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"Already too late": A qualitative study of respite care among mothers of children with special healthcare needs and disabilities

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ABSTRACT

Background: Parents of children and youth with special healthcare needs (PCHN) are under particular pressure that can lead to physical, emotional, and social difficulties. Respite care services provide temporary relief for PCHNs from their caregiving responsibilities. Several studies have examined why PCHNs do not make greater use of these potentially supportive services, but existing studies do not focus on the psychological or subjective aspects of this process.
Objectives: The present study aims to understand the reasons why PCHNs, mothers in particular, (do not) use these services, with the underlying goal of understanding what parents' needs and expectations are regarding these services.
Methods: The present study is based on a qualitative thematic analysis of the experience of respite services of 14 Belgian mothers PCHN.
Results: The results showed that PCHNs regularly exceed their limits and are often on the verge of physical and emotional exhaustion and that respite services could be a way to meet their needs. However, issues of availability and accessibility impede equal access to these services.
Conclusions: These findings highlight the need for a comprehensive approach to respite care, by including PCHNs in the process as early as possible, not normalizing exhaustion as the trigger, and not focusing solely on the needs of children when the need arises.
Implications for practices: Increasing the flexibility of the services, providing a reassuring environment, facilitating administrative procedures, and providing information about these services as early as possible appear to be priorities for facilitating the use of respite care services.

Parenting is a source of joy and accomplishment but can also be a challenge in daily life (Mikolajczak & Roskam, 2018). This tension is heightened for parents caring for a child who is ill or has a disability (Gérain & Zech, 2020). Currently, an estimated 4% of households in the European Union include children aged 0–16 who face a limitation in daily activities due to a health condition (Eurostat, 2018), leading their parents to be "parent carers", also known as parents of child (ren) or youth with special healthcare needs (PCHN) (Whitmore, 2016). In addition to their already potentially demanding parenting role, PCHNs are required to perform a wide range of additional care-related tasks (e.g., hygiene and medical care, coordination, logistics, and information seeking). This task overload has been shown to put parents under pressure, including poorer mental health indicators than parents of typical children (Gérain & Zech, 2020), and can lead to physical, emotional, and social difficulties. This includes reduced vitality, poorer sleep quality, more depressive emotions, and impaired social functioning (Hatzmann et al., 2008; Scherer et al., 2019). Mothers of CHN have also been shown to be more likely to develop depression, heart disease, or diabetes than mothers of healthy children (Fraser et al., 2021).

Several services and institutions are designed to provide daily support to these parents (Tétreault et al., 2014). These forms of support aim at helping the parents through a large set of services, from meals-on-wheels or providing information, to helping with paramedical care. In the face of the important array of tasks that PCHN must perform and the associated risk of exhaustion, a particular form of support service is growingly implemented, respite care (Knighting et al., 2021).

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Respite care can be defined as the provision to the PCHN of temporary relief from their caregiving responsibilities (Whitmore, 2016). Respite care generally takes the form of residential respite (i.e., institutions hosting for a short period the CHN with or without the PCHN being present) or of an in-home respite (where a professional caregiver comes into the home and takes care of the child while PCHN can do something else) (Knighting et al., 2021). Other forms of respite care also exist such as hospital-based overnight care, breaks in another family's home, residential holidays, and breaks provided through leisure schemes (McConkey & Adams, 2000). To date, there is conflicting evidence that respite care services offer a benefit for the CHN, but growing evidence shows that it benefits the PCHN through having more free time, better mental health, the opportunity to better adjust to their role, and better relationship quality with their partner (Broady & Aggar, 2017; Knighting et al., 2021; Remedios et al., 2015; Suzuki & Kamibeppu, 2022).

Beyond the sole criteria of the efficacy of respite care, it is observed that PCHN are in demand of such services, irrespective of the specific diagnosis of their child (Cooke et al., 2020; Huus et al., 2017; Remedios et al., 2015). This observation must however be contrasted by accounts of the difficulties PCHN have to access these services (Broady & Aggar, 2017; Cooke et al., 2020). Despite the importance respite can hold in their expectations, PCHNs appear to only make limited use of these services (Knighting et al., 2021). This necessarily raises the question of the reasons for that gap.

Several studies have investigated barriers and facilitators of using respite care services. In their synthesis addressing respite in children with autism spectrum disorder, Cooke et al. (2020) highlighted that access to these services could be qualified as a "relentless journey" due to the numerous difficulties, but they showed that we lack evidence in terms of the subjective experience of the PCHN on how they experience this journey. Some evidence exists regarding what can be qualified as a complex parental decision-making process (Dubois et al., 2018): a recent study highlighted institutional and structural barriers to access to such services (Graaf et al., 2022); a review highlighted barriers and facilitators but for young adults (above 18 years old) (Knighting et al., 2021); and a study on the subjective experience focused on the American context (Whitmore & Snethen, 2018). These investigations show that attempts have been made to understand the barriers and facilitators, but they lack the focus on psychological or subjective aspects of that journey in the context of West European social welfare systems.

Objective and design overview

Based on these elements, the present study aims at understanding the reasons why PCHNs, mothers in particular, (do not) use respite care services with the underlying goal of understanding what are the needs and expectations of the PCHN regarding such services.

Methods

To answer those questions, the present study is based on a qualitative thematic investigation of the experience of respite care of mothers PCHN in Belgium. This study uses the Journal Article Reporting Standards for Qualitative Research (JARS-Qual, Levitt et al., 2018).

Researchers' description

This project was initiated by the King Baudouin Foundation to map the current supply of respite care services in Belgium and understand the subjective experiences of the PCHN in this context, to develop the supply of respite care services and providing national recommendations for increasing quality and access to these services. Several Belgian researchers and collaborators were involved. Two of them are researchers and professionals working with PCHN, including in respite care. Two collaborators are members of the King Baudouin Foundation. The interviewer is a reporter trained in research to conduct semi-directive interviews. The last author is a researcher working in informal care research.

Participants' recruitment and selection process

To be included in this study, mothers had to meet the following inclusion criteria: a) to be a parent of a child with a disease or disability between 0 and 18 years old and b) to be willing to share their experience with respite, c) in French or Dutch. The choice of participants was based on a desire to cover the whole country from a geographical point of view with a linguistic parity of interviewees, as disability policy is a regionalized issue in Belgium. The original estimate was to interview 2 participants per province (Belgium has 10 provinces). Regular discussions within the research team throughout the data collection process led to stopping the interviews once the participants' responses no longer provided new evidence to address the research objectives i.e., after 14 interviews. The sampling was purposive (Campbell et al., 2020), to have mothers from different socioeconomic backgrounds with children with diverse health problems. Mothers were recruited through the professional activity of 2 researchers in the team who referred mothers PCHNs to participate in the study.

Based on these criteria, 14 mothers participated in the interviews: 5 in Flanders, 5 in Wallonia, and 4 in Brussels, with an adequate distribution across all provinces of Belgium. The profile of the children was diverse in terms of pathology, care received, and age (see Table 1).

Data collection

Given the exploratory nature of our study, based on the absence of a clear theoretical rationale for that context and the need to let the participants express their subjective experiences, we opted for a qualitative approach based on individual semi-directed interviews with mothers PCHN. We did not aim to verify hypotheses but to gain a better understanding of a phenomenon that is little described in the literature. Interviews were conducted by the interviewer, either in French or Dutch. They took place between January 15, 2021, and March 13, 2021. Two mothers were met face-to-face, 9 parents were met virtually (via Zoom or Teams), and three through a phone interview. The duration of the interviews was between 60 and 90 min. One interview had to be interrupted several times due to the child's medical condition and was eventually cut short.

The interview guide included open-ended questions about family composition, mothers' need for respite, barriers, or difficulties in accessing respite services, and gaps in the existing offer in Belgium. It can be found in Appendix 1. Participating mothers PCHNs signed a consent form for their participation and use of their data before their interview.

Data analysis

All interviews were recorded and transcribed in full for thematic analysis (Braun & Clarke, 2006, 2019, 2020) as part of an iterative process of data collection and analysis. This method of data analysis was chosen to favor a broad view of the experience of PCHN. It has the double advantage of being iterative while allowing a global understanding of a phenomenon (Mucchielli, 2009). The thematic categories were initially partially predefined according to the research objectives: a) the respite experience of PCHN (to understand the reasons why PCHNs (do not) use respite care services) and b) the identification of the gaps (through PCHN's needs and expectations). As the iterative process of collecting and analyzing information progressed, sub-categories were created within these two broad categories as part of an inductive approach. The objective of this first stage of analysis was to code the data collected while remaining very close to the empirical material, based on verbatim statements directly extracted from the transcript. A

Table 1
Description of the interviewed mothers.

N°	Gender	Partnered/solo	Number of children	Age of children	CHN age	CHN gender	Diagnostic	Professional status of parents	Province
1.	F	Partnered	3	14–12-9	12	F	Autism and mental disability	Mother part-time Father full-time	West Flanders
2.	F	Partnered	3	20–18-17	18	F	Autism and mental disability	Mother 4/5 Father full-time	West Flanders
3.	F	Partnered	3	11–9-4	9	M	Multiple disabilities	Mother 3/5 Father full-time	Brussels
4.	F	Partnered	5	33–32–31-26-18	18	M	Down syndrome and behavioral issues	Housewife Father retired	Brussels
5.	F	Divorced	2	10–8	10	M	Genetic disease with rare cardiopathy	Mother full-time Father full-time	Liege
6.	F	Partnered	3	14–13-11	11	F	Overall developmental delay	Mother full-time Father full-time	Antwerp
7.	F	Partnered	3	12,5–14-7	7	F	Cardiopathy and leukemia	Mother burnout Father full-time	Walloon Brabant
8.	F	Partnered	3	9–7-4	7	M	Down Syndrome	Mother full-time Father full-time	Antwerp
9.	F	Partnered	2	14–4,5	14	M	Fragile X syndrome	Mother work leave Father full-time	Hainaut
10.	F	Single mother	1	6	6	M	Orphan disease	Part time	East Flanders
11.	F	Partnered	2	17–14	17	M	Autism	Mother 3/4 Father full-time	Luxemburg
12.	F	Partnered	2	8–2.5	8	M	Genetic disease and epilepsy	Mother sick leave Father full-time	Brussels
13.	F	Partnered	3	7–5-3	5	M	Refractory epilepsy	Mother full-time Father full-time (+ both complementary activities)	Namur
14.	F	Partnered	3	11–5-3	3	M	Neurodegenerative disease	Mother full-time Father househusband	Brussels

Note: CHN = Child with healthcare needs. F = Female. M = Male.

second step of categorization allowed to take a certain distance from the participants' comments and classify them into themes (Paillé & Mucchielli, 2003). They were enriched and discussed within the research team throughout the analysis process in a triangulation approach (Guion et al., 2011). The results presented here are summaries of these themes, illustrated by anonymized quotes. Table 2 displays examples of quotes for each theme.

Ethical considerations

The present study followed ethical institutional guidelines and stemmed from a larger project that received ethical approval from the local ethics committee. It complies with the Declaration of Helsinki (Ethical Principles for Medical Research Involving Human Subjects). The procedures involved in this research were fully explained to the participants before they agreed to participate and provided their consent to the use of their data for scientific purposes. Confidentiality, anonymity, and privacy were maintained throughout the research process. Only the interviewer and first author had access to the identification of the participants and the other authors had access to pseudonymized data (i.e., content of the interviews). Data were stored on institutional encrypted repositories, in accordance with data protection regulations.

Results

The results of our study are organized around several key themes that elucidate the complexities of the respite care experience for parents of children with healthcare needs (PCHN). First, “An important, urgent, constant need” delves into the physical and psychological difficulties PCHN face, often silently, until their distress reaches an acute level. Respite care isn't seen as a regular support system but as an extreme solution to avoid total burnout. The second theme, “Rhythm and Isolation”, highlights the inherent disparity between the lives of families with CHN and those without. The special needs of a child often disrupt family dynamics and social connections, which indirectly increases the burden on parents and reduces opportunities for informal respite. The third theme, “A Difficult Search and a Disparate, Insufficient, and Sometimes Inaccessible Offer”, emphasizes the difficulties parents face while seeking respite services, including limited availability, long waiting lists, geographic inequality, financial constraints, and burdensome administrative processes. “An Emotional Experience”, the fourth theme, delves into the emotional turmoil parents experience when they consider or use respite services. It explores feelings of guilt, failure, loss of control, and an ever-present worry about their child's well-being, even when they are in respite care. Finally, the theme “Respite Care: Identifying Gaps” underscores the existing gaps in the current respite care system and offers insights into what PCHN see as potential solutions. This includes the need for more specialized services, flexibility in service availability, proactive professional support, and a simplified respite process that takes into account the immense physical and emotional demands of caring for a child with high needs. These themes provide a nuanced understanding of the respite experience from the perspective of PCHN, revealing not only the struggles they endure but also their resilience and determination in their caregiving role.

An important, urgent, constant need

The mothers PCHN interviewed are aware that they regularly exceed their physical and psychological limits to take care of their child and try to preserve a personal and family balance already weakened by the illness or disability of the child. Their need for respite does not only consist of a few days' stay in a care facility dedicated to respite, even if the fact of being momentarily relieved of their responsibilities or the constant call of “Mum!” is vital for many mothers to hold on over time. The need for respite also translates into the need to have small moments for oneself, to take a walk, for a dinner as a couple, to be at home without being disturbed, simply enjoying the silence. These moments are rare, too rare, and yet the need is real.

The process of entrusting their child to a respite care facility is not simple; it takes time. Many of the PCHN interviewed did not express their needs until several years after the start of care, despite knowing about the existence of a respite facility when the accumulated sleep

Table 2
Examples of quotes for each theme.

Themes	Quotes
An important, urgent, constant need	*I don't have the strength to do it. Just packing and making sure he has everything he needs with him takes three hours. I'm at the end of my tether, and the mental pressure to organize such a trip is too great. It's easier for me to take care of him myself than to have to explain everything from A to Z to a respite care facility.*
	Asking for respite to really get away from constantly going off lights and alarms.
	You can't ask what isn't there…
Rhythm and isolation	*During the week, when M. is in boarding school, we are like a "normal" family, but on weekends, we are again that family constrained by baby schedules.*
A difficult search and a disparate, insufficient, and sometimes inaccessible offer	*It's like being in a refugee boat and having to push someone else out of it to survive the crossing*
	You are almost tempted to keep your mouth closed when you have found a good solution.
	Are there other parents who might need it more than me?
An emotional experience	*She's constantly on my shoulder, even when she's not here.*
	I have already lost so much control, so I don't want to give up that control.
	My feelings as a mom are hurt. A service, no matter how professional, tends to catalog the disabilities and no longer see the child behind them.
Respite care: identifying gaps	*It's a tough question: when do I feel the need to take a break? You know the supply isn't there, so you make do with what you have*
	Respite care is only for emergencies now. But we live in an emergency all the time…
	If that process of acceptance doesn't happen, it will be harder for parents to call for help.
	What alignment of the planets does it take to have a place in a respite service?
	What is the point of informing parents about a service that, once contacted, simply offers registration on a two-year waiting list?
	If families have to adapt to respite services, part of the respite effect is lost anyway.

deprivation and physical and emotional exhaustion became unbearable, and their body signaled that they were in danger of collapsing.

They are often supported and even pushed in their decision-making by the professionals who care for their children and who notice their growing fatigue. However, they do not always feel understood and heard in their needs. According to them, respite services and the professionals who accompany them do not always realize that when they finally ask for respite, they've been "drowning" for a long time; they only ask for help when they have no other choice.

Guilt often gets in the way of making that decision. Entrusting their child to the care of an unfamiliar person or team means facing several issues, such as the fear that their child will not be as well cared for as at home; that they will not be as safe as at home; that the caregivers will not be able to detect a problem; that the child will not be comfortable with caregivers who do not know what every gesture, every head movement, every look, every sound means.

Organizing a respite stay is also a great mental burden for PCHN. Gathering all the child's things, making sure they haven't forgotten anything puts a strain on the PCHN: "*I don't have the strength to do it. Just packing and making sure he has everything he needs with him takes three hours. I'm at the end of my tether, and the mental pressure to organize such a trip is too great. It's easier for me to take care of him myself than to have to explain everything from A to Z to a respite care facility*".

Rhythm and isolation

While siblings are still young, being a PCHN fits more seamlessly into the "flow" of family life, because what they do for the CHN, also meets the needs of the siblings, all of whom are still dependent on their parents. This situation changes when the other children in the family grow up and develop other needs and become more autonomous: "*During the week, when M. is in boarding school, we are like a "normal" family, but on weekends, we are again that family constrained by baby schedules*".

It is a gap that also isolates families socially and consequently impairs their ability to receive informal respite. Like many parents, the interviewed PCHN would like to be able to rely on family members to recharge their batteries. For many participants, family members were reluctant to commit to this, either out of fear or unwillingness to provide the care needed. Grandparents cannot always cope with intensive and increasing care for CHN and drop out. Families caring for a sick or disabled child are therefore missing those small moments of respite from the daily grind that "normal" families can enjoy when, for example, children go to spend the weekend with grandparents. The need for respite care is even more important during the school holidays. Not only to reconcile work and family life but also to find time for the other children in the family, who often lack attention from their parents.

While for some mothers, work is a kind of refuge, allowing them to escape the "disability bubble", working life is also impacted by the reality of a child's illness or disability, forcing some mothers to stop working, which sometimes puts the family in a precarious financial situation, and therefore hinders access to respite solutions. Many parents - almost always the mother - consequently exhaust all possible forms of parental leave, care credit, and career breaks, which, in the long run, also influence their career and retirement prospects.

A difficult search and a disparate, insufficient, and sometimes inaccessible offer

For some mothers, it took several years to find out that there are respite formulas they could use because no one brought it to their attention. All interviewed PCHNs highlighted that the offer of respite care is too limited, whether for residential care or care at home, for short or long periods, for planned stays, or for emergencies. This observation is even more striking during school holidays when waiting lists are very long. This means that stays must often be planned up to a year in advance. Therefore, the offer lacks flexibility while living with a CHN is full of uncertainties, which makes it impossible to anticipate when respite will be needed. In addition, the more intensive and specialized the child's care needs are, the more limited the supply is, while the need for respite is greater for the parents involved. This observation is particularly striking for parents of children with autism or behavioral issues, as they are excluded from some respite facilities.

Because there is not enough capacity for everyone, parents tend to measure their need for respite to the needs of other parents who may need it more than they do. It can go as far as to refuse to contact a respite service to make room for others: "*It's like being in a refugee boat and having to push someone else out of it to survive the crossing*". Thus, some parents feel that they are competing with other parents, and that represents an important barrier to request such service.

As a result, PCHN feel that they have to "do it yourself" to find respite by, for example, turning to students training in the healthcare field to provide babysitting at home for a few hours. Not all have sufficient financial means to fund such additional support services, especially since parents of a child requiring intensive care experience financial stress. For one interviewed mother, both parents worked full-time, and both had additional jobs on the side to pay for home adaptations. In several families, one of the partners had reduced their working hours or stopped working because it was paradoxically more financially sustainable than having to pay for support. Every euro is counted,

despite the presence of financial aid in one region. This applies particularly to more precarious families (e.g., single parents or with low income) for whom the difficulties accumulate and may reinforce each other.

The geographical dimension was also important, as respite care services are unevenly distributed throughout the territory. Half the country does not yet have one residential respite home for children with important medical needs. These parents then spend many hours traveling to a respite center, or they give up on the idea because of the distance.

Finally, the administrative steps that allow access to respite are sometimes very burdensome, very long, and energy-consuming. *"An introductory interview, an intake interview, a home visit, a four-page questionnaire, the collection of medical certificates …"*, are all sources of discouragement that hinder access to respite.

An emotional experience

Feeling welcome in a respite facility, without judgment, is the most important element for parents who accept respite. The quality of the first contact lays the foundation for the trust that is gradually established between a respite service and a family. Added to this are other ingredients for a successful respite experience, such as honest and transparent communication, creativity, affection for their child, and the desire to help them experience happy moments by stimulating them and giving them the chance to discover and experiment. Finally, an adapted medical and paramedical follow-up (e.g., doctor or nurse who is present, contact with family GP), specialized educators, and driven trained volunteers to supervise the child during their stay allow the parents to be reassured and condition their capacity to let go.

During the respite stay, the child is never absent from the mothers' thoughts. The mental burden remains even when the child is in respite care and therefore, even when PCHN have time for themselves, they struggle with the mental burden: "*She's constantly on my shoulder, even when she's not here*". In those moments, mothers experience guilt or sadness that their family is not complete. The first respite episodes are especially emotionally difficult. Sometimes they remain so for a long time. It becomes even more difficult when the child realizes that their family is having a good time with their siblings while they are in respite care.

Overall, and while they acknowledge that respite can be beneficial, interviewed PCHN reported that entrusting their child to such a service generates feelings of failure about their parenting, a loss of control that they find difficult to contemplate: "*I have already lost so much control, so I don't want to give up that control*". Accepting respite also means admitting to the outside world that their child has a disability and that they are not only a mother but also a family caregiver, with the implicit message that they cannot handle the situation on their own. This duality also puts them in the difficult position of at the same time wanting to take a few days off from their caregiving role while maintaining their parenting role.

Respite care: identifying gaps

Because of the lack of available respite spaces and the guilt they feel, parents become exhausted and finally access respite only too late or never. There is a certain fatalism or resignation in their words: *"It's a tough question: when do I feel the need to take a break? You know the supply isn't there, so you make do with what you have"*. Therefore, every interviewed mother stressed the need to develop more specialized or medicalized respite services allowing children to access activities adapted to their needs, including small structures better distributed throughout the territory. Mobile teams ("flying teams") from these respite institutions could also offer specialized respite care at home for a shorter period, allowing for more flexibility, including the possibility of being called at the last minute. That way, PCHN would feel more comfortable entrusting their children to familiar faces in a familiar environment. These mobile teams could be a stepping stone to residential respite care, which often represents a more difficult step to take for parents, especially when children are very young.

Currently, respite is seen as a last resort: *"Respite care is only for emergencies now. But we live in an emergency all the time"*. Parents felt that they would be better able to continue caring for their child in the long term if the services had the following characteristics: a) knowing the service is always available, b) that it can be set up quickly (i.e., in case of emergencies), c) requires a limited amount of preparation beforehand, d) is available before they are completely exhausted, and e) being sure that their child is in safe hands. With these conditions in place, the parents would be more willing and more receptive to benefit from these services.

Some mothers have indicated that they had needed intensive emotional and psychological support in the months and years following birth or diagnosis of their child. In that context, they emphasize the need to receive information about respite care services from a maximum of sources, especially through care professionals but also special education schools. It seems that it would be easier for parents to move towards respite care and accept help if they receive professionals' support and adequate information from the beginning of their journey. In their view, respite is seen as a process that takes time: "*If that process of acceptance doesn't happen, it will be harder for parents to call for help* ".

Their ideal would be to call upon a reference person for respite care, who could liaise with the respite care services, coordinate the various parties involved with the child and their families, and support the parents in the practical organization of a respite stay, based on the parent's specific needs. Logistical help with travel, medical and paramedical appointments, and daily organization would also be a real relief. Overall, being able to count on people who can accompany exhausted parents on the obstacle course when searching for appropriate help and equipment would make a difference.

Discussion

Synthesis of the results

In response to the objectives of this research – to better understand the reasons why PCHN, and particularly mothers, (do not) use respite care and to question their needs and expectations of respite care services – these results highlight a real need for respite in parents who regularly exceed their limits and continually border on physical, psychological, and emotional exhaustion. Guilt and mental burden hinder a long and fragile decision-making process, tinged with multiple emotions. Other obstacles were highlighted by the participants, such as the search for a solution, which can quickly become an obstacle course due to the limited number of places and the administrative procedures that complicate the process. Moreover, in such a small country, the offer of respite care is disparate and insufficient, sometimes inaccessible, depending on the place of living, the household income, the dependence of the child, and the specificity of their needs. Many parents facing this reality find themselves socially isolated as sources of support tend to dry up over time, depending on the evolution of the child's illness or disability. To fill the gaps identified by the respondents, they emphasize the need to develop residential respite care, but also respite at home, with the implementation of mobile teams that could intervene even at the last minute, depending on the family's needs. Receiving appropriate emotional support and being informed of respite possibilities as soon as the diagnosis is announced would allow for better support for the parent. It could alleviate the search that everyone is currently doing on their own and the feeling of sometimes taking the place of parents who need it more.

Social inequalities

It is striking that the issue of social inequality came up repeatedly in the participants' discourse. In the literature, it has been shown that in lower-income neighborhoods, parents are less likely to report their child's disability in state and welfare support (Bywaters et al., 2016). If the child's disability is not declared, access to accompaniment or support solutions is even more complex. More globally, it has been shown that parents of children with complex chronic conditions face more social inequalities than parents of healthy children (Dowling & Dolan, 2001). This is particularly striking regarding our result that mothers are often more affected professionally, echoing broader observations of the differentiated impact of motherhood based on gender (e.g., Cukrowska-Torzewska & Matysiak, 2020). Social inequities in PCHN are therefore a source and a consequence that should be addressed in policies targeting families.

On a broader scale, this recurring observation throughout the interviews shows that it is necessary to go beyond the individual level and to think on a societal scale to integrate the experiences and needs of these families into our public policies to broaden the concept and offer of respite. This would mean that parents would no longer have to wait until they have reached a level of exhaustion that puts their health at risk before allowing themselves to benefit from the support to which they are entitled but which they refuse because they feel guilty about "pushing out of the way a parent who needs it more than they do", as one mother put it, comparing it to the experience of refugees in lifeboats.

The need for personalized support and comprehensive care

Another salient finding is that respite care is still often focused on housing the child in a safe environment to allow parents to take time for themselves. Yet, when children are welcomed into a respite home and given care and time tailored to their needs, parents are often left alone, faced with the guilt of having entrusted their child to strangers for a break, with the feeling that they can no longer manage, and left alone with their exhaustion. The results of a previous study carried out in Belgium (Dubois et al., 2020) underlined the need to not only focus on the child's illness or disability and to focus more on the parent's needs when conceiving, developing, and implementing respite care services, rather than exclusively focusing on the child.

What type of support should then be offered to families when it comes to respite? A global approach to family care, while providing more targeted interventions for each of the family members (for the child, for the parents, and the siblings). This calls for recognizing the skills of the parent but also meeting their identity as a man or woman, in their complexity, and not only their identity as PCHN (Peille, 2016). This is consistent with insights into the Family Quality of Life (FQOL). Family quality of life is concerned with the degree to which individuals experience their quality of life within the family context, as well as with how the family has opportunities to pursue its important possibilities and achieve its goals in the community and the society in which it is a part (Brown & Brown, 2014). Respite care gives parents and siblings the space to focus on what is important for their quality of life. Taking care of your health (e.g., by resting), having time for leisure and enjoyable social contacts, and having adequate support by services are 4 dimensions of FQOL on which respite care has a direct positive impact.

Spaces to be heard in their suffering and desires as individuals should allow PCHN to settle while the child is in care. Offering parents group interventions would allow them to feel less alone while facilitating the expression of emotions and drawing on each other's resources. Siblings must also be able to express themselves and be heard in what they are experiencing. They must have a space to express their own needs and desires and equally talk about jealousy or even hostility towards the sibling with a disability. Group sessions supervised by professionals would allow this to happen while respecting each person's pace (Gauthier, 2013).

Increasing the offer of respite is certainly a solution to be considered and implemented without delay, but the presence of two competing temporalities complicates the decision-making process of parents (Chenard, 2015). They are torn between a) the long time they need to accept their own need for respite in a "respite process" and b) the urgency to implement solutions to avoid falling into exhaustion or to be able to face unexpected and immediate needs of daily life. These competing demands should also be considered by healthcare professionals who propose such solutions to PCHN and see that they are reluctant to use them.

Strengths and limits

One of the strengths of this study is that it is based on a qualitative design, which captured the complex experiences, emotions, and challenges of PCHNs in accessing respite care services. Through this method, it was possible to highlight the emotional challenges that PCHNs face, and how their subjective experience may be influenced by the challenges they face during their journey to respite services. Furthermore, by showing that some barriers are individual (e.g., the process of personal acceptance) and others contextual (e.g., accessibility), the present study provides parallel avenues for action to promote respite care accessibility. Among these, the importance of proactive communication and the creation of flying respite teams seem to be particularly promising. Finally, and because mothers PCHNs are often difficult to recruit because they are very busy and because the study took place during the COVID-19 pandemic, data collection was adapted to meet all participant's needs and preferences (e.g., using videoconferencing), apparently without compromising the quality of the results.

In terms of limitations, focusing only on mothers provided interesting insights, but does not allow for a potential gender-based comparison. Although women are more likely to be caregivers and to participate in caregiving studies, this may have limited the potential gender leverage that can be suggested based on these results. Also, the specific geographic focus provided important insights that can be generalized but may be limited to countries with comparable health and social services. Finally, the sampling may have influenced the present results, as all participating mothers were contacted through convenient sampling, and saturation was reached before other recruitment methods were needed.

Implications to practice

The results from this study have several implications for providing and organizing respite care for PCHN. Firstly, they show that the need for respite extends beyond temporary institutional care and includes smaller, everyday moments of personal time. Service providers should therefore adopt a flexible, individualized approach to respite that accounts for these small moments as complementary ways of providing respite. Secondly, emotional challenges associated with the decision to use respite lead to a significant emotional burden that may hinder adequate use. Providers should work towards establishing trust and ensuring clear, transparent communication to acknowledge and help mitigate guilt and fear early in the process. Thirdly, administrative procedures can often pose an overwhelming obstacle to accessing services. As such, efforts should be made to simplify and streamline these processes, minimizing the bureaucratic burden on parents. A dedicated coordinator or liaison ("single person of contact"), who could guide parents through this system, could be an effective solution. Fourth, the mismatch between the demand for respite services and the available supply indicates a need for increased resources and capacity building within the sector. The introduction of mobile "flying teams" who can provide home-based respite care could enhance service flexibility and reach, particularly in regions currently underserved. Furthermore, this would cater to parents who prefer their children to receive care in a familiar

environment. Lastly, parents often reach a point of exhaustion before accessing respite services. Professionals should proactively communicate about available respite services from the beginning of the care journey, ensuring parents are well-informed and feel supported in seeking help.

Conclusion and perspectives

In conclusion, allowing each PCHN to rest and be heard is already offering a moment of respite, a time to recharge their batteries. It allows them to question the meaning of what is experienced, identify the personal and environmental resources, find their pathways to a better Family Quality Of Life, and choose respite solutions as a powerful element in sustainable care for their child.

Going beyond the individual framework to question the needs at the societal level would allow researchers and professionals to consider policies that offer these families the legitimacy to exist with the richness of their differences. Informing and training professionals to recognize the signs of parental fatigue, guiding them towards support solutions, and offering them global support at the same pace as their child would allow them to act before exhaustion. Then these parents could express their needs and professionals could co-construct with them global responses adapted to their demands, in sufficient numbers to avoid the guilt of having stolen the neighbor's place. Policies must prioritize investing in children and their families and ensure that adequate and quality support is provided through a systemic two-generation approach based on the interrelated well-being of children and their parents.

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CRediT authorship contribution statement

Anne-Catherine Dubois: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing – original draft, Writing – review & editing, Project administration. **Noor Seghers:** Conceptualization, Writing – review & editing. **Isa Van Dorsselaer:** Investigation, Data curation. **Yves Dario:** Conceptualization, Writing – review & editing. **Isabelle Swolfs:** Conceptualization, Writing – review & editing. **Pierre Gerain:** Writing – original draft, Writing – review & editing.

Data availability

The data that support the findings of this study are available from the corresponding author (ACD) upon reasonable request.

Declaration of Competing Interest

None.

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Appendix 1. Interview guide

0) Context

Can you give us information about the composition of your family?

What is the health-related difficulty that one of your children has? Which care does it require?

A) Circumstances

At what times or in what circumstances do you rely (or would you like to be able to rely) on respite care?

Are there times in your child's life/illness course when you need respite care more than at other times?

Are there times during the year when you need respite care more than at other times?

B) Planning and crisis

Can you estimate and plan your need for respite in advance?

Are you more often in need of respite in the very short term (a few days or weeks) or slightly longer term (a few months)?

Do you often need crisis care?

C) Searching and finding

Do you find respite care easily if you need longer-term help? If you need short-term help? Do you find respite care quickly when things suddenly become too much?

On average, how long do you have to search before you find respite care?

What elements are decisive for you in your choice of offerings? What do you balk at?

Do you find the offer you are looking for?

Do you sometimes/often have to settle for an offer that is not fully in line with what you need? With what your child needs?

If you did not find (appropriate) organized respite care, did you find alternatives?

D) The search process

How do you search for services for your child? Do you find information about the offer easily? What is the quality of that information?

Do you have an overview of available places easily?

Can you find respite care in your own region or do you have to look outside?

Are there opportunities you would like to see offered in your region that are not there?

Are the facilities you want to use easily accessible?

E) Application and cost

Is it immediately clear how much your own share of the price is?

What is the application process like?

F) Satisfaction

Are you satisfied with the respite care you found? Why yes? Why not?

References

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597.

Braun, V., & Clarke, V. (2020). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, 1–25.

Broady, T., & Aggar, C. (2017). Carer interventions: An overview of service effectiveness. *Journal of the Australasian Rehabilitation Nurses Association*, *20*(2), 5–11. https://search.informit.org/doi/abs/10.3316/INFORMIT.139535079788122.

Brown, R. I., & Brown, I. (2014). In A. C. Michalos (Ed.), *Encyclopedia of quality of life and well-being research*, *20*. (pp. 5–11). Dordrecht: Springer. https://doi.org/10.1007/978-94-007-0753-5_1006.

Bywaters, P., Brady, G., Sparks, T., & Bos, E. (2016). Inequalities in child welfare intervention rates: The intersection of deprivation and identity. *Child & Family Social Work*, *21*, 452–463. https://doi.org/10.1111/cfs.12161.

Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., ... Walker, K. (2020). Purposive sampling: Complex or simple? Research case examples. *Journal of Research in Nursing*, *25*(8), 652–661. https://doi.org/10.1177/1744987120927206.

Chenard, J. (2015). *Trajectoires décisionnelle de parents d'un enfant ayant une condition médicale complexe.* (Doctoral dissertation)Montréal, Canada: Université de Montréal.

Cooke, E., Smith, V., & Brenner, M. (2020). Parents' experiences of accessing respite care for children with Autism Spectrum Disorder (ASD) at the acute and primary care interface: A systematic review. *BMC Pediatrics*, *20*(1), 244. https://doi.org/10.1186/s12887-020-02045-5.

Cukrowska-Torzewska, E., & Matysiak, A. (2020). The motherhood wage penalty: A meta-analysis. *Social Science Research*, *88–89*, Article 102416. https://doi.org/10.1016/j.ssresearch.2020.102416.

Dowling, M., & Dolan, L. (2001). Families with Children with Disabilities—Inequalities and the Social Model. *Disability & Society*, *16*(1), 21–35. https://doi.org/10.1080/713662027.

Dubois, A. C., Cuvelier, S., Murinni, C., & Aujoulat, I. (2018). Avoir recours à du répit: regards sur la prise de décision des parents d'un enfant gravement malade. *Pratiques Psychologiques*, *24*, 257–275.

Dubois, A. C., Schell, M., Boland, M., Gerrienne, H., Javaux, A., & Aujoulat, I. (2020). *L'éducation thérapeutique des proches aidants: une réponse émergente aux besoins de répit des parents d'un enfant malade ou en situation de handicap. Résultats d'une recherche participative en Région wallonne (Belgique). Educ Ther Patient/Ther Patient Educ 202012. (pp. 10203), 10203.*

Eurostat. (2018). *Living conditions in Europe: 2018 edition*. Publications Office of the European Union. https://data.europa.eu/doi/10.2785/39876.

Fraser, L. K., Murtagh, F. E., Aldridge, J., Sheldon, T., Gilbody, S., & Hewitt, C. (2021). Health of mothers of children with a life-limiting condition: A comparative cohort study. *Archives of Disease in Childhood*, *106*(10), 987–993.

Gauthier, M. (2013). Handicap et fratrie. *Les Lettres de la SPF*, *29*, 97–108. https://doi.org/10.3917/lspf.029.0097.

Gérain, P., & Zech, E. (2020). Do informal caregivers experience more burnout? A meta-analytic study. *Psychology, Health & Medicine*, *1–17*. https://doi.org/10.1080/13548506.2020.1803372.

Graaf, G., Baiden, P., Boyd, G., & Keyes, L. (2022). Barriers to respite care for children with special health care needs. *Journal of Developmental & Behavioral Pediatrics*, *43*(3), 117–129. https://doi.org/10.1097/DBP.0000000000000992.

Guion, L. A., Diehl, D. C., & McDonald, D. (2011). *Triangulation: Establishing the validity of qualitative studies: FCS6014/FY394, Rev. 8/2011. Edis, 2011. 8*. 3–3.

Hatzmann, J., Heymans, H. S., Ferrer, I. C., van Praag, B. M., & Grootenhuis, M. A. (2008). Hidden consequences of success in pediatrics: Parental health-related quality of life – Results from the care project. *Pediatrics*, *122*(5), e1030–e1038. https://doi.org/10.1542/peds.2008-0582.

Huus, K., Olsson, L. M., Elgmark Andersson, E., Granlund, M., & Augustine, L. (2017). Perceived needs among parents of children with a mild intellectual disability in Sweden. *Scandinavian Journal of Disability Research*, *19*(4), 307–317. https://doi.org/10.1080/15017419.2016.1167773.

Knighting, K., Pilkington, G., Noyes, J., Roe, B., Maden, M., Bray, L., ... Spencer, S. (2021). Respite care and short breaks for young adults aged 18–40 with complex health-care needs: Mixed-methods systematic review and conceptual framework development. *Health Services and Delivery Research*, *9*(6), 1–268. http://www.ncbi.nlm.nih.gov/books/NBK568069/.

Levitt, H. M., Bamberg, M., Creswell, J. W., Frost, D. M., Josselson, R., & Suárez-Orozco, C. (2018). *Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report*, *73*. (pp. 26–46). American Psychologist, 26–46. https://doi.org/10.1037/amp0000151.

McConkey, R., & Adams, L. (2000 Sep). Matching short break services for children with learning disabilities to family needs and preferences. *Child: Care, Health and Development*, *26*(5), 429–444. https://doi.org/10.1046/j.1365-2214.2000.00163.x (PMID: 10998005).

Mikolajczak, M., & Roskam, I. (2018). A theoretical and clinical framework for parental burnout: The balance between risks and resources (BR2). *Frontiers in Psychology*, *9*. https://doi.org/10.3389/fpsyg.2018.00886.

Mucchielli, A. (2009). *Dictionnaire des méthodes qualitatives en sciences humaines*. Malakoff: Armand Colin.

Paillé, P., & Mucchielli, A. (2003). L'analyse à l'aide des catégories conceptualisantes. *L'analyse qualitative en sciences humaines* (pp. 147–179). Paris: Armand Colin.

Peille, F. (2016). Accompagnement des familles dont un membre présente une situation de handicap. *Empan*, *104*, 89–96. https://doi.org/10.3917/empa.104.0089.

Remedios, C., Willenberg, L., Zordan, R., Murphy, A., Hessel, G., & Philip, J. (2015). A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions. *Palliative Medicine*, *29*(3), 223–230. https://doi.org/10.1177/0269216314560008.

Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS One*, *14*(7), Article e0219888.

Suzuki, S., & Kamibeppu, K. (2022). Impact of respite care on health-related quality of life in children with medical complexity: A parent proxy evaluation. *Journal of Pediatric Nursing*, *67*, e215–e223. https://doi.org/10.1016/j.pedn.2022.07.009.

Tétreault, S., Blais-Michaud, S., Marier Deschênes, P., Beaupré, P., Gascon, H., Boucher, N., & Carrière, M. (2014). How to support families of children with disabilities? An exploratory study of social support services. *Child & Family Social Work*, *19*(3), 272–281.

Whitmore, K. E. (2016). The concept of respite care : The concept of respite care. *Nursing Forum*, *52*(3), 180–187. https://doi.org/10.1111/nuf.12179.

Whitmore, K. E., & Snethen, J. (2018). Respite care services for children with special healthcare needs : Parental perceptions. *Journal for Specialists in Pediatric Nursing*, *23*(3), Article e12217. https://doi.org/10.1111/jspn.12217.

Glossary

PCHN: parents of children with healthcare needs
KBF: King Baudouin Foundation