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“Can someone tell me what’s going on with my child?”: A qualitative study on parental health-seeking behavior for infant regulatory problems

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Abstract

Background According to the principles of infant mental health care, young children’s gradual attainment of self-regulation is closely tied to co-regulation provided by the caregiver(s). Sometimes, these co- and self-regulatory processes are not seamless and regulatory problems (RP) can arise, which manifest themselves according to age and developmental stage of the child. Parents of children with RP often face prolonged periods of seeking specialized care and become entangled in a cycle of ineffective health-seeking behaviors. The present study aims to understand parental health-seeking behavior in response to their infant’s RP, and the missed opportunities therein, by retrospectively analyzing the healthcare journey of families.

Methods Respondents were sampled in collaboration with child psychiatrists from two tertiary care infant mental health day clinics, using extreme case study sampling. Semi-structured interviews were conducted with 14 families (10 fathers and 15 mothers). The mean age of the infants at the time of admission was almost 11 months. The research interviews were qualitatively analyzed via reflexive thematic analysis in NVivo, within the design of a qualitative descriptive study.

Results Four main themes are identified. (1) ‘The need for answers’ highlights the fact that parental concerns about what is normal infant behavior, and about possible underlying causes, are significant triggers for seeking (professional) help. (2) ‘The search for recognition and understanding’ identifies the profound impact on parents of being validated by their social network, but also by healthcare providers, in order to obtain timely referrals to specialized care. (3) ‘The lack of a broader approach’ discusses the importance of a holistic approach, which considers not only the physical but also the socio-emotional health of the infant, along with the well-being of parents. (4) ‘Lost in a healthcare maze’ emphasizes how parents feel abandoned by healthcare providers during their search for help.

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Conclusions The complex and fragmented nature of parents' search for help often results in delayed referrals to specialized care. Parents believe that the care pathway for families with infants experiencing RP could be improved by addressing the identified missed opportunities.

Keywords Infant mental health, Regulatory problems, Health-seeking behavior, Missed opportunities, Healthcare providers, Holistic health, Qualitative research, Extreme case sampling

Text box 1. Contributions to the literature

- This study is the first in Belgium to explore the health-seeking behavior of families with an infant experiencing persistent, severe regulatory problems, by interviewing both fathers and mothers.
- Public health policies should prioritize infant mental health, including regulatory problems, for instance, by incorporating these concepts into medical guidelines and by creating specialized Belgian initiatives.
- This work holds the potential to mitigate future barriers to care and to enhance matched care for families with an infant with regulatory problems.

Background

In recent years, research on infant mental health (IMH) has grown considerably. According to the Developmental Origins of Health and Disease (DOHaD) hypothesis, the first 1000 days of a child's life establish a foundational blueprint for their future mental well-being [1, 2]. In line with the principles of IMH care, young children's gradual attainment of self-regulation is closely tied to co-regulation provided by the caregiver(s). Co-regulation functions as a dyadic communicative system between caregivers and infants, in which caregivers are sensitive to the signals of the infant and respond by meeting the infant's needs [3]. Self-regulation involves balancing internal processes (physiological, emotional, cognitive) and behavior, as well as external influences [4].

Self- and co-regulation act as the foundation of infant socio-emotional development and are anchored in biopsychosocial literature. Tronick's Mutual Regulation Model (MRM) [5, 6] explains that infants develop self-regulation skills through repeated cycles of co-regulation with caregivers, internalizing parental responsiveness via dyadic matches, mismatches, and repair. As such, caregiver and infant become 'attuned' to one another at a bodily, physiological, neural, behavioral, emotional, and cognitive level. This 'biobehavioral synchrony' serves as the underlying mechanism of co-regulation and eventually supports the child to self-regulate [7, 8]. The ongoing process of infants experiencing stress or overwhelming emotional arousal and the sensitive response of parents to calm their infant and meet its needs as a reaction, sets the basis for a secure attachment relationship [9]. Winnicott's holding theory complements this by emphasizing the importance of a caregiver's ability to provide a supportive and nurturing environment, a 'holding environment', which is crucial for the infant's emotional development [10]. Moreover, within Tronick's model, parents not only directly influence the regulation process but also serve as buffers against external environmental stressors like neighborhood violence or poverty. If the caregiver is able to self-regulate the dysregulating effects of stressful external factors, (s)he is more likely to act as a buffer of these effects on the infant [5, 11]. This is in line with Sameroff's transactional model [12] and Bronfenbrenner's bioecological theory [13–15] that emphasize the importance of the (wider) environment in studying disease and health and highlight the mutual influence between the child and their environment.

However, sometimes, the co- and self-regulatory processes are disrupted and regulatory problems (RP) may arise. The term RP is currently commonly used in the literature and clinical practice to describe challenges in emotional and behavioral regulation [16]. RP can have a wide range of manifestations, varying according to the age and developmental stage of the child [17]. Inconsolable crying, persistent sleeping problems, and persistent feeding problems are among the most frequently reported RP during the first year of life; approximately 20% of infants experience at least one RP [18, 19]. A smaller subset, ranging from 2 to 9%, exhibit more complex patterns of RP, including the simultaneous occurrence of multiple problems and/or the persistence of these problems [19]. Most early RP are transient and resolve spontaneously as the child matures [20]. However, the more severe combinations of multiple or persistent RP have been associated with behavioral problems in childhood and may increase the risk of neuropsychiatric disorders such as ADHD [17, 21–23]. Moreover, RP could influence later-life outcomes, including social and academic functioning, interpersonal behavior and mental health [24–26], highlighting the importance of early intervention.

Parents of children with persistent severe RP often struggle to access specialized care due to the diagnostic and therapeutic complexities involved. Care pathways for these children are inherently complex as children rely on adults, mostly their parents, to recognize their problems, determine whether they require services, and seek help on their behalf [5]. Furthermore, it is important for health professionals to be alert to the possibility of overdiagnosing or misdiagnosing infants with RP as having a medical condition [27, 28]. Indeed, research suggests that only a minority of infants with RP (less than 10%) have an underlying organic cause, such as gastroesophageal reflux (GER), cow's milk protein intolerance (CMPI) or lactose intolerance [29, 30]. On the other hand, there is also a risk of underdiagnosis, resulting in a lack of necessary interventions. Parents may try other approaches (e.g., acupuncture, herbal remedies), all with weak evidence for effectiveness [31, 32]. The lack of effective and consistent treatment options for RP leads to a cycle of ineffective health-seeking behaviors among parents and exacerbation of RP [33, 34]. The scarcity of adequate services, especially within the Flemish context, frequently necessitates referral to highly specialized care providers as a last resort.

To date, knowledge regarding parents' health-seeking behavior in response to their infant's RP and the missed opportunities in this process is limited. Notably, existing studies on this topic predominantly focus on the experiences of mothers [35], while fathers' narratives remain largely unexplored. This study aims to address these gaps by retrospectively analyzing the healthcare journey of families who sought professional help because of persistent, severe infant RP, prior to their admission to an IMH day clinic.

Materials and methods

This study is part of the larger research project Co-PRIME (Co-regulation as the foundation of PReventive Infant MEntal health care). Co-PRIME is a collaborative initiative aimed at preventing mental health problems in young children. The project brings together three Flemish (Dutch-speaking part of Belgium) universities, the University of East London, and various community partners. It focuses on the critical role of co-regulation in developing self-regulation during infancy [36].

Research design

A qualitative descriptive study using semi-structured interviews was performed [37, 38]. Given the limited scientific knowledge on the subject, we opted for a qualitative descriptive design. This approach allows us to obtain a detailed and in-depth understanding of parents' health-seeking behavior for their infant's RP, and to explore the missed opportunities as reported by the parents.

Setting and sample

The Flemish healthcare system is organized in a stepped care model. Specifically for pediatric care, there is a Flemish pre to 0th/1st line childcare service, called Growing Up. Growing Up aims to follow up every newborn up to 3 years old and reaches more than 90% of all Flemish infants and young children [39]. Primary care providers (e.g., general practitioners, midwives and psychologists) offer accessible healthcare for a wide range of health issues. For more specialized care, patients can be referred to secondary care specialists (e.g., pediatricians, more specialized midwives and psychologists), often located in hospitals. Tertiary care is reserved for the most complex (mental) health conditions.

The sample for this study was drawn from two specialized tertiary IMH day clinics: [1] the Infant Unit of the University Psychiatric Center of Leuven (kleine K) and [2] the University of Antwerp Child and Adolescent Psychiatry (UKJA). These clinics focus on providing comprehensive care to families of infants with persistent severe RP. A detailed description of the treatment phases and programs offered by each clinic can be found elsewhere [33, 40]. Recognizing that tertiary care typically serves as the endpoint for many families seeking care, we selected this setting to foster a comprehensive understanding of the entire care trajectory. This sampling strategy is a form of extreme case sampling, and the cohort represents a distinct and extreme subset of the broader population of parents caring for children with RP [41]. By sampling from this population, we can gain valuable insights into the challenges and missed opportunities faced by parents at various stages of the care process.

The inclusion criteria for parents were as follows: [1] Being admitted with their infant to the 'baby group' for infants aged 3 to 18 months (developmental age) at the time of admission [2], Being discharged from kleine K or UKJA between January 2023 and March 2024 [3], Being at least 18 years old [4], Absence of pre-existing psychiatric disorders (e.g., major depression, major anxiety disorder, psychotic disorder) at the time of admission and [5] Absence of severe genetic abnormalities or life-limiting illnesses in their infant (because the care trajectory is then more complicated for medical reasons).

Based on these criteria, the heads of the IMH facilities, who are child psychiatrists, identified eligible families from their clinics for our study based on their medical records. The eligible families of each facility (22 from Kleine K and 24 from UKJA) were selected to receive an invitation from the child psychiatrist to participate in a face-to-face interview. Those who agreed were contacted by the first author (FH) for the planning of an interview. After agreeing to participate, and after giving written informed consent, the parent was included in the study. Ultimately, 25 parents (14 families) participated in the study, 21 parents from kleine K and 4 parents from UKJA.

Demographic characteristics of participants

Fourteen families (10 fathers and 15 mothers) participated in this study. Eleven families had a father-mother constellation, two families consisted of a father and a mother who were separated and one family had a mother-mother constellation. In three families, only the mother participated in the interview; the father declined to participate. Most mothers and fathers were born in Belgium. The mean age at the time of the interview was

39 and 35 for, respectively, fathers and mothers. The majority of fathers had a bachelor's or master's degree (80%) and each father was engaged in a professional activity at the time of the interview. Most mothers had a bachelor's or master's degree (87%), but only 60% were engaged in a professional activity at the time of the interview. The mean age of the infants at the time of admission was almost 11 months and the mean duration of admission was almost eight months. More detailed participant characteristics are presented in Table 1.

Data collection

16 in-depth semi-structured interviews were conducted by two female qualitative researchers and nine interviews were conducted by the first author alone. To mitigate potential influence, mothers and fathers were interviewed separately. During three interviews, the infant was also present. The interviews were conducted between March 2024 and October 2024 and took place at a location of the participant's choice. 15 interviews occurred online via Microsoft Teams, four interviews took place at the participant's home and six interviews took place at a research facility of the universities involved. The

Table 1 Overview of socio-demographic characteristics of interviewed parents and their families

A. Characteristics by gender	**Fathers (*N* = 10)**	**Mothers (*N* = 15)**
Mean age, at the time of the interview, in years	39.2	34.7
Median age, at the time of the interview, in years (Q1;Q3)	40 (37;43)	34 (31;38)
Nationality (n)		
Belgian	8	13
Belgian with migration background	1	1
Dutch	0	1
Spanish	1	0
Education level (n)		
Until 18 years	1	2
Bachelor's degree	2	4
Master's degree	5	8
PhD	1	1
Missing	1	0
Employment, at the time of the interview (n)		
100% employed	6	2
90% employed	2	1
80% employed	2	3
60% employed	0	1
40% employed	0	2
0% employed	0	5
Student	0	1
B. Characteristics by family	(*N* = 14)	
Family constellation (n)		
Father-Mother, living together	11	
Father-Mother, separated	2	
Mother-Mother	1	
Parity, at admission (n)		
Primiparous	7	
Multiparous*	7	
Infant's gender (n)		
Boy	7	
Girl	7	
Mean age of infant at admission to IMH clinic, in months	10.6	
Median age of infant at admission to IMH clinic, in months (Q1;Q3)	8.5 (4;15)	
Mean total duration of admission, in months	7.9	
Median total duration of admission, in months (Q1;Q3)	6 (5;11)	
Mean waiting period before admission, in weeks	9.8	
Median waiting period before admission, in weeks (Q1;Q3)	2.5 (2;8)	
Pregnancy, regarding the admitted infant (n)		
Natural	10	
In Vitro Fertilization (IVF)	4	

*In one family, a foster child was already part of the household before the birth of a biological child interviews were conducted in Dutch and lasted between 65 min and 140 min (mean: 99 min).

We iteratively developed a semi-structured interview guide, with open-ended questions based on the available literature and the expertise of the multidisciplinary team. Test interviews were conducted to refine the interview guide for optimal clarity. The interviews started with the open-ended question: "How is your child doing at the moment?". Thereafter, the participants were encouraged to give a detailed account of their healthcare journey, from their initial experience of difficulties up to the point of tertiary care. Specifically, the researchers focused on the care families received, and the care they lacked, during the parents' search for help for their infant's RP, prior to their admission to the IMH day clinic. Examples of specific questions from the interview guide include: "Before you were admitted to the IMH day clinic, can you tell me who and what helped you in your search for help?", "How did you experience this period in general?" and "What message would you give to healthcare professionals to help them handle this better?". The detailed interview guide can be found in the appendix. Probing questions were asked to obtain in-depth answers and were adapted to the participants' responses. Interviews were audio-recorded and the interviewers maintained field notes during the interviews. After the interviews, parents were asked about their sociodemographic background (see Table 1) and their reflections on the interview.

Data analysis

Interviews were transcribed verbatim in Dutch. The names of the respondents, specific healthcare providers and clinics were removed from the transcripts to respect their anonymity and privacy. Respondents were given pseudonyms to ensure their anonymity throughout the research. Additional nonverbal elements were incorporated. Each interview was then reread in order to gain a tentative holistic understanding and a deeper familiarity with the responses.

Alongside data collection, interview transcripts were analyzed using Braun and Clarke's reflexive thematic analysis [42–44]. The analysis adopted an inductive (bottom-up) latent approach, within an interpretivist and constructivist paradigm, allowing patterns to emerge from the data without preconceived theoretical frameworks [45]. The process typically involves six steps. Firstly, the first author familiarized herself with the data to obtain a comprehensive overview by reading and rereading the transcripts of the interviews. Secondly, interesting features of the data were systematically coded by the first author in an iterative process using NVivo 14. A selection of data was independently coded by two female researchers to ensure intercoder reliability. In the third, fourth, and fifth steps, themes were generated by grouping codes, reviewed for accuracy, and then defined and named to explain their significance. Finally, writing up involved creating a clear and structured narrative that showcases the findings and their significance. The process of analysis started immediately after the first interview had been conducted, and continued until data saturation had been reached. To enhance reflexivity, the entire research team engaged in ongoing discussions to define, refine, and agree upon theme and subtheme definitions and content. This iterative, forwards-and-backwards approach aimed to achieve thematic saturation. To confirm saturation, four more interviews were conducted after which no new themes emerged.

Demographics were analyzed using Microsoft Excel 365. The SRQR quality checklist was employed to ensure the quality of the qualitative research [46]. The quotes presented in this paper were translated into English.

Ethics statement

This study was conducted according to the guidelines of the Declaration of Helsinki and all procedures involving humans were approved by the Ethics Committee for the Social Sciences and Humanities (registration number SHW_2023_307). Written informed consent was obtained from each participant before the start of the interview. In line with ethical research practices, participants were explicitly informed of the voluntary nature of their participation, the possibility to withdraw at any time during the study, and the confidentiality protocols. We provided parents with information about available support services in case emotional issues resurfaced during the interview. To compensate for their time and effort, all participating parents were provided with a €15 gift voucher.

Reflexivity and methodical considerations

Reflexivity involves acknowledging and analyzing how a researcher's biases and perspectives might impact their research, allowing them to approach data with greater openness and consider diverse perspectives [43, 47]. The first author (FH), a medical doctor, led the qualitative research. She kept reflective journals to document her thoughts, feelings, and potential biases throughout the study. This practice helped her remain aware of her own influence on the research process. To strengthen the reliability of the coding process, two additional researchers (a sociologist SDB and a child and adolescent psychiatry resident HW) independently coded parts of the interview transcripts. The independently generated codes were compared and discussed in detail with the lead researcher. Additionally, the research team continuously collaborated to establish, adjust, and reach consensus during the coding process. The diverse perspectives

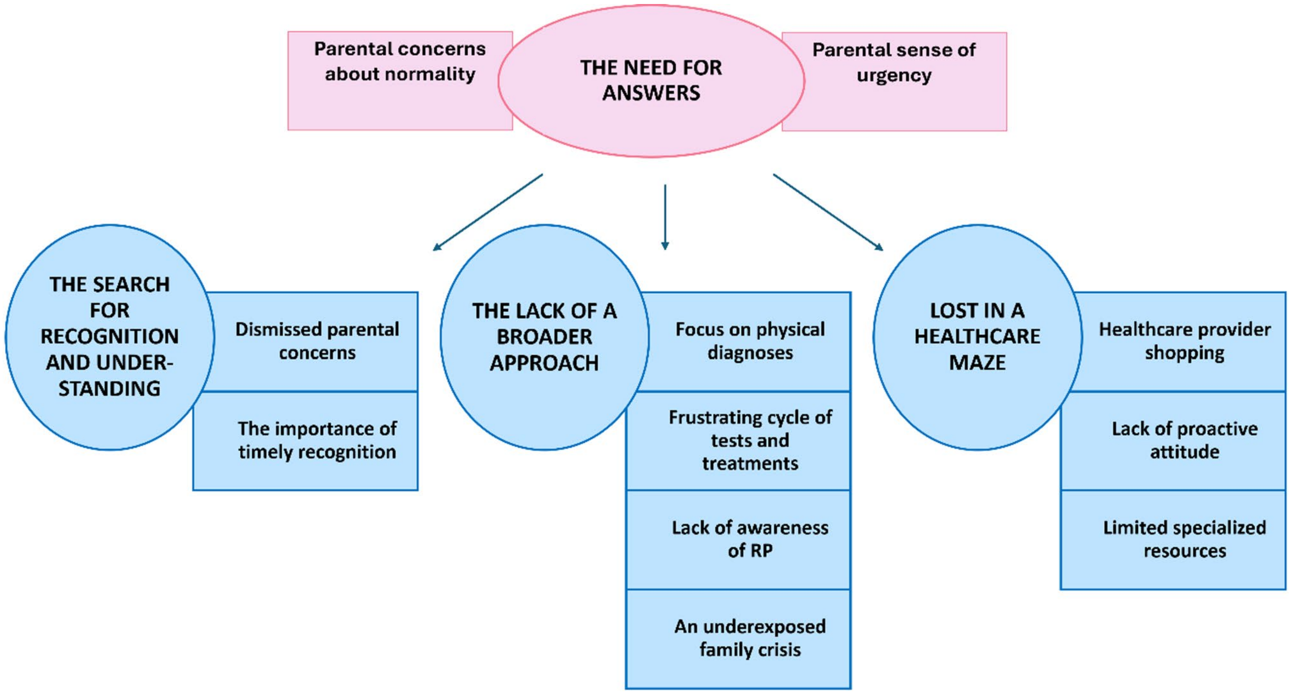

Fig. 1 Final thematic map

Table 2 RP quoted by parents during the interview

RP identified by parents	Fathers (*n* (%))	Mothers (*n* (%))
Appearing strained	3 (30%)	4 (26.7%)
Appearing unhappy	2 (20%)	6 (40%)
Avoiding eye contact	0	1 (6.7%)
Clenched fists	2 (20%)	2 (13.3%)
Clingy to parent	2 (20%)	7 (46.7%)
Constipation	1 (10%)	0
Difficult to feed	5 (50%)	9 (60%)
Excessive sleeping	0	1 (6.7%)
Fluttering	0	1 (6.7%)
Frightened expression	1 (10%)	2 (13.3%)
Inconsolable crying	7 (70%)	11 (73.3%)
Losing control around strangers	1 (10%)	1 (6.7%)
Overreacting (e.g. to pain, noise…)	3 (30%)	6 (40%)
Overextending (limbs or body)	2 (20%)	2 (13.3%)
Sleep disturbances	8 (80%)	11 (73.3%)
Sleep onset insomnia	7 (70%)	12 (80%)
Stiff body	2 (20%)	1 (6.7%)
Vomiting	1 (10%)	2 (13.3%)

within the research team enhanced the analytical process and minimized individual biases, ensuring the results were not solely influenced by one perspective.

Results

Four overarching themes and several subthemes emerged from the data, all capturing missed opportunities identified by parents of infants with RP. Figure 1 highlights the themes and subthemes.

The need for answers

Parental concerns about normality

During the interviews, fathers and mothers were asked about behaviors they perceived as atypical, which they now recognize as RP. The responses were diverse, encompassing a broad spectrum, from overextending the limbs or body to being clingy to the parent (see Table 2). Nevertheless, the three most frequently reported RP were crying, sleep disturbances and feeding problems.

Initially, a number of parents believed that their infant's atypical behavior was temporary and harmless, interpreting it as a result of the early stages of child development. However, over time, many parents changed their minds about interpreting their infant's behavior as typical. This realization was often triggered by multiple factors, such as the consistent nature of the infant's behavior, the infant's increasing age rendering the argument of "growing out of it" no longer viable and the feeling that they had exhausted all possible parental interventions.

At first, you think to yourself, it can't be perfect all the time, it's normal, so let's wait and see, it will get better. But it persisted, day in, day out. We thought, this is really not normal anymore. My wife is also a childminder, for seven or eight years now, and she has helped so many children and parents, including the children with sleep and feeding problems. And those issues got resolved after a while. But not with us. We couldn't get a handle on our own child. She always said "I can't do anything more, I have done everything I could and should do". (James)

A limited number of parents perceived their infant's behavior as 'not normal', 'different' or 'atypical' from the beginning, even though they were uncertain about the potential cause. For some parents, the primary explanation for this was their contrasting experiences with the older siblings.

We came home and immediately noticed that something was wrong. She cried all day long. We couldn't do anything to comfort her. We spent the whole day walking around, singing, and trying different things... And then we knew, this isn't working, this isn't good for her, this isn't good for us (Elise).

In some families there was a discrepancy, with mothers expressing greater concern about their infant's behavior or development compared to fathers, who maintained a more expectant attitude. However, in most cases, both partners shared a similar intuition regarding the behavior of their infant.

My wife has been saying for I don't know how long, "My child is different". And I always said "Yes, it will be fine, he will manage well". "But he can't talk yet. He can't speak yet". "Yes, that will be fine. Einstein also only started talking from the age of four". So I always see positive things and I always put a positive spin on it. So in that regard, actually, when my wife says or notices something, only then I start looking at it. (Alexander)

Parental sense of urgency

Many parents reported feeling a pressing need to consult a healthcare provider when their infant experienced, for instance, inconsolable crying. This urgency stemmed from parental uncertainty regarding their infant's behavior and the potential for serious underlying health issues requiring immediate professional evaluation and intervention. They sought urgent medical consultations, hoping that prompt diagnosis and intervention would quickly ameliorate their infant's behavior. At that point, the overriding question for parents was: "What's going on with my child?".

And I had to go as soon as possible. Because at that moment, you don't know that it's going to be something long-term. You know that he cries a lot. And that it's very extreme. And you think, there is something wrong. And maybe it can be solved. And maybe the pediatrician will see something like, oh, he has this or he has that. I wanted to know. It could be many things. But you don't realize yet that it's going to be a child with RP. (Sophia)

The search for recognition and understanding

Throughout their search for answers, parents expressed feeling disempowered by the tension between their own intuition and the beliefs of others. Despite having a strong feeling that something was wrong with their child, parents' concerns were often acknowledged (too) late.

Dismissed parental concerns

Parents who voiced their worries about their infant were initially reassured about typical infant behavior. From their family and friends, parents often received dismissive remarks, for example "All babies cry" and "It will get better". Healthcare providers frequently told parents that the behavior of their infant fell within the normal range of development, such as the peak of infant colic at six weeks of age. They were advised that their infant's behavior was expected to improve within a few weeks, which in certain cases restored their hope.

I remember that (name of pediatrician) told me at eight weeks, "This is now the peak of the cramps, and hang in there a little longer, in a few weeks it will get better". (Emma)

Other parents mentioned that the divergence between an infant's behavior at home versus that in an unfamiliar setting often led them to feel that their concerns were being dismissed. The parents perception was that people in their social network and healthcare providers needed to witness the behaviors firsthand before acknowledging their concerns.

We always noticed that when we went somewhere, she would withdraw into herself, so she didn't cry much. And the doctor, of course, would get the opposite impression, that she is fine, and she doesn't cry and she eats well. (Lisa)

Apparently, (name of child) was always very calm at my parents' house when he stayed over. And because of that, they thought there was nothing wrong. That was difficult for me because then I suddenly came up with (name of IMH clinic) and I got a lot of pushback, but I persevered. I thought, no, this is no way to live. You can all go jump in a lake, but I'm going to do this now for me and my child. Because I feel that this is not okay. (.) And then, there was one evening when I was at my family's house with (name of child), and he suddenly had a huge tantrum, and everyone got goosebumps. And I said, "This is what I experience every day, all day long!". So, and... Then finally, there was a little bit of realization. (Isabelle)

Other situations occurred in which parents received unsolicited advice and criticism that was incongruent with their personal beliefs. For many parents, these dismissive responses made them question their intuition and doubt the severity of the situation, often delaying them from seeking (further) professional help.

The advice we got from our family... We did nothing right. "You need to put her in a routine. Then she will sleep". But that wasn't the case. (...) We just felt that there was something wrong with her, but we couldn't understand what it was exactly. And our family didn't understand that at all. (...) So yes, when did we realize that there was something with her? Actually, from the beginning. But because it was somewhat overshadowed by *our family's judgment and so… we just had to be strong enough to go against that. (Marie)*

I have such a good relationship with (name of general practitioner). And yes, now I found it strange that he said, "Come on, you have so much experience, just put him to bed and let him cry, and then he will learn". And I said, "No, no, it's not just crying. It's really screaming his lungs out". And he said, "Then take him to your sister's for the weekend, then he will learn that mom is not there, and then he will learn to be quiet". But I thought, no, that's not the solution. (…) And I developed such an aversion to the medical field actually. (Evelyn)

A significant number of parents have been subjected to insensitive remarks from healthcare professionals. Parents reported that these comments were deeply hurtful, as they felt a profound sense of misunderstanding from healthcare providers who failed to recognize the immense challenges they were facing at home. Parents agreed that the manner in which information is conveyed significantly impacts interactions. They would have appreciated a more comprehensive understanding of their circumstances.

There was an assistant who made an unfortunate remark in the emergency room: "Are you going to throw your child out of the window or not? No, go home. Yes, then we'll admit you." I thought, what is the value of that question? We come because we are seeking help; otherwise, she would already be out of the window, and we wouldn't need to come anymore. Those are the kinds of remarks… that I really blame. And I consider it a professional mistake. You really shouldn't make such stupid remarks! (Emily)

We were treated terribly by (name of pediatrician). (Name of child) was crying and arching his back, and I said, "Look!" and the pediatrician said, "Oh, yes, I don't document those things". So, she kept saying "You are imagining all those things". She completely tore us down, and we left feeling very bewildered. (William)

Remarkably, one family noticed that the physician's viewpoint seemed to shift after the father accompanied the infant to the appointment instead of the mother. The mother, who had consistently felt dismissed when expressing her concerns, believed that the physician had initially attributed the infant's behavioral issues solely to her parenting. However, observing the infant's reaction to the father seemed to offer the physician a broader perspective on the factors contributing to the infant's behavior. The altered perspective led the physician to refer the family to the IMH clinic following a single consultation with the father, in contrast to the multiple consultations with the mother that resulted in no such referral.

So back to that one pediatrician nearby, where I had already been many times. And I felt that he always thought that I was the mom who spoiled my child too much, not letting go properly. But my husband was there with (name of child), who was sick, because I had gone to work. And the pediatrician saw how (name of child) reacted when my husband had to undress him for the examination. How loud he was screaming during that doctor's examination and so on. (…) I think that then… he thought "Well, this is with the dad, and with the dad, the child also behaves like this, I haven't seen many babies screaming so loud just to get dressed again". (Emma)

Overall, almost all parents encountered challenges in communicating their parental concerns, leading to feelings of misunderstanding and disbelief. As a result, they often felt compelled to advocate forcefully for their concerns to be acknowledged.

So indeed, you are constantly in that mode of "We should see now that it's serious", but we also have to be able to convey it. So those healthcare providers were always a few steps behind how we experienced it. (George)

The importance of timely recognition

Parents highlighted that it would have saved them a lot of energy and stress if they had been taken seriously from the beginning, instead of having to constantly argue, search for information and make appointments with several healthcare providers. The absence of recognition and timely referrals to specialized care left parents with a sense of wasted time and energy and a belief that earlier intervention could have been beneficial.

But I do think that if we had been believed from the beginning, things would have been different, because being believed is where it starts. (…) There was a professor of pediatrics who holds the principle that a mother is always right, until proven otherwise. That should be the starting point everywhere. And I can imagine that there are incredibly many children and incredibly many worried parents. But I think everyone deserves the benefit of the doubt. It's about a small child who is essentially helpless. And the parents are too. Because otherwise, the consequences are enormous. The consequences for both the child and the parents. (Emily)

Some parents expressed the profound impact of being validated by their social surroundings and healthcare providers. The acknowledgment of the atypical nature of their experiences, coupled with the assurance of accessible support, offered a crucial sense of hope, alleviating the pervasive feelings of isolation and misunderstanding that had previously burdened them.

But (name of psychologist), she was the first person to finally bring some recognition. Because we didn't get that from anyone. Not from family, not from friends, not from the healthcare providers. And then the ball actually started rolling quite quickly. We were able to quickly schedule an appointment at (name of IMH clinic). And it was so nice to have someone acknowledge that what you *are going through is… (becomes emotional) not normal. (William)*

The lack of a broader approach

Throughout their search for answers, parents highlighted that the focus was almost exclusively on possible physical causes in the infant. Socio-emotional factors in the infant and the well-being of the parent(s) were largely overlooked.

Focus on physical diagnoses

Many parents reported how general practitioners or pediatricians typically first focused on ruling out physical causes for their infant's symptoms, such as GER or CMPI. In some cases, parents had initiated medical consultation driven by their own suspicion of GER or CMPI. Other parents expressed skepticism regarding the diagnosis. Ultimately, a significant proportion of infants received a diagnosis of GER and/or CMPI, 64% (9 out of 14) and 36% (5 out of 14), respectively.

The first doctor I saw said, "Yes, he just has reflux". I think the first thing doctors say is reflux. "Just give him medication". I didn't do that. Because I didn't believe in it. There were no signs for it. Not that I don't believe in medicine. I absolutely do, I believe in it, but that didn't feel right to me. (Sophia)

The diagnosis of GER and/or CMPI often led to prescriptions for medications like omeprazole or a switch to cow's milk-free formula. Non-pharmacological interventions were also suggested, such as trying a different bottle and attempting an alternative preparation. Moreover, parents commonly turned to alternative treatments, including osteopathy and sleep coaching. Driven by a sense of desperation, parents were inclined to try any advice given to them, in the hope of effecting some positive behavioral change in their infant. Nevertheless, despite numerous interventions offering only temporary relief or partial solutions, parents perceived that the major issue remained unresolved.

We had a very good general practitioner. She had worked with Growing Up for a long time, so she knows children. She said, "Give omeprazole and in a few days your child will be happy again". So, omeprazole was the first thing we tried, but the problem wasn't solved. Then we thought, "Maybe it's cow's milk protein intolerance". So, we started with specialized milks. She responded well at first, but very quickly you could see: that wasn't it either. (John)

We tried many things. In the end, you would spend money on anything just to have less crying. (Lucy)

Not only healthcare providers, but also web-based medical information, online forums, and the parents' network attributed the behavior to common medical conditions such as GER and/or CMPI. Indeed, the corresponding recommendations for this did not provide a straightforward solution for the infant's symptoms. The absence of comparable experiences led parents to feel increasingly isolated and atypical.

And I also looked for those groups, online or something. But I didn't find anything. Some people might not need that, but I was really looking for similar experiences. And the only thing I read was, "Yes, we changed the milk, and it was instantly better". Or, "We dealt with the reflux, and we had a different child". And we were so eagerly waiting for when that different child would arrive (laughs cynically). And then you feel like you don't relate to anyone. I really felt like we were such an exception. That we didn't have a normal baby life. (Charlotte)

Upon reflection, many parents were no longer convinced that their infant's symptoms were attributable to GER or to CMPI (only), even though these conditions were initially considered the most likely explanations.

And then eventually, after dealing with all the physical issues, you end up thinking, "There was never -really!- a solution". We eventually wondered, "Well, he was eating cheese without any problems, so did he really have a cow's milk protein intolerance?". (Thomas)

Frustrating cycle of tests and treatments

Many parents described that tests and treatments were repeated, over and over again, in a frustrating cycle of 'trial and error'. Parents reported that physicians only focused on finding a medical explanation for the infant's symptoms. Consistently, parents were reassured that all tests were normal and there was no (other) medical explanation (anymore) for the presenting symptoms in the infant. The healthcare focus on the infant, which indicated 'nothing wrong' medically, conflicted with the parents' experiences as they earnestly sought an explanation for their infant's behavior.

"Look, she is at a healthy weight, her head circumference is good, she urinates enough, she drinks enough, she breathes well, we don't see any infection in her blood values, her lungs are good, the ultrasound is good, everything is good, voilà, your child is perfectly healthy". And yet she cries 18 h a day. Well, that's just… it doesn't make sense… Because I think, as a person, you look for a reason. Because then you think, so it must be my fault. Or our fault. We are doing something wrong, we are doing it incorrectly. And that's really tough, that even emergency doctors and pediatricians say, "There is nothing wrong". (Henry)

After all medical possibilities were ruled out, parents highlighted the fact that that the healthcare providers were just as confused as they were.

The pediatrician investigated all possible medical issues, but really from the perspective of "We have to find something". But then there came a point where I said it's *nothing medical anymore. Because all medical issues are covered. And then you saw that she was stuck as well. (Charlotte)*

Lack of awareness of RP

Nearly all parents were frustrated that healthcare providers tended to focus primarily on physical symptoms and conditions of an infant's health, often overlooking issues related to emotional regulation and other non-physical aspects. The majority of parents noted a significant gap in healthcare provider knowledge regarding 'RP', including a lack of familiarity with RP itself, its management, and the availability of specialized care at IMH clinics. Indeed, most parents agreed that they had never heard of RP before being referred to a specialized IMH clinic and that it would have been helpful if they had known about the existence and management of RP much earlier.

I feel that caregivers focus a lot on the tangible, so the physical, like, "Oh, he has this, or that, or that". But indeed, everything related to regulation and everything that happens around it, they might not be aware of, because I think they didn't even know about (name of IMH clinic). (...) I think there's just too little known about it. (Thomas)

A significant number of parents recommended incorporating awareness and knowledge of RP into the education of healthcare providers. They emphasized that, while healthcare providers should focus on medical aspects, they must also acknowledge broader issues and be aware of RP to better address the needs of families.

I actually think that this should be included in the education for midwives, pediatricians, and so on. It doesn't have to be extensive, but just to make them aware that it exists. And how can you refer the right families to this or that service? (...) They can focus solely on the medical aspect for all I care, but they must recognize that there is something more going on over there. I needed that at the time. (William)

In addition, some parents advocated for greater public awareness about the possibility of having an infant with RP, as they contended that it is more prevalent than is commonly perceived. They argued that more awareness would enable earlier identification of the condition and expedite access to relevant support services and interventions.

But that's more of a societal problem. I think it would be good if people who want to have children just knew that, it is an option, a baby with RP. That sounds really strange now, because everyone knows in essence what it is and that it exists. But it seems so unusual. And I realized that it's actually not that unusual at all. (...) Yes, everyone has that idea. It's maybe normal that when you get pregnant, you have this imaginary child. And you imagine all sorts of things about it. A bit in a kind of naive optimism or something. I think that's also good. Because you can't really start preparing for the worst... that's such a pessimistic approach. That's also not something I wish for pregnant people, certainly not. But so, I don't know. That maybe it should be talked about more... (Audrey).

An underexposed family crisis

Exhausted by the significant strain of the search for help for their infant and the constant medical appointments centered around their infant, parents indicated that they became oblivious to the toll the whole situation was taking on themselves. They recognized that they were experiencing an overwhelming level of stress that significantly compromised their cognitive functioning, hindering their ability to accurately perceive and process information. Consequently, they might have overlooked or misunderstood offers of help or advice, no matter how well-intended. Hence, parents emphasized the importance of timely intervention to prevent them from becoming so overwhelmed that recovery became prolonged.

I was in such a total stress mode at that time that very little really got through. I think that even if there had been someone who understood what I needed and wanted to offer it to me, I might not have been able to accept it or understand what they actually meant. (...) So what did I need at that time? Probably someone who could have prevented me from going so far into the red, because I was so far in the red that it took a long time for my brain to have space again to think differently, to look at myself and my children with some distance. That just wasn't possible. So I think the main point is that, if parents don't get the kind of help they actually need in time, even if they don't know what they actually need themselves, they get so far off track that it takes a lot of time just to bring them back to a place where they are receptive to therapy. (Claire)

However, certain parents pointed out that a singular focus on parental mental health would neglect the broader needs of the infant and the dynamics of both the parent-infant and parent-parent relationships. Hence, an approach that considers and addresses both infant behavior and parental well-being could better identify at-risk families, thereby allowing a timely provision of specialized care.

When we went to (name of center for mental health care) for a month, they said, "Both issues are beyond our expertise, we think you need more specialized help, especially for (name of child). We can guide you as a couple and as parents and help with your concerns, but we also see that (name of child) is exceptionally restless". They thought it would be better if we moved on to (name of IMH clinic). (...) There, the focus was indeed much more on (name of child). (Lily)

Overall, parents expected that healthcare providers would not merely attend to their infant, but that they would actively engage in further questioning about the

Table 3 Professional healthcare workers contacted in response to RP, as reported by the parents

Professional healthcare workers	Fathers (*n* (%))	Mothers (*n* (%))
Acupuncturist	0	1 (6.7%)
Adult psychiatrist	1 (10%)	1 (6.7%)
Adult psychologist	2 (20%)	7 (46.7%)
Allergist	0	1 (6.7%)
Baby coach	1 (10%)	1 (6.7%)
Center for child care and family support	0	1 (6.7%)
Center for mental health care	0	1 (6.7%)
Child psychologist	0	1 (6.7%)
Emergency department	2 (20%)	5 (33.3%)
ENT specialist	0	1 (6.7%)
General practitioner	8 (80%)	13 (86.7%)
Gynecologist	0	1 (6.7%)
Lactation coach	1 (10%)	2 (13.3%)
Midwife	2 (20%)	8 (53.3%)
Neonatologist	1 (10%)	1 (6.7%)
Neurologist	0	1 (6.7%)
Nutrition coach	1 (10%)	1 (6.7%)
Growing Up	4 (40%)	11 (73.3%)
Osteopath	2 (20%)	11 (73.3%)
Pediatrician	8 (80%)	15 (100%)
Physiotherapist	3 (30%)	1 (6.7%)
Pulmonologist	0	1 (6.7%)
Sleep coach	0	4 (26.7%)
Speech therapist	1 (10%)	2 (13.3%)
Therapist/Coach	1 (10%)	3 (20%)

well-being of parents, including their emotional state, coping strategies and support networks. Several parents expressed a desire to address the domestic crisis with their healthcare provider, however, they felt that the short routine appointments did not provide adequate opportunities to discuss these matters. According to some parents, Growing Up could play a pivotal role, particularly because they focus on both the individual infant and the family unit, reach nearly all families in Flanders, and provide free, repeated consultations.

What would I want to tell caregivers? That they need to ask more questions and pay less attention to the symptoms, but keep looking at the bigger picture. How is it in that family? How is the stress on that family? How is the connection between those parents and that child? Look much, much further than the symptoms people come in with. And don't fall into tips and tricks like "Just rub her forehead, then she'll sleep" (laughs cynically). But really look comprehensively at what is actually going on underneath. That's what I would say. A child that doesn't eat. What's behind that? There's much more behind it than they assume. (...) Yes, besides the medical AND psychological aspects, of course. And especially the parent-child connection. If the parent isn't doing well, the child isn't doing well either, and vice versa. And they need to be aware of that. (Marie)

Lost in a healthcare maze

Throughout their search for answers, parents encountered significant difficulties in identifying appropriate sources of support. Incohesive care provision and the lack of proactivity from healthcare providers complicated parents' efforts to seek help.

Healthcare provider shopping

Driven by a desire to find an explanation for their infant's behavior, parents consulted a broad range of professionals, as evidenced in Table 3. A significant proportion of parents primarily sought advice from general practitioners and pediatricians, with a substantial number also consulting Growing Up, osteopaths and midwives. It is noteworthy that no parent mentioned having sought the expertise of a child psychiatrist and only one parent mentioned a child psychologist before the admission to the IMH clinic.

First an osteopath, then clinic after clinic. And then specialist after specialist. (...) I knew there was something. And we saw many specialists to find something. Which led to nothing... (Olivia).

For some parents, even a few days could seem like an eternity, as they were trapped in a domestic crisis. Consequently, certain parents found themselves unable to access timely medical care due to extended waiting lists and turned to emergency departments (20% of the fathers and 33% of the mothers; see Table 3) as a last and only resort when they felt overwhelmed by their infant's behavior.

In the past, you would go to the pediatrician. Now you have to wait three weeks for an appointment. I find that incredibly frustrating. So you can't really get medical help unless you go through the emergency room. (...) So the fact that you already hit a wall there, I found that really difficult. Because the emergency room is suddenly such a bigger hurdle to overcome. (Henry)

Conflicting opinions and advice as a result of seeking advice from different healthcare providers left parents feeling directionless. This overwhelmed parents, creating a growing disconnect from their own parental intuition and their infant's emotional needs. This prolonged uncertainty often led to a decline of trust in the medical establishment and feelings of despair and hopelessness among many parents.

The midwife said, "That tongue-tie is borderline. It can be lasered, but I'm not sure". Then I went to the baby speech therapist, and she said, "In my opinion, it should be done". Then I asked an osteopath, but he said, "Can she drink properly at the breast, is milk coming out of her mouth?" I said, "No, it's not". And he also said, "Then it *doesn't need to be done". And someone else said it should be done. And I was like, really, I don't know what to do anymore. (Evelyn)*

A small number of parents expressed that their experience with a previous child had equipped them with the knowledge of how to navigate the healthcare system, allowing them to receive help earlier.

So it's actually because we had to wait so long with the eldest that we are now quicker with the youngest, because the pediatrician knew about the issues, the psychologist, my psychiatrist... Well, everyone knew about the issues in our family, so we got in everywhere faster. (...) Before you get to the right help, you have to speak to the right person... It's difficult to get the right help. Once you're in that whirlwind like with the eldest, then you get to the right help. (Anna)

Lack of proactive attitude

Parents emphasized that they did not expect healthcare providers to solve all their problems immediately, but rather that they acknowledge that they had reached the limits of their expertise, instead of persisting in their own diagnostic and therapeutic approach. Numerous parents experienced a lack of initiative from healthcare providers when considering what might be wrong and proposing possible interventions. Some parents expressed surprise and disappointment at the lack of timely referrals to services that could be helpful for the families. This delayed or absent referral left some parents feeling abandoned by their healthcare providers and seemed to prevent them from efficiently navigating the healthcare system.

I find it quite remarkable overall. Again, there are many people who have done a lot for us and meant a lot to us. But from the general practitioner to the pediatrician to the nutrition team, to neonatology,... No one, no one had the reflex to say "This is trauma and you need to go to child psychiatry". (Patrick)

Parents eventually ended up at specialized tertiary care IMH clinics in various ways, but nearly all parents reported experiencing a delayed referral. Four families were referred by their pediatrician, three by Growing Up, two by their general practitioner, one by a center for mental health care, one by an adult psychologist and one by an emergency nurse. Remarkably, two families identified the IMH clinic through their own initiative (via a podcast and a television program) and found themselves advocating for a referral, having to persuade healthcare providers who were unfamiliar with the IMH clinics.

They said that you can't register yourself at (name of IMH clinic). And then it was like, oh, here we go again. "You need a doctor for that". And then I asked at Growing Up. And they said they can't do the referrals. And then you're like, okay, yes, then the general practitioner or the pediatrician. They don't know about it. So you have to convince them yourself: please help me! (laughs cynically). (Charlotte)

Many parents emphasized the importance of healthcare professionals adopting a more proactive approach and more active collaboration and communication. According to parents, this could facilitate continuity of care and individualized referrals aligned with the unique needs of each family.

Limited specialized resources

Upon first hearing about the concept of IMH clinics, some parents approached it with a degree of skepticism, uncertain about what to expect from the clinic and considering it as yet another avenue to explore. Other parents were eager to explore the potential benefits of an IMH clinic, considering it to be the most appropriate response to their needs. Nevertheless, parents encountered a variable waiting period prior to their admission to the IMH clinic, with an average duration of nearly 10 weeks (see Table 1). A significant number of parents described that waiting period as 'suffering and surviving', expressing a desperate need for immediate intervention after exhausting all other available options. Hence, parents emphasized the need for bridging support until the treatment at the clinic could start.

We had our intake at (name of IMH clinic), but then we had to wait a long time before we knew we could actually start at (name of IMH clinic). I think that was especially frustrating because they had indicated that (name of child) would really be in the right place there. But when we couldn't start right away and the problems persisted... yes, that was frustrating. It was also extra frustrating for us when we were at (name of IMH clinic) and suddenly babies of 2–3 months old were allowed to start. And we had to wait another 6 months while (name of child) was already much older. (David)

A number of parents acknowledged that the extended waiting lists highlight the scarcity of IMH clinics available to provide support for families in Flanders.

That couldn't go fast enough for me, because there was still a waiting period until a spot became available. I was really hoping every day for a phone call. That happened quite quickly and we are very grateful for that, because we heard from other parents who had to wait longer. This proves that there should actually be many more spots like this available throughout Flanders! (Audrey)

More generally, several parents perceived the mental health services in Belgium to be inadequate. Consequently, parents experienced a profound sense of helplessness and despair, especially when their requests for help were ignored.

There are just few options. Not only for children, but also for adults. Psychological care is just a disaster in Belgium. And there are only a few people who take you seriously. I *have often thought, I can understand why some mothers harm their children. If you really say it and you ask for help, and still, no one wants to do anything. Then I can imagine that some parents don't realize that what they are doing is not okay. That things happen that shouldn't. Also, it's sad to see, because I have worked in care myself. (Lucy)*

Discussion

The present study was designed to retrospectively explore parental health-seeking behavior in response to persistent severe infant RP (e.g., excessive crying, sleep disturbances and feeding problems) and the missed opportunities therein. This study addressed the period prior to admission to an IMH day clinic for persistent severe infant RP. Semi-structured interviews were conducted with 14 families (10 fathers and 15 mothers). Data were analyzed using reflexive thematic analysis, resulting in the identification of four main themes and several subthemes.

Firstly, the need for answers was identified as an important theme. While many parents initially attributed their infant's unusual behavior to typical development, others more rapidly perceived the behavior as atypical. Upon recognizing the atypical nature of their infant's behavior, parents sought answers in order to understand what was happening with their infant. Some parents consequently felt a compelling need to seek a consultation with a healthcare provider as soon as possible, as they were apprehensive about the presence of severe underlying medical conditions. These findings are similar to findings from recent qualitative research by Hornsey et al. [48] with parents of unsettled babies in the UK, in which uncertainty about normality and concerns about underlying causes seemed to be important triggers for support seeking (from health professionals or elsewhere).

Secondly, throughout their search for answers, parents encountered a profound lack of recognition. Feeling heard and understood was instrumental in the parents' search for care, and in securing a timely referral to specialized services. Indeed, regardless of the treatment model, parents responded positively to therapists who demonstrate empathy and establish trust and respect [49]. Despite parents' quest for recognition and validation, their actual experiences often fell short of these expectations. Parents were often overly reassured and educated by healthcare providers about normal sleep, eating and crying patterns or behavioral strategies, as was found in previous studies on this topic [18, 29, 50]. Their concerns often seemed to be trivialized and dismissed, prompting them to question the validity of their own circumstances and needs, which frequently delayed them in seeking (further) professional help. They acknowledged that healthcare providers are indeed medical experts, but they emphasized that this does not negate the fact that parents are experts on their own children. This is also reflected in a recent survey study of parents experiencing excessive infant crying in the Netherlands [51], where feelings of not being taken seriously emerged as an important recurrent theme.

Thirdly, throughout their search for answers, parents in this study noted that healthcare providers prioritized physical issues (e.g., reflux) and overlooked a broader approach, including socio-emotional aspects of the infant's health and parental well-being. This is in line with several studies in the literature, for example, one by Nuyts et al. [35], which demonstrated that professionals concentrated predominantly on the infant's medical state, thereby impeding a more comprehensive approach to the infant's behavior (e.g., the parent-infant relationship). Nevertheless, our understanding of health has evolved significantly over the past decades. Moving beyond a strictly biomedical approach, aimed at treating acute illness, contemporary biopsychosocial models emphasize the importance of psychological, social and behavioral factors in health and disease management [52]. This idea is illustrated by Bronfenbrenner's bioecological theory [14], which emphasizes the interrelatedness of environmental systems, from the immediate setting (microsystem) to the broader culture (macrosystem). Central to this theory is the concept of 'proximal processes', the close interactions between a child and its immediate environment that shape its development and influence long-term (mental) health outcomes [13, 15]. Similarly, Sameroff's transactional model emphasizes the mutual influence between an individual and their environment. Especially, the effects of stress and social adversity have been discovered to deeply affect the body, leaving lasting imprints [53–55]. However, parents in our study noted that once a physical diagnosis was established, further investigation frequently ceased, indicating premature closure, a recognized bias in medical decision-making. Premature closure is defined as a tendency to prematurely terminate the decision-making process, accepting a diagnosis before it has been fully confirmed, or dismissing other plausible explanations once a potential diagnosis is identified [56]. Hence, there is evidence to suggest that infants may have been over- or mislabeled with physical diagnoses, resulting in unnecessary medication and overtreatment, similar to findings from other research [57–59]. Overdiagnosis or misdiagnosis can lead to adverse consequences, including potential side effects from unnecessary medication, resource depletion and higher healthcare costs [57, 59]. Parents in this study naturally expected healthcare providers to conduct thorough medical evaluations to rule out any physical causes, as these could be the sole reason for their child's symptoms. However, parents observed a general deficiency in awareness and knowledge regarding the existence of RP. If professionals were more familiar with the clinical presentation of RP, they could identify the problem earlier, potentially disrupting the vicious cycle and maximizing developmental outcomes. Furthermore, parents in our study observed that healthcare professionals primarily concentrated on the infant, but parents also needed to be recognized within the context of their challenging circumstances, as there is evidence for an association between perinatal depression in the parent and adverse birth and infant health outcomes [60]. However, some parents noted that focusing solely on parental mental health might lead to neglect of the infant's needs and the complex parent-infant and parent-parent relationships. Indeed, due to the challenging circumstances of an infant with RP, parents can become highly stressed and exhausted. These parents may find it more difficult to access or rely on their usual intuitive and co-regulatory capacities in managing their infant's dysregulated behavior. This can contribute to a cycle of mutual dysregulation between parent and infant, further intensifying stress for both and putting pressure on the attachment between parent and child [9, 33]. This phenomenon is well-explained by Tronick's Mutual Regulation Model [5, 6], which highlights the dynamic process of interaction and regulation between parent and child. Therefore, the concept of IMH highlights that the child's emotional well-being is inseparable from that of their immediate surroundings [61]. From the perspective of Donald Winnicott [10], this involves both addressing the infant's symptoms and also supporting the parents in re-establishing or strengthening their capacity to provide a 'good enough' holding environment. As Winnicott [62] once stated: "There is no such thing as a baby, there is a baby and someone".

Fourthly, throughout their search for answers, parents were trapped in a healthcare maze. In this study, it is notable that parents consulted various types of healthcare providers, including emergency services during crises. However, none of the parents mentioned seeking a child psychiatrist, and only one mother reported visiting a child psychologist with her infant. This suggests that not only healthcare providers but also parents themselves had a blind spot for the socio-emotional aspect of infant development. Parents perceived the received support as insufficient, leading them into a vicious cycle of consulting various healthcare providers without feeling that their needs were being met. In other research, explanations for doctor shopping may vary from physician-related factors to patient-related factors [63], but the use of multiple healthcare providers seems to be associated with poor continuity of care and may add excess costs to the health care system [64, 65]. Moreover, increased utilization and intensity of healthcare services are the main drivers of healthcare spending growth, as a report from the American Hospital Association revealed [66]. Therefore, preventing parents from doctor shopping is crucial to reduce public health costs and societal impacts. Another finding that emerged in this study is that nearly all parents experienced a delayed referral to specialized care as they felt abandoned by their healthcare providers in navigating the complex healthcare system. Parents emphasized that a more proactive approach from healthcare providers, and more active communication and collaboration between healthcare providers themselves, could facilitate the continuity of care and individualized referrals aligned with the unique needs of each family. Similar research highlights how a fragmented care provision system complicates communication and referrals between healthcare providers, which could lead some parents to drop out of the care pathway before receiving appropriate care [35, 67, 68]. Moreover, several studies suggest that general practitioners and pediatricians are well-positioned to play a crucial role in identifying IMH problems and coordinating care [69, 70]. A matched care approach, rather than a stepped care approach, appears to be important in this context. Matched care involves tailoring treatment to the individual patient's unique characteristics, including the severity of their condition, their mental and social skills, environmental factors, and their specific needs and desires. This ensures that families are connected with appropriate support as quickly as possible, preventing them from lingering with unresolved questions and avoiding both under- and overtreatment [71]. This is particularly important for families with young children, as the child's development progresses rapidly. The principle of matched care aligns with Sameroff's transactional model of development [12], which emphasizes that a child's development is shaped by reciprocal and unique interactions between the child and their environment (including their parents). This model highlights the importance of context and individual differences, rejecting a 'one-size-fits-all' approach. Consequently, support services should be tailored to the specific needs of each family. Last but not least, when parents in this study eventually reached a specialized IMH clinic, there was often a waiting period before they could start, which, according to them, highlights the shortage of IMH clinics available to support families.

Limitations and future research

The present study was subject to some limitations. Firstly, participant recruitment might have been susceptible to a potential selection bias; participants who are already well-informed and involved with the topic, may be more likely to volunteer, potentially leading to biased results. Secondly, there was an imbalance in the number of participating parents from the two involved IMH clinics: only four parents were recruited from UKJA, compared to 21 from kleine K, due to recruitment challenges in UKJA. Despite additional efforts, including personal invitations from the child psychiatrist via telephone, participation from UKJA remained limited, possibly due to factors such as complex circumstances of families in a large city like Antwerp. Thirdly, despite our intention to reach a heterogenous sample, our sample consisted mainly of highly educated, employed parents who were living together. It can, however, be assumed that if even highly educated families encounter difficulties in accessing specialized care, more vulnerable families might face even greater barriers. Fourthly, the results should be interpreted with caution, considering that they primarily reflect the experiences of families whose infants exhibited prolonged RP and who accessed tertiary care. These families may have highlighted gaps in earlier care trajectories that may not apply to those who received earlier support in primary or secondary care. Last but not least, it is important to discuss that some interviews were conducted remotely via Microsoft Teams. Although qualitative interviews conducted in-person are often considered the gold standard, with other methods viewed as inferior, online interviews can be necessary or advantageous in certain situations. For instance, in this study, there was a significant practical benefit for some parents to conduct the interviews online. Although the literature suggests that online interviews could affect the depth or nature of the data collected [72, 73], the interviewers did not perceive this to result in less in-depth interviews. For instance, the longest interview was conducted online, and respondents sometimes became emotional in both in-person and online interviews.

Despite these limitations, this study makes valuable insights into parents' health-seeking behavior in response to their infant's RP, by including fathers and mothers. Efforts were made to reduce biases common in qualitative research, such as recall bias (by contacting parents soon after completing their trajectory in the IMH clinics) and social desirability response effects (through sensitive interviewing techniques encouraging honesty [74]).

Recognizing the limitations, this study underscores the need for further research. Given that every situation has multiple perspectives, this study focuses on the experiences of parents. Further complementary qualitative research with different healthcare professionals (such as midwives, medical doctors, psychologists,…) is needed to explore their perspective and identify opportunities for improving practice. Additionally, interviewing parents who received appropriate support in primary or secondary care could provide further insights.

Implications for policy and practice

In addition to its scientific value, this study has practical and public policy implications. It could be beneficial to develop an intervention designed for parents with concerns about their infant's behavior. Parents could access an online initiative with valuable information on typical infant development and a range of infant (mental) health issues, in line with initiatives in other countries, such as IMH Nederland in the Netherlands [75], and Wessex Healthier Together in the UK [76]. Incorporating parents' voices in an online tool could enhance the perceived trustworthiness of information for parents, a method that has already proven effective in other digital self-management interventions [48, 77]. In Flanders, Growing Up currently offers a website and videos with information about a child's normal development, along with stories from parents [78]. Moreover, the online initiative could assist parents in identifying and accessing appropriate professional support services. Additionally, it could be beneficial for parents to find emotional support through shared experiences with other parents to foster a deeper understanding, empathy, and sense of community. It is desirable that an online platform form the initial phase of the intervention, complemented by appropriate face-to-face therapy where necessary and beneficial. Such blended tool principles [79, 80] are increasingly being adopted in mental health care to maximize the benefits of both treatment modalities. To better support healthcare providers in offering care to families, concepts such as IMH and RP should be integrated into healthcare education and guidelines. Through greater integration of this topic into educational programs, healthcare providers who commonly encounter these families would be better prepared to recognize the signs of RP. Unfortunately, despite the widespread adoption of *Domus Medica* [81] and *Nederlands Huisartsen Genootschap* (NHG) [82, 83] guidelines for preconception, prenatal and postnatal care by Belgian physicians, these guidelines do not yet explicitly address the vision of IMH or the concept RP. Another crucial step could be to develop a screening tool that could assist healthcare providers in identifying at-risk families early, thereby facilitating timely intervention. Such a screening tool is currently unavailable in Flanders and would represent a significant advancement in healthcare. Moreover, it is important that healthcare providers can efficiently navigate through the landscape of IMH services. Initiatives like the World Association for Infant Mental Health (WAIMH) Vlaanderen [84], the Flemish expertise network called Perinet [85], research on improved care pathways in the perinatal period [86] and the development of a digital platform 'Born in Belgium' [87] focus on the mental health of parents and children in the first years of life and map perinatal mental healthcare in Flanders. These initiatives can aid healthcare providers in referring families to specialized care. It is, therefore, important that all these initiatives reach healthcare providers to ensure that parents do not feel lost in their (mental) healthcare journey. Last but not least, one might suggest that the capacity of IMH care should be expanded, so that families receive timely support.

Conclusions

Parents' uncertainty about what is considered typical infant behavior and their concerns about underlying causes seem to be important triggers for seeking support. For parents, feeling heard and understood was key in their search for support and timely referrals. Furthermore, it is important for healthcare providers to focus on socio-emotional aspects of the infant's health instead of physical causes only and to be alert to the needs of the whole family, including parental well-being. Therefore, there is a need to promote awareness of RP more widely among both healthcare professionals, for instance, by integrating this information into existing guidelines and education, as well as the general public. Moreover, preventing parents from healthcare provider shopping is crucial because of its significant societal implications. A more proactive stance from healthcare providers, coupled with enhanced collaboration among them, could ensure timely referrals that meet the unique needs of each family, according to the principles of matched care. Finally, it is advisable to increase the capacity of IMH care to ensure families can access specialized help more promptly.

Appendix: Interview guide

Introduction:

- Welcome the parent and thank them for their time.
- Briefly introduce myself.
- Explain purpose of the interview and the study.
- Explain the 'rules of the game' (e.g. no wrong answers, interested in their experience,…).
- Explain and sign informed consent.
- Opportunity to ask questions.

Icebreaker questions:

- How is your child doing at the moment?
- When do you think the regulatory problems (RP) started in your child? How did it show itself?
- When did you first start worrying about your child's behavior?

Main questions about the care trajectory (up to the point of tertiary care):

- Before you were admitted to the IMH day clinic:
  - Can you tell me who and what helped you in your search for help?
    - Who: e.g. partner, informal network, formal caregivers,….
    - What: e.g. materially, financially, emotionally, practically, advice,….
  - To what extent did you feel heard/understood by X?
  - What do you think helped you the most?
  - What did you feel was missing?
  - How did you experience this period in general?
- How did you learn about the IMH day clinic? What did the admission do to you?
- If certain help had been available earlier, do you think your care pathway would have been different, or do you feel this was the path you were 'meant' to follow?
- What message would you give to healthcare professionals to help them handle this better?

Conclusion:

- Summarize the key points discussed.
- Ask: Do you feel that you have been able to fully share your story about the care for the RP that you sought and received? Is there anything else you think we haven't asked about this topic? What was the most important thing you shared?
- Thank the participant again for their time and insights.
- Collecting demographic data.

Abbreviations

RP	Regulatory Problems
IMH	Infant Mental Health
DOHaD	Developmental Origins of Health and Disease
GER	GastroEsophageal Reflux
CMPI	Cow's Milk Protein Intolerance
Co-PRIME	Co-regulation as the foundation of PReventive Infant MEntal health care
kleine K	Infant Unit of the University Psychiatric Center of Leuven
UKJA	University of Antwerp Child and Adolescent Psychiatry
NHG	Nederlands Huisartsen Genootschap (Dutch General Practitioners Association)
WAIMH	World Association for Infant Mental Health

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Author contributions

SDB and FH conceptualized the study, with iterative feedback from GVH, EW and KP. FH developed the interview guide, with iterative feedback from SDB, GVH, EW, KP, MD and BRHVdB. BS, HVdS and FH were involved in the recruitment of participants. FH and SDB conducted the interviews, 16 interviews were conducted by SDB and FH together and nine interviews were conducted by FH alone. FH transcribed and coded all interviews, using NVivo 14. SDB and HW coded and interpretated a selection of data to ensure intercoder reliability. FH took the lead in writing the manuscript and SDB, GVH, EW, KP, BS, HVdS, MD, BRHVdB and HW substantively revised the manuscript. FH prepared the figures and tables. All authors read and approved the final manuscript.

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Data availability

The datasets used and/or analyzed (e.g. coded transcripts) during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was conducted in accordance with the Declaration of Helsinki and was approved by the Ethics Committee of the University of Antwerp, Belgium (protocol code: SHW_2023_307). Participation was confidential, voluntary, and written informed consent was obtained from all participants involved in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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