbated by feelings of guilt and failure.

Impact and Implications for Patient Care: Insight gained from this review could inform interventions to support parents, reducing inaccurate medicalization.

Health visiting teams supporting parents with unsettled baby behaviour could focus on supporting a positive parenting identity by managing expectations, normalizing the

continuum of infant behaviours, reducing feelings of guilt or uncertainty and helping parents regain a feeling of control.

Reporting Method: ENTREQ guidelines were adhered to in the reporting of this review.

Patient or Public Contribution: Parent input was crucial in the design phase; shaping the language used (e.g., 'unsettled babies') and in the analysis sense-checking findings.

KEYWORDS
crying, infant, parenting, qualitative research, systematic review, unsettled babies

1 | INTRODUCTION

In clinical practice, primary care practitioners such as Midwives and Health Visitors as well as nursing colleagues in the acute setting regularly see families with unsettled babies who are in great distress, expressing concern about infant behaviours such as perceived excessive crying, sleep problems, vomiting, rashes or changes in stools.

There is concern that unsettled baby behaviours are being increasingly attributed to medical causes such as cows' milk allergy (Boyle & Shamji, 2021; Elizur et al., 2013; Munblit et al., 2020; Pérez-Escamilla et al., 2023; Rollins et al., 2023; van Tulleken, 2018; Vincent et al., 2022) and other functional gastrointestinal disorders such as reflux (Salvatore et al., 2018). The frequency of these behaviours in healthy babies leaves room for understandable misinterpretation (Vincent et al., 2022). This is compounded by commercial industries, who have devoted significant sums of money to healthcare professional training and funding for clinical guidelines as well as marketing directly to parents and curating social media adverts that could heighten health concerns around common baby behaviours such as crying and vomiting (Pérez-Escamilla et al., 2023; Rollins et al., 2023; van Tulleken, 2018; Vincent et al., 2022).

For a small number of babies, unsettled behaviours are symptomatic of a medical issue. However the most recent Lancet breastfeeding series notes an increasing problem of attributing medical diagnoses to normal baby behaviours, particularly cow's milk allergy or reflux (Pérez-Escamilla et al., 2023; Rollins et al., 2023). This 'mislabelling' (Elizur et al., 2013) may have a detrimental impact on breastfeeding at a vulnerable time for the baby and family (Munblit et al., 2020) and could introduce unnecessary or ineffective medications with associated risk of side effects (Carey, 2013; Hudson et al., 2012).

Having an unsettled baby is distressing for families, and impacts on parents' well-being, sleep and family strain (Brand et al., 2014), as well as being detrimental to the parents' relationship (Doss & Rhoades, 2017). At its extreme, perceived excessive crying is thought to be a trigger of abuse and non-accidental injury (Barr, 2014).

Unsettled baby behaviours also represent a large and rapidly increasing cost to parents and healthcare systems (van Tulleken, 2018). NHS spending for specialist milk formula increased by 700% from £8.1 million to £60 million between 2006 and 2016, without evidence of any increase in allergy prevalence (van Tulleken, 2018). Prescribing rates of medications for reflux have also increased between 2010 and 2016 (Cowie et al., 2018), introducing risks of side effects and a range of potential negative impacts on dietary and nutritional outcomes for the parent and baby in the short and long term (Munblit et al., 2020). Internationally, the mislabelling of unsettled baby behaviours may exemplify how health inequalities are exacerbated at a global level through gendered power systems, structural inequalities and commercial influence (Baker et al., 2023). For example, mislabelling unsettled baby behaviours as medical concerns may exacerbate breastfeeding difficulties, which is a global public health issue (Pérez-Escamilla et al., 2023). It is clear therefore that unsettled babies inaccurately labelled with allergy or reflux are rapidly becoming an important health priority across the world.

This paper is the first to synthesize the research of parent experiences of unsettled baby behaviours and aims to explore how parent experiences and views contribute to the inaccurate attribution of medical labels such as allergy and reflux. An in-depth insight into how these illness-related perceptions of baby behaviours are formed could inform development of resources and support structures to meet the needs of parents with unsettled babies. This paper reports on a systematic review and thematic synthesis of qualitative research exploring parent experiences of unsettled babies, with a particular emphasis on their thoughts and feelings that might lead to medical labels for their baby's behaviours.

2 | THE REVIEW

The protocol for this systematic review was registered on Prospero (CRD 42022355249).

Approved by University of Southampton Research Governance ERGO 88132.

3 | AIM

The aim of the study was to explore parents' experiences of unsettled babies, including perspectives on medical labels.

4 | METHODS

4.1 | Design

A qualitative evidence synthesis was conducted using thematic synthesis (Thomas & Harden, 2008) and including the production of a conceptual model. Review methods are defined according to the typology of reviews (Grant & Booth, 2009). The review was reported according to the Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) guidelines on the synthesis of qualitative research (Tong et al., 2012). This is a 21-item checklist covering five key domains—introduction, methods and methodology, literature search and selection, appraisal and synthesis of findings.

4.2 | Search methods

SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) (Cooke et al., 2012) search tool was used to structure the pre-planned search strategy (SPIDER breakdown is summarized in Supplementary Material S3). The search was designed to be broad and sensitive in approach in order to detect the wide variety of behaviours viewed by parents as 'unsettled' in our public engagement work. Key search terms were chosen to identify studies on parent experiences, beliefs, thoughts, or attributions about and relationships with their baby; where the baby is 'fussy', unsettled, difficult temperament; has a label of cow's milk allergy, colic or reflux; or is exhibiting non-specific gastrointestinal symptoms known to cause anxiety and prompt consideration of allergy or reflux. Additional search terms were identified through use of mixed methods and qualitative search filter resources (University of Washington, 2023; University of York, 2023). Full search strategies for all databases are available in Supplementary Material S2.

4.2.1 | Databases

The main search was written for the database considered likely to contain the most relevant research; determined to be CINAHL; this was then adapted for replication in Medline, Embase, PsychINFO and Cochrane clinical trials register (for mixed methods trials). Searches were completed on the 23 March 2022 and rerun on 14 April 2023.

4.2.2 | Grey literature

Academic conference proceedings, parent blogs, charity, news outlet and other organization websites were searched for grey literature which may fit the inclusion criteria. Articles were screened if they appeared in the first five pages of Google search and had titles which appeared relevant to the review topic. Relevant free text terms for Google and Google Scholar were used such as 'unsettled baby parent experience' (Google) and 'Qualitative baby allergy/reflux' (Google scholar). A full list of free text terms can be found in Supplementary Material S1. Forward and backward citation searching of included papers was also completed, using Google Scholar 'cited by' tool for the forward search and hand searched reference lists of included studies for the backwards search.

4.3 | Inclusion criteria

Primary, qualitative research studies with data about parent experiences of unsettled infants <12 months of age were included. Unsettled behaviours were defined as perceived excessive crying with one or more additional complaint such as vomiting, skin problems or stool problems. Studies about infant crying alone were only included in the search, however excluded at the full text stage unless the findings or results section contained discussion of other behaviours, for example gastrointestinal symptoms or discussion of how parents construct medical- or illness-related narratives of the crying. Studies focused on experiences of IgE-mediated allergy were excluded as this presentation is markedly different and can have potentially life-threatening implications; as such it represents a different experience for parents. Studies aiming to evaluate an intervention or tool were excluded if these did not focus directly on parent experience of unsettled infants. There is a well-established concern around commercial influence on academic publication, particularly in the field of unsettled babies, reflux and cows' milk allergy (Hennessy et al., 2019; Rollins et al., 2023; Shenker, 2018). Therefore studies which reported involvement or funding from the formula milk industry were excluded to protect against possible commercial bias of the results. No language or date restrictions were applied.

4.4 | Search outcome

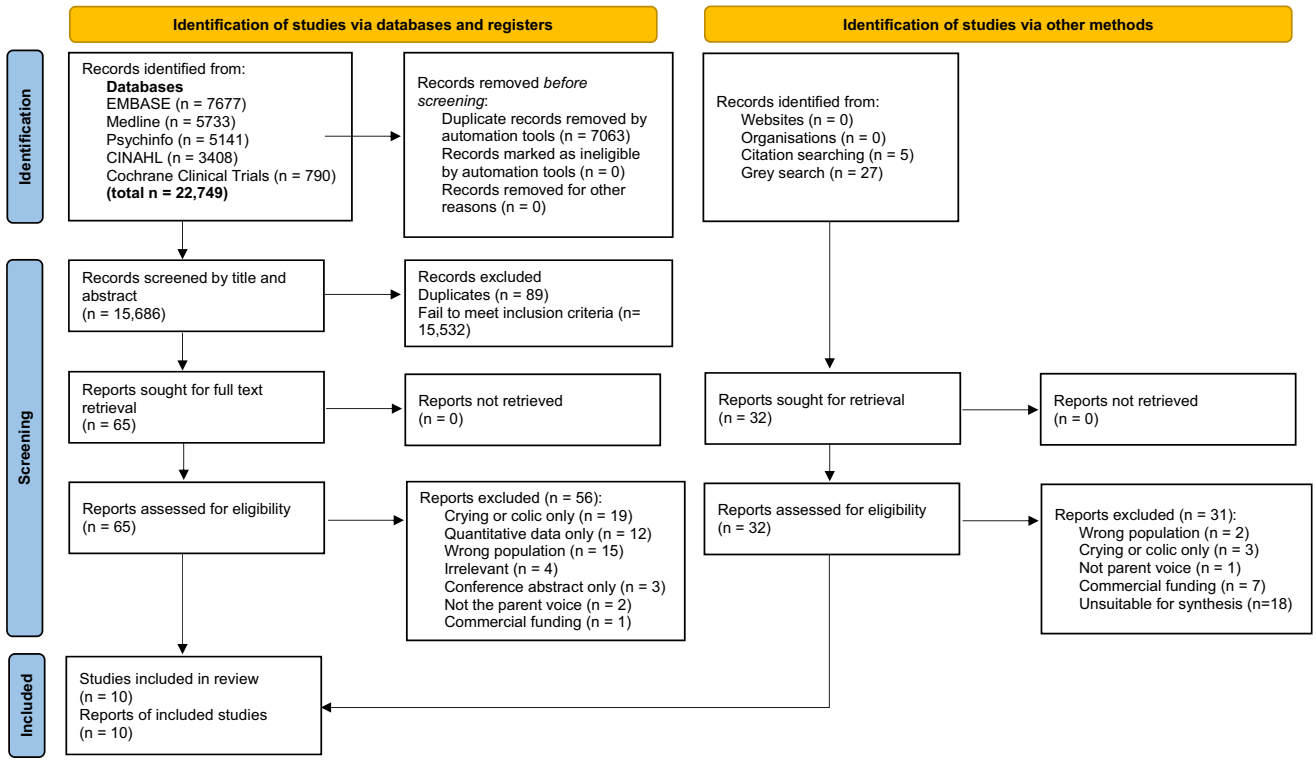
Following deduplication in Endnote, the records were imported into RAYYAN (systematic review screening software) where title and abstract screening was completed by the primary author (AD). A random 20% of papers were also screened independently by a second author (SH) and any disagreements were resolved by discussion (less than 1%). The full texts of potentially eligible papers were then screened for eligibility by AD, of which 20% were again independently screened by SH. There were no disagreements at full-text screening stage.

Searches identified 22,781 papers, reducing to 15,686 after automatic removal of duplicates in Endnote. Title and abstract screening resulted in 97 records sought for full-text retrieval. Full-text review following the initial search on 23 March 2022 resulted in nine

included studies for synthesis. On rerunning the searches using an identical method on 14 April 2023 in preparation for publication, one new article was identified which met inclusion criteria. See PRISMA flowchart (Figure 1) for full breakdown.

4.5 | Quality appraisal

The Critical Appraisal Skills Programme (CASP) (CASP, 2022) checklist was used to assess the trustworthiness of the studies by AD. IM



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. For more information, visit: http://www.prisma-statement.org/

FIGURE 1 PRISMA flow diagram of included studies. Searches rerun on 14 April 2023.

TABLE 1 CASP quality assessment results.

Study reference	Was there a clear statement of aims for the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?
Ghio et al. (2022)	Yes	Yes	Yes	Yes	Yes
Harskamp van Ginkel et al. (2022)	Yes	Yes	Yes	Yes	Yes
Nuyts et al. (2021)	Yes	Yes	Yes	Yes	Yes
Jurich (2021)	Yes	Yes	Yes	Yes	Yes
Kidd et al. (2019)	Yes	Yes	Yes	Yes	Yes
Megel et al. (2011)	Yes	Yes	Yes	Yes	Yes
Gunnarsson and Hydén (2009)	Yes	Yes	Yes	Yes	Yes
Cox and Roos (2008)	Yes	Yes	Yes	Yes	Yes
Lauritzen (2004)	Yes	Yes	Yes	Yes	Yes
Long and Johnson (2001)	Yes	Yes	Yes	Yes	Yes

Note: Colours indicate a traffic light system (green for yes, yellow for can't tell and red for no).

also completed quality ratings for each study to ensure rigour and any disagreements were resolved through discussion. CASP checklist scores for each included study can be found in Table 1. No papers were excluded on the basis of this analysis, but the process informed subsequent analysis.

4.6 | Data abstraction

Paper full texts were uploaded into NVivo software and read by the first author (AD) to identify data and findings to code. As proposed by Thomas and Harden (2008); data abstracted for coding were not limited to one section of each paper, rather text presenting findings was included wherever it was located in the paper. Some text was found in the 'abstract' as well as 'results' sections of the papers, some had no explicit 'results' section but instead a longer 'discussion' section. All text labelled as 'results' or 'findings' was included; both the data itself in the form of direct quotes from parents and the authors' findings or summaries of the data.

4.7 | Synthesis

Thematic synthesis (Thomas & Harden, 2008) was chosen due to the relatively large number of papers and the heterogeneity in their methodological approaches.

Data were coded line by line by the primary author to capture meaning and context. (AD). A detailed code book was written reflexively through the coding process, adding new codes and consolidating others where necessary. The code book contained illustrative quotes from the data to allow for exploration and comparison. These inductive codes were initially organized in a hierarchical structure, with conceptual codes nested within broader conceptual codes. This had the goal of allowing for 'translation' of the concepts across studies while maintaining the detail and granularity of the data.

Descriptive themes were then derived inductively. By looking for similarities and differences between the codes the hierarchical codebook was subsequently refined into descriptive themes. Patterns, interactions between themes and meaning derived from themes was then summarized in analytical themes. This was done through a process of reflexive revision and discussion with the study team, again seeking out alternative interpretations and explanations to ensure rigour.

4.8 | Patient and public involvement and engagement (PPIE)

The views of a diverse range of parents were sought, as per the UK standards for public involvement in research issued by the National Institute for Health and Care Research (NIHR) (Boyle & Shamji, 2021). Parents were involved in formulating the research question during the design phase of this review.

Parents were also involved as research partners in prioritizing themes and framing concepts to bring diverse perspectives to the review. This was done through four informal engagement sessions at 'drop-in' baby groups and through a series of three weekly, 3 h 'listening cafes' with the same eight parents attending each week. These 'listening cafes' focused on the inclusion of parents from low-income families who would not typically be involved in research.

Input from PPIE was crucial in shaping the language used (e.g., 'unsettled babies') and in sense-checking the themes and concepts emerging from the systematic review. The listening cafes

Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Comment
Yes	Yes	Yes	Yes	High	Very high-quality paper
Yes	Yes	Yes	Yes	High	Very high-quality paper
Yes	Yes	Yes	Yes	High	Very high-quality paper
Yes	Yes	Yes	Can't tell	High	High-quality paper
Yes	Yes	Yes	Yes	High	Very high-quality paper
Can't tell	Yes	Yes	Can't tell	High	Moderate quality paper
Yes	Yes	Yes	Can't tell	High	High-quality paper
Yes	Yes	Yes	Yes	High	Very high-quality paper
Yes	Yes	Can't tell	Yes	Moderate	High-quality paper
Yes	Yes	Yes	Can't tell	High	High-quality paper

spontaneously raised many similar perspectives to those represented in the systematic review. Many parents from the listening cafes were able to personally relate to the themes developed from this data.

5 | FINDINGS

5.1 | Study characteristics

In total 10 studies were included. These studies were published between 2001 and 2023 and conducted in United Kingdom ($n=2$), Sweden ($n=2$), Turkey ($n=1$), South Africa ($n=1$), Canada ($n=1$), USA ($n=1$), Belgium ($n=1$) and the Netherlands ($n=1$). Table 2 reports the key study characteristics. Of the included studies, eight completed interviews or focus groups with parents directly, while two collected online data from relevant online parenting discussion forums. All studies used qualitative methodology and reported qualitative data; all focused-on parent experiences of unsettled babies, and all included parents' consideration of or relationship to a medical diagnosis/label or medical causes for their baby's behaviours. Three studies did not report number of participants. The remaining seven included a total of 103 mothers and 24 fathers.

5.2 | Critical analysis assessment

Table 1 presents results of the CASP analysis. All studies were rated very high or high quality, with the exception of Megel et al. (2011) which was rated moderate quality. All papers were deemed to be of sufficient quality for inclusion.

5.3 | Thematic synthesis

This paper presents two analytic themes and eight descriptive themes derived inductively from the data. It further presents a conceptual model which proposes the process parents may go through when faced with a baby they perceive to be unsettled.

Only one of the papers contained every descriptive theme (Harskamp van Ginkel et al., 2022). The numbers of descriptive themes in each paper ranged from three to eight. All but one paper contained both analytical themes. Jurich (Jurich, 2021) was the exception to this, with no theme of 'Identity as a good parent' emerging from this paper. This disconfirming case could be because of the narrow focus of the paper on descriptions of a physical symptom—primarily an analysis of forum posts about infant stools. Themes contained in each paper are mapped out in Table 3.

Quotes are labelled as 'Author quote' when they are the author's' interpretation developed from interview data in the source study or 'Parent quote' when directly from parents and reported word for word in the source study. All quotes are referenced with their source study.

5.3.1 | Analytical theme 1: Identity as a good parent

Parents spoke about the 'struggle' they experienced in constructing an identity for themselves as a 'good parent'. They related this to having an unsettled baby and feeling that they should be able to explain and/or control their baby's unsettled behaviours. This analytical theme included the descriptive themes of 'transition from 'me' to 'me as a parent', 'guilt and failure' and 'feeling responsible and wanting control'.

Transition from 'me' to 'me as a parent'

Some studies described a sense of transition into a new identity as a parent. This was experienced in a variety of ways. Some parents described a feeling of losing a sense of their own identity and feeling consumed entirely by their baby. Although a 'change in' or 'loss of' one's own identity is not unique to the experience of parents of unsettled babies, parents in these studies often described the all-consuming nature of their baby's behaviour as not allowing space for themselves.

> *Parent quote*: 'you, as anything more than a mother, takes a backseat. There was no differentiation of me as a person'
>
> (Cox & Roos, 2008)

Many also described how their self-image of who they thought they would be after the baby was born was challenged by the reality they faced after the birth.

> *Parent quote*: 'I never thought I wouldn't cope'
>
> (Cox & Roos, 2008)

> *Parent quote*: 'I have always thought I'm going to have a child and nature will prepare you for it'
>
> (Nuyts et al., 2021)

Some studies also found that parents spoke about their expectations of themselves as being shaped by their own parenting experiences (both good and bad) and role models for parenting around them.

> *Author quote*: 'Expectations were also influenced by their own parenting experiences as a child. When mothers experienced a problematic parenting situation as a child, they were determined to be better parents for their children'
>
> (Nuyts et al., 2021)

Guilt and failure

The majority of the papers described parents' anxiety about being 'good enough'. This was a prevalent theme that presented in a variety of complex ways throughout the data set. Often parents of unsettled babies spoke about feeling like a failure and experiencing extreme guilt, in part because they sometimes experienced negative

TABLE 2 Characteristics of included studies.

Authors (year)	Country	Parent participants (*n*)	Parent characteristics	Principle focus	Format of data	Study design	Method of data analysis
Nuyts et al. (2021)	Belgium	Mothers (*n* = 13)	Caucasian, born in Belgium. Majority professional, well educated, living with a partner. Some had mental health treatment during the study	Mothers' experiences and needs around accessing an infant mental health facility for persistent, severe *infant regulatory problems*	In-depth interviews	Qualitative Analysis Guide of Leuven (QUAGOL). Inspired by grounded theory.	QUAGOL coding
Megel et al. (2011)	USA	Mothers (*n* = 12)	Middle class women with partners. White (*n* = 11) and Hispanic (*n* = 1)	Mothers' experiences of parenting an *irritable infant*	In-depth interviews	Grounded theory	Grounded theory
Harskamp van Ginkel et al. (2022)	The Netherlands	Mothers (10), fathers (10)	Medium to highly educated, all parents worked 3 or more days per week	Parent experiences of healthcare support for *excessively crying* infants	Interviews	Exploratory qualitative study	Thematic analysis
Jurich (2021)	Turkey	Members of a social media allergy group (*n* = not known)	Unknown	How parents manage risk and make decisions on infant *food allergy*	Online forum posts	'Netnography'—internet based qualitative methodology	Ethnographic analysis
Long and Johnson (2001)	UK	Mothers (*n* = 14) Fathers (*n* = 6)	Majority white	Parents' experiences of *excessive crying*	Questionnaire, interviews and observations	Pragmatic ethnography, adapted grounded theory	Grounded theory
Cox and Roos (2008)	South Africa	First-time mothers (*n* = not given)	Urban, white, married, professional women between 25 and 35 yrs	Experiences of first-time mothers with *colic* infants	In-depth interviews	Phenomenological interviews	Descriptive analysis
Lauritzen (2004)	Sweden	Mothers (*n* = 15) and fathers (*n* = 7)	Varied Socio-economic Status, Swedish origin (*n* = 22) other origin – not given (*n* = 1)	How parents experience and understand *allergy* diagnosis in their young children	In-depth interviews	Not stated	Narrative analysis
Kidd et al. (2019)	Canada	Mothers (*n* = 21)	Majority highly educated, white, food-secure households well above the poverty line	Parents' perceptions of maternal diet in infant *cry–fuss behaviour*	Focus groups and interviews	Qualitative study	Content analysis
Gunnarsson and Hydén (2009)	Sweden	Mothers (*n* = 18), father (*n* = 1)	Not given	How child *allergy* is constructed and organized by parents in a moral everyday context	Interviews	Not stated	Narrative analysis

(Continues)

TABLE 2 (Continued)

Authors (year)	Country	Parent participants (*n*)	Parent characteristics	Principle focus	Format of data	Study design	Method of data analysis
Ghio et al. (2022)	UK	Users of online discussion forums on infant crying (*n* = not known)	Not given	To explore online parent discussions about infant *crying*	Online forum posts	Not stated	Thematic analysis and discursive psychology analysis

feelings about their baby, negative feelings about being unable to 'help' their baby or both. Many also expressed a fear of judgement from others because of their baby's behaviours, perhaps reflecting their own internal sense of guilt.

> *Author quote*: 'It seems that even though parents may have known that they had acted in a proper and responsible manner, exhausting every opportunity to help the baby, they could not rid themselves of thoughts of having failed'
>
> (Long & Johnson, 2001)

> *Parent quote*: 'My baby is telling me I am not a good mother'
>
> (Megel et al., 2011)

> *Parent quote*: 'I felt like the worst mother ever because what kind of mother can't comfort their own child'
>
> (Nuyts et al., 2021)

Many parents also found it difficult to bond with their baby, which further added to their sense of guilt and failure.

> *Parent quote*: 'There are times when you feel: "leave me alone, I don't even want to hold you," and then you feel so bad'.
>
> (Cox & Roos, 2008)

> *Parent quote*: 'There were times when you want to throw him against the wall…[sometimes I feel] like running away'.
>
> (Cox & Roos, 2008)

The complexity of the parent-infant relationship was clear, since within the same study parents expressed both feelings of rage (as above) while also demonstrating empathy for their baby.

> *Parent quote*: '"It's terrible to see her in pain"… "[it's like] having really bad heartburn"'. (Cox & Roos, 2008)

Some parents expressed explicitly that they hoped for a medical cause for the crying as a way to assuage their feelings of guilt and failure.

> *Parent quote*: 'For a long time I thought… It cannot be just the crying, there has to be something wrong with my child. Somehow I even wanted it to be cow's milk intolerance, so I knew that I wasn't doing anything wrong. I felt like I was failing as a mother because I could not help him'.
>
> (Harskamp van Ginkel et al., 2022)

Some papers described a fear of judgement, where parents said they felt other people (observers, family members or healthcare

TABLE 3 Analytical and descriptive themes mapped onto included studies.

Themes	Study reference									
	Harskamp van Ginkel et al. (2022)	Jurich (2021)	Long and Johnson (2001)	Cox and Roos (2008)	Lauritzen (2004)	Kidd et al. (2019)	Nuyts et al. (2021)	Megel et al. (2011)	Gunnarsson and Hydén (2009)	Ghio et al. (2022)
Descriptive themes within 'Identity as a good parent' analytical theme										
Transition from 'me' to 'me as a parent'	✓			✓	✓		✓	✓		
Guilt and Failure	✓		✓	✓			✓	✓		✓
Feeling responsible and wanting control	✓		✓	✓	✓	✓	✓	✓	✓	✓
Descriptive themes within 'Searching for an explanation' analytical theme										
Expectations of myself, my baby and what is 'normal'	✓	✓		✓			✓	✓	✓	✓
Feeding is linked to unsettled behaviour	✓	✓		✓		✓				
Finding help	✓	✓	✓	✓		✓	✓	✓	✓	✓
Lack of certainty	✓	✓		✓	✓	✓	✓	✓	✓	✓
Hypervigilance and desperation	✓	✓			✓				✓	

professionals) felt that they as a parent were responsible for their baby's crying. Parents reported that at times this led to them isolating themselves at home and added to their existing feelings of being alone in their suffering.

> *Parent quote*: '[I want others to] think that my baby was perfect and not that he cried all the time"..."People would look at you like" "what are you doing to that kid?"'
>
> (Megel et al., 2011)

> *Parent quote*: 'I just felt like nobody understood where I was coming from, what I was experiencing and what my child was really like'
>
> (Cox & Roos, 2008)

Feeling responsible and wanting control

Many parents spoke explicitly or implicitly of their difficulties experiencing 'helplessness' in managing their unsettled baby or a fear of losing control. A few also reflected on the challenge their infant's behaviour presented to their own self-control. Authors noted that parents felt responsibility lay with them to uncover the cause and find a solution to the problem.

> *Parent quote*: 'For as long as he carries on crying I can't help feeling that I ought to be trying something else. I'm sure it's all to do with being a mother. A mother ought to be able to make things better. But you can't. There's nothing to be done. I do know it, inside. But that doesn't stop the guilt'
>
> (Long & Johnson, 2001)

> *Author quote*: 'caregivers perceive themselves as advocates for the crying infant. It felt as though parents perceived themselves responsible completely, and therefore should know and understand the meaning behind every move and sound the infant makes, thereby knowing when something is wrong'
>
> (Ghio et al., 2022)

Some parents spoke about the lack of control over their baby's behaviours as being extremely distressing and debilitating.

> *Parent quote*: 'I felt that it would never end, the total utter helplessness to the point where you feel that you can't make this better and then losing hope that it would ever come to an end." "I reached breaking point and I gave up - this feeling of, "I can't do anymore for you"'.
>
> (Cox & Roos, 2008)

Some parents reported a feeling of 'living on the edge' (Long & Johnson, 2001) and said they were scared of losing their own self-control and harming their baby, as in this example:

> *Parent quote*: 'I think you get used to a level, even though it's a very low level. Then, when you get too much aches and pains, and the pressure is too much, it takes you over the edge. And it might not take much to send you over that edge, either. You start thinking "I shouldn't be picking the baby up because I'm starting to lose control"'.
>
> (Long & Johnson, 2001)

Data from several studies suggest that the search for an explanation—especially when it ended in a diagnosis or in medication—appeared to be useful for parents as a way to exert some control over the infant's behaviours, thereby empowering the parents to be able to 'do something about it'. The need for a firm plan was important for parents in regaining a sense of control.

> *Parent quote*: 'The first thing she said was: "How are you holding up?" And then, yes, I started crying, because I was just so exhausted. But she gave me hope: "You are not leaving here without us making a plan that you can use and hold on to"'.
>
> (Harskamp van Ginkel et al., 2022)

> *Author quote*: 'The mothers' search for information on the causes of and treatment for colic offered hope that understanding and control could be gained'
>
> (Cox & Roos, 2008)

Some studies also found examples where both relentless advocacy to healthcare professionals and suffering a personal hardship (e.g., through dietary restriction) were valuable to parents. These appeared to be being used as opportunities within their control to construct an image of themselves as a good parent; both to themselves and to others perceived as judging them.

> *Author quote*: 'responses included encouragement that the original poster (OP) should go back again, seek further assessment and advice and "fight" for the infant'
>
> (Ghio et al., 2022)

> *Parent quote*: 'when it's for your kid, it's easy to do' [discussing a heavily restricted diet while breastfeeding]
>
> (Kidd et al., 2019)

> *Parent quote*: 'He told me that as long as the baby is gaining weight and growing, peeing normally and there is nothing different with his poop, I have nothing to worry about. It was not what I wanted to hear, because my baby is in pain and I want him to feel better ASAP. Anyway he told me to take him to the GP

tomorrow and have him checked again. Will do! As many times as I need!'

(Ghio et al., 2022)

Author quote: 'Having control means for many parents in this study being able to help their children (to relieve their "suffering"), and at the same time presenting and maintaining oneself as a good, morally responsible, parent. For instance, food avoidance is a way for parents to try to control the child's well-being and health in terms of preventing illness, as well as a means of defining the situation and interpreting symptoms'.

(Gunnarsson & Hydén, 2009)

5.3.2 | Analytical theme 2: Searching for an explanation

This analytical theme comprises five descriptive themes. The search for an explanation was underpinned by parents' 'Expectations' of themselves, parenthood and their baby. It often centred around 'Infant feeding' and involved 'Help seeking'. The search was characterized by a 'Lack of certainty' and 'Hypervigilance and desperation'.

All papers described parents searching for an explanation for their baby's behaviours and four papers described this as a repeated 'cycle' or 'pattern' of failed attempts (Cox & Roos, 2008; Lauritzen, 2004; Long & Johnson, 2001; Megel et al., 2011).

Parent quote: 'We started our cycle of chiropractors, reflexologists, homeopaths, medication for reflux; we changed his formula a hundred times; we have a hundred bottles, a hundred teats; it was this desperate clinging to something'

(Cox & Roos, 2008)

Author quote: 'repeated attempts had to be made to establish a diagnosis and to find a cure. Such attempts failed, leading to a repeated cycle of hope and disappointment'

(Long & Johnson, 2001)

Author quote: 'Searching involved cycles of seeking potential causes of the crying and treatments to soothe the baby, seeking help, isolating self and baby as protection from judgmental others (stigma), and experiencing hope followed by discouragement. Consequences of the cyclic search processes included exhaustion, frustration, guilt, helplessness and disappointment on the part of the mother'

(Megel et al., 2011)

Expectations of myself, my baby and what is 'normal'

This descriptive theme includes data with parents describing their own expectations of themselves as parents or of parenthood, their expectations of their infant and their expectations of what constitutes 'normal' baby behaviour. All of these had an impact on their overall search for an explanation. Where parents had expected a settled, happy baby whom they could easily soothe and these expectations did not match with their experience, this seemed to heighten their certainty that the behaviours were abnormal and intensify their search for an explanation.

Parent quote: 'I thought it's all going to be wonderful and I'm not going to have a crying baby so when she came out and it was just this screaming all the time I really had a rude awakening'

(Cox & Roos, 2008)

Parent quote: 'I had a lot of preconceived ideas of how I was going to bring this baby up, then he ended up being colicky and I felt like burning [the parenting book]'

(Cox & Roos, 2008)

Author quote: 'The thematic analysis identified a tension between interpreting what is "normal" crying and when crying is a sign of an "underlying problem leading to the search for a diagnostic label. This tension seemed to be heightened when expectations that infancy should be a "happy time" were threatened by excessive crying'

(Ghio et al., 2022)

Feeding is linked to unsettled behaviour

Parents' accounts almost universally linked unsettled baby behaviours to feeding and parents often were quick to blame breastmilk for these behaviours. In many studies, this manifested implicitly in the data—parents were immediately assuming that the baby's intolerance of their milk feed was the cause of behaviours. Negative emotions emerged around infant feeding and repeated changes were made to the parent and baby diet in a bid to reduce unsettled behaviours.

Parent quote: 'it's a vicious cycle; you feed him and it calms him for a few minutes and then he gets more cramps, then he screams some more, so you can't keep on feeding, but then he doesn't get enough food'. [Another mother reflected] 'I just wished we didn't have to feed him'

(Cox & Roos, 2008)

Parent quote: 'Even my husband was like, "Seriously now, when are we going to have that conversation about you not breastfeeding anymore?" and I said

"We are not going to have that conversation. I am determined to work through this." He was like "OK, I guess if you want to keep going, but I am serious. When are we going to stop hearing a screaming baby? When are we going to get him formula?". (Kidd et al., 2019)

Parent quote (online forum): 'Could it be a dairy allergy? My lo [little one] had reflux and it was caused by an allergy to dairy and soy. The crying was one of our first clues. You will be prescribed special formula if you're bottle feeding… if you are breastfeeding cut dairy and soy out of your diet. It will take about 2 weeks for the dairy and soy to come out of their system so won't work straight away. Very common to be allergic to both. Good luck!'

(Ghio et al., 2022)

Finding help

Parents reported they were often driven to seek medical help in their search for an explanation and that their experiences of healthcare professionals were largely negative. Parents felt dismissed and fobbed off and there was a sense of disillusionment with the healthcare system as a whole.

In contrast, when discussing helpful interactions parents talked about needing reassurance and emotional containment from a person they trust. In these helpful interactions, they were able to feel validated and listened to and supported to understand that their baby's unsettled behaviours were not their fault.

Author quote: 'Parents scrutinise the children's problems carefully before seeking medical aid, and seek professional help with the "social baggage" of an already constructed and organized illness'. (Gunnarsson & Hydén, 2009)

Parent quote: 'A lot of the time they all said the same thing. It's just like a fob-off isn't it? To me, that's an easy way out for them. I don't think they're interested really. They don't believe what you say. They think you're exaggerating.... it's because they don't know. They just fob you off. The doctor was a waste of time'. (Long & Johnson, 2001)

Parent quote: 'I think probably it was reassurance [thinking]. Yes. That was it. Reassurance. Because I was a first time mother I needed things explaining and I always thought it was just me. But [named health visitor] kept telling me it wasn't my fault. That was good. I needed that'.

(Long & Johnson, 2001)

Lack of certainty

Many of the studies found that the search for an explanation is complicated by a lack of certainty and clarity. This manifested in a variety of ways including the unsettled behaviours themselves being difficult to measure or describe, the different uses of different medical labels, the conflicting advice received by parents and the different definitions of 'normal' baby behaviour.

Across the data set there was a lack of certainty about what constituted a 'normal' level of unsettled behaviours such as crying and vomiting, where those behaviours indicated a medical problem and exactly what medical label or term might be most appropriate.

Even among cases where medical labels had been applied, the nature of the unsettled behaviours and the search for an explanation meant that uncertainty often remained in the parent's mind.

Author quote: 'at times reflux was not described as a label but as a symptom indicating that the baby had an allergy. Colic sometimes seemed to be viewed as a label itself but most times colic was perceived as a 'gateway' to another label such as 'silent reflux' or 'acid reflux'. Terms such as allergy, intolerance or 'lactose overload' were used interchangeably'.

(Ghio et al., 2022)

Author quote: 'There remained at least some diagnostic uncertainty even after a diagnosis had been made'.

(Gunnarsson & Hydén, 2009)

Hypervigilance and desperation

It appeared to some parents that as their desperation increased to find a solution and a cause for their baby's symptoms, so too did their level of vigilance and worry. This introduced additional difficulty for parents in separating normal behaviour from symptoms of illness.

Author quote: 'It was common that parents in their interviews referred to an increased "awareness" in terms of stating that they "had to" become like "detectives" to discern what the causes of the children's problems were. It was more than merely "awareness" in that sense. Once the children's problems had been interpreted as abnormal, what was salient in the parents' stories was their problem readiness. Being detectives meant for the parents being able to help their children through finding out what was wrong'.

(Gunnarsson & Hydén, 2009)

Parent quote: 'The quest for an explanation and a cure came to be all-important. "It rules my life!"… "There have been times when my whole life revolved around seeking explanations for the crying"'. (Long & Johnson, 2001)

> *Parent quote*: 'I think that's probably where I got it wrong, though, or at least made it worse for myself. I couldn't stop trying to find the cause. I mean, you don't stop until well, in my case until he'd grown out of it. Doing at again makes you really think hard. I'm already looking for the cure before he's even born'
>
> (Long & Johnson, 2001)

5.4 | Illness-related interpretations of unsettled baby behaviours: A conceptual model

A model (see Figure 2) was developed to summarize the findings of the review, illustrating the experience parents may go through when faced with a baby they perceive to be unsettled.

This model was developed inductively from the data. Methods used in the generation of this model were influenced by critical interpretive synthesis techniques (Dixon-Woods et al., 2006) of concurrent iteration of the research question, applying both critique and themes to produce a new theoretical conceptualization. Themes presented in Table 3 through thematic synthesis were also used to inform the model.

The model illustrates that the search for a medical explanation for baby's behaviours might be motivated by parents' need to create and maintain their identity as a 'good parent'. This may be achieved by requiring parents to experience personal hardship or efforts for their baby (through dietary exclusion or advocacy to health professionals) and/or by allowing parents to regain a sense of control over their baby's behaviours, reducing their feelings of guilt and responsibility. Parents also hope that the search for a medical explanation may provide some relief from their uncertainty.

In this way, the search offers a sense of control and an opportunity for parents to assuage feelings of guilt they have internalized when faced with their own perception that they have failed.

Review findings suggest that parents can become trapped by feelings of guilt in a cycle of searching for an explanation, which ends when the baby grows out of the behaviours, or when the parent finds validation, control and/or external attribution for their baby's behaviours. As Figure 2 illustrates, this can be achieved either through medical diagnosis (route 'a') or through an experience of being validated and listened to, readjusting expectations and acquiring understanding and acceptance of their baby's behaviours as normal (route 'b'). Route 'a' or 'b' could occur in any interaction with any healthcare professional although route 'b' is likely to require more time. Historically, as the main professional group of diagnosticians and prescribers; medical professionals may utilize route 'a', however they also have the skills in relationship building and therapeutic communication required to use route 'b'. Equally nursing or other allied healthcare professions can initiate route 'a' by suggesting a medical or external cause for infant unsettled behaviours to a parent. In either case, parents need to acquire the confidence to recognize that unsettled behaviours are not their fault. In either case, parents need to acquire the confidence to recognize that unsettled behaviours are not their fault.

6 | DISCUSSION

This systematic review of international literature generated a new explanatory conceptual model which proposes the possible experience parents may go through when faced with a baby they perceive to be unsettled.

Parents of unsettled babies are often struggling to construct an identity of themselves as a 'good parent' and experiencing feelings of guilt and failure. This may manifest as a search for a medical explanation for the unsettled behaviours. This search may provide an opportunity for parents to advocate for the baby, regain a sense of control and reassure them that their baby's behaviours are not their fault.

It is hoped that this review and resulting conceptual model may contribute to a growing body of literature which suggests that supporting parent self-efficacy and positive parenting identity may help to resolve concerns for parents of unsettled babies (Ball et al., 2020; Bamber et al., 2019; Botha et al., 2020; Fallon, 2021; Gilkerson et al., 2020). It is further hoped that this systematic review may offer some understanding of the parental needs underpinning these interventions and therefore support knowledge of which interventions may work for whom and in what contexts.

The importance of parental understanding of normal baby behaviours and expectations of themselves and their baby was an important theme developed through this review. This is an enduring problem identified in research spanning the last two decades. This research suggests that societal misunderstandings and myths about normal baby sleep, feeding, behaviour and development persistently frame evolutionarily normal and adaptive baby behaviours, such as waking frequently, feeding often and wanting to be held; as a 'problem' that needs to be 'fixed' (Blunden et al., 2011; Cleugh & Langseth, 2017; Rudzik & Ball, 2016). More recent literature suggests that this 'problem' framing may exacerbate mislabelling and inaccurate medicalization, as we found in this review (Rollins et al., 2023). It has been suggested that commercial manufacturers of infant milk substitutes may also bolster this view of baby behaviour and contribute to parent worries by positioning unsettled behaviours as symptoms of a medical diagnosis (Pérez-Escamilla et al., 2023; Rollins et al., 2023). Normal baby behaviours often contrast with societal expectations of parents and a modern 21st century lifestyle, making responsive, baby-led parenting challenging in a routine driven culture (Berecz et al., 2020; Brown, 2018; Büskens, 2001; McKenna & McDade, 2005). The result of this can be that parents feel a failure, or as if their baby's behaviour is somehow 'wrong'; and it is possible that these feelings may contribute to parental health anxieties when their baby displays behaviours such as fussiness, crying or disturbed sleep (Gordon & Hill, n.d.).

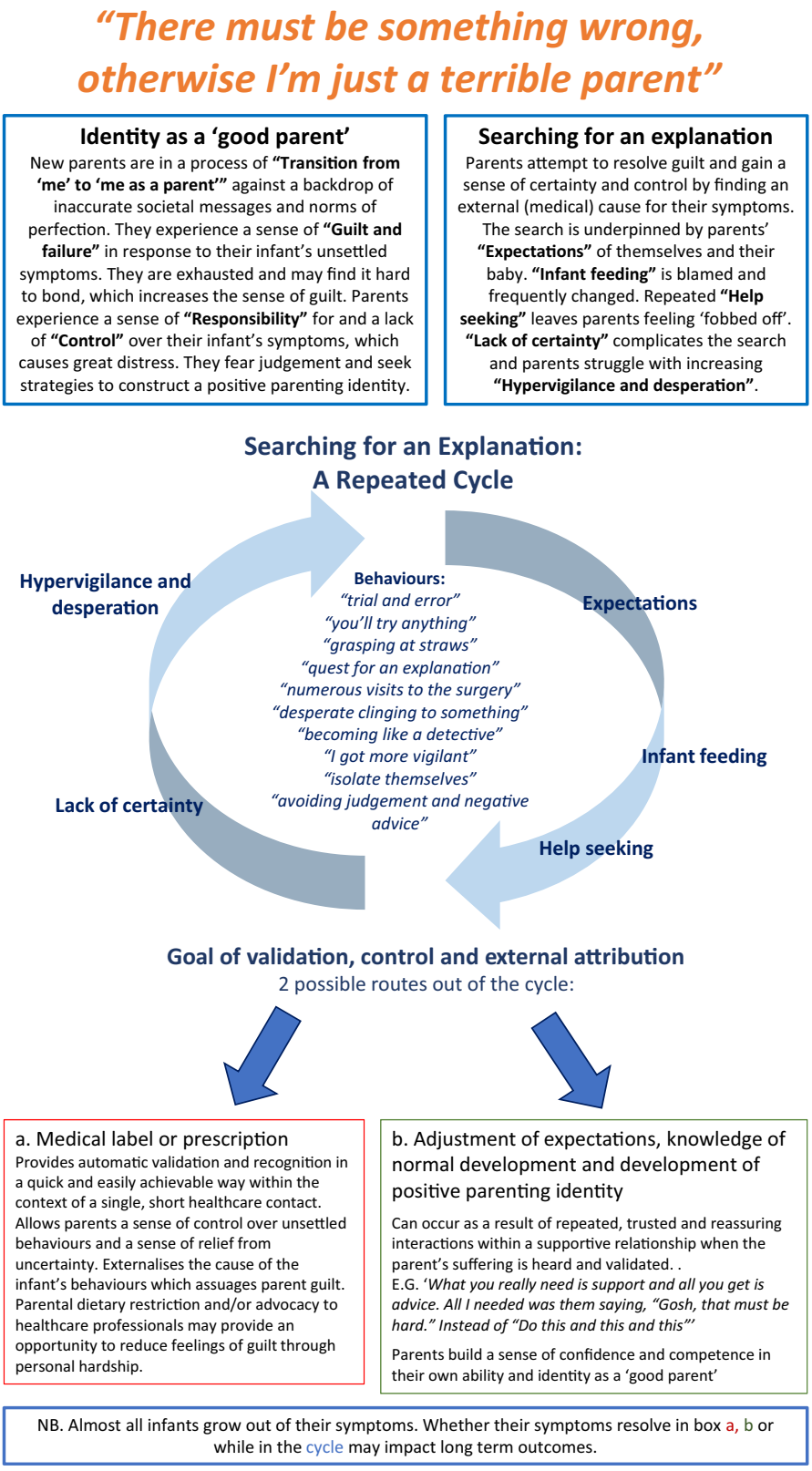


FIGURE 2 Proposed Model of how and why parents reach illness-related interpretations of unsettled infant behaviours.

Our review found that for parents of unsettled babies, their identity as a 'good parent' was very important and felt under threat. Looking more broadly at the literature, a recent narrative review on 'good parenting beliefs' (Weaver et al., 2020) synthesized the research into parents' perceptions of 'good parenting', much of which is in the context of a significantly ill child, palliative care or bereavement. In this context, parents' ability to cope with their child's illness is found to be directly related to their own assessment of whether or not they have met their own personal requirements of good parenting (Weaver et al., 2020). The findings of the current systematic review suggest that this may apply similarly to parents of generally well but unsettled babies, who

need to build a positive parenting identity to help them cope with parenting challenges. Health visiting teams, as well as midwives in the antenatal period, could explore the possibility of bolstering good parenting beliefs as a supportive strategy to help new parents cope with unsettled babies.

Good parenting beliefs are described as definable, distinct, dynamic, supported or undermined by the professionals around the family and duty-directing (Weaver et al., 2020). Parents describe that their own internal model of good parenting will guide or 'direct' their behaviour and decision making in interactions with clinicians (Weaver et al., 2020). This may help to explain the findings of this review which noted the parents' sense of duty to be a strong advocate for their baby and the way in which they used interactions with healthcare professionals to bolster their own parenting identity. It seems plausible therefore that if parents believe that the way to be a 'good parent' is by fighting for their infant to obtain a medical diagnosis or prescription for their unsettled behaviour, this is likely to drive repeated help seeking in primary care.

In their discussion of the 'good parent' role in parent–clinician conflict (Moore & McDougall, 2022), authors unpick the ethical value of the parent role as being valuable in and of itself. This may offer an alternative perspective to view the discussions between clinicians and parents when parents are feeling 'fobbed off' and describing a need to 'fight for' their baby's needs. In their role as parent, they have a specific and very important agenda which may not always align with what clinicians such as health visitors and their teams, believe to be in the 'best interests' of the child. In this situation, clinicians are therefore required to balance a thorough physical examination and serious consideration of the parent's health concerns with good communication skills and empathy in reassuring parents and managing potential conflict.

Finally, some of the experiences of parents described in this review mirror the emotions described in the psychological literature as 'parental burnout'. This condition occurs when parents' coping resources are overwhelmed by chronic parenting stress and it is characterized by exhaustion, emotional detachment from children, loss of pleasure in parenting and lack of recognition of themselves as the parent they used to be or want to be (Mikolajczak & Roskam, 2020). Recent research has been focusing on measuring and understanding parental burnout because of its importance for both child and parent outcomes and wellbeing (Roskam et al., 2018, 2021). Although the studies included in this review did not specifically measure burnout or reference the parenting burnout literature, future research could explore whether the experiences of some parents of unsettled babies may constitute parenting burnout.

6.1 | Strengths and limitations of this review

This is the first systematic review of international research to provide an understanding of the experiences and perspectives of parents of unsettled babies in relation to the process of acquiring medical labels such as allergy and reflux. As such it offers a new insight into the current unmet need experienced by parents which could usefully inform nursing practice. Findings were similar across a number of different international health care contexts. It further offers a possible new explanatory model to understand this need. Good practice guidelines for qualitative systematic review reporting (Tong et al., 2012) were followed throughout. Trustworthiness was maintained through second screening titles and abstracts and thorough use of PPI.

Due to capacity restraints this review was unable to consider parents' thoughts, attitudes and expectations about unsettled babies in pregnancy. Future research could synthesize research into the antenatal period, since this time is likely to be important, particularly for expectation formation (Moore & McDougall, 2022; Weaver et al., 2020).

6.2 | Limitations of included studies

Included studies were limited by a lack of sample diversity—only four studies included data from fathers (total $n = 27$) and no data from parents of other genders; low numbers of parents from ethnic minority or lower socio-economic groups and no known data for non-biological parents. In many cases, these data were not gathered or reported in the papers. Where it was reported, sample demographics such as education levels or employment status were used as proxy indicators of socio-economic status. Good parenting beliefs have been found to be significantly different across cultures (Lin et al., 2023). Families on a low income may also be disproportionately affected by the impacts of misdiagnosis, such as premature cessation of breast/chestfeeding, the need to purchase formula milk (Salvatore et al., 2018) and the disproportionate impacts of health inequalities (Marmot, 2020). The inclusion of these families must therefore be a high priority for all future research.

Despite the systematic search identifying 10 studies with useful data for inclusion, there are very few which focus entirely on parents' perceptions of medical labels in relation to their unsettled baby. In the majority of studies data were included in studies of parent experiences of their unsettled baby more broadly, or parent experiences of healthcare interactions for their unsettled baby. Future research focused specifically on parents' experiences of medical labels for their unsettled babies is needed and should be inclusive of underserved communities.

7 | CONCLUSION

7.1 | Implications for practice

Health visiting teams, and other professionals working with families who are worried about their baby's unsettled behaviour could understand parents' 'search for an explanation' in the context of an

attempt to create a positive parenting identity during the transition to parenthood. Help for families of unsettled babies could focus on managing expectations, normalizing the continuum of infant behaviours, reducing feelings of guilt or uncertainty and helping parents regain a feeling of control. This may help reduce inaccurate medicalization of unsettled infants.

In addition, health visitors, nurses and midwives should also be aware that parents seeking help for unsettled baby behaviours frequently feel dismissed or ignored in contacts with healthcare professionals. Care should therefore be taken to validate the parent's experience and listen to their concerns, maintaining an awareness of key medical red flags.

Specifically, health visitors', nurses' and midwives' support to parents of unsettled babies could focus on:

- Therapeutic, active listening techniques
- Working in partnership with parents to build a personalized action plan
- Strengths-based communication

Offering reassurance while attempting to validate parent concerns may be a difficult balance for clinicians, therefore service providers and commissioners should be aware of the need for adequate time and emotional capacity in the workforce to provide authentic, empathic emotional support to new parents.

ACKNOWLEDGEMENTS

I would like to acknowledge the help and support of the parent representatives who supported the development of this work and whose perspectives and contributions were vital to the success of the review. Amy Dobson, Doctoral Research Fellow, NIHR award reference number C008 is funded by the NIHR for this research project. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR, NHS or the UK Department of Health and Social Care. For the purpose of open access, the author has applied a Creative Commons attribution licence (CC-BY) to any Author Accepted Manuscript version arising from this submission.

CONFLICT OF INTEREST STATEMENT

None.

PEER REVIEW

The peer review history for this article is available at https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jan.16166.

OPEN RESEARCH BADGES

This article has earned an Open Data badge for making publicly available the digitally-shareable data necessary to reproduce the reported results. The data is available at [[insert provided URL from Open Research Disclosure Form]].

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author, AD, upon reasonable request.

ETHICS STATEMENT

Any data utilized in the submitted manuscript have been lawfully acquired. Genetic resources were not required or used. The protocol for this systematic review was registered on Prospero (CRD 42022355249). Approved by University of Southampton Research Governance ERGO 88132.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Dobson, A., Hornsey, S., Ghio, D., Latter, S., Santer, M., & Muller, I. (2024). 'Either something's wrong, or I'm a terrible parent': A systematic review of parent experiences of illness-related interpretations for unsettled babies. *Journal of Advanced Nursing*, *00*, 1–18. https://doi.org/10.1111/jan.16166