

# Exploring the Experiences of Dutch Parents Caring for Children with Profound Intellectual and Multiple Disabilities: A Thematic Analysis of Their Blogs

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## Abstract

The current study analyzed blogs written by four Dutch parents of children with profound intellectual and multiple disabilities, with the aim of deepening the understanding of the parents' concerns. Thematic analysis was conducted and five main themes were identified: *Dealing with uncertainties* addressed the impact of unpredictability present in the everyday lives of parents, *Love and loss* described the complexity of concurrently cherishing the child and grieving various types of loss, *Struggling with time, energy and finances* detailed imbalances and struggles related to parents' personal resources, *Feeling included in communities and society* specified social consequences, and *Relating to professional care services* reflected on stress and support associated with professional care delivery. The study findings demonstrate how care professionals should acknowledge parents' vulnerabilities by being aware of their existential distress and empowering parents to exercise control of family thriving.

## Keywords

The Netherlands, blog, parents' experiences, child with profound intellectual and multiple disabilities, UN convention on the rights of persons with disabilities, humanization of healthcare policy

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## Introduction

Child disability can have extensive implications not only for the children affected but also for their closest relatives and especially their parents and siblings. Children with profound intellectual and multiple disabilities (PIMD) form a specific group within a wider group of children with disabilities and have a unique profile (Nakken & Vlaskamp, 2007; Van der Putten et al., 2017). They are affected by profound cognitive disabilities and extensive neuromotor and sensory dysfunctions. Associated with these dysfunctions, individuals with PIMD often suffer complications such as spasticity and scoliosis, epilepsy syndromes and gastrointestinal, respiratory and/or feeding difficulties (Nakken & Vlaskamp, 2007; Nieuwenhuijse et al., 2019). Generally these children have limited possibilities to develop and have to be understood by their intimate caretakers by forms of nonverbal communication and body language (Jansen, 2015; Van der Putten et al., 2017). Their high dependency along with their risk for developing life-threatening medical complications can make

parenting children with PIMD enormously challenging. In modern societies, most parents of children with PIMD and interrelated fragile health commit to caring for their children at home and include the children in everyday family life (Breitkreuz et al., 2014; Luijkx et al., 2017). Caring for children with PIMD in the family environment is in line with the Convention on the Rights of Persons with Disabilities (United Nations, 2006).

Previous research has identified that parents of children with PIMD often struggle with finding and maintaining a careful balance between the many matters affecting them (Breitkreuz et al., 2014; Geuze & Goossensen, 2019;

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Whiting, 2014). Studies have identified impacts on physical and psychological (mental) health and described challenges regarding the loss of free time and social activities, financial difficulties related to reduced income and higher costs, lack of access to professional services and the impacts on care for siblings and the life partner relationship (Muir & Strnadová, 2014; Tadema & Vlaskamp, 2010; Woodgate et al., 2012). Studies have also revealed positive experiences, namely, increased closeness in families and communities, increased spirituality, enhanced arrangement of personal resources and a sense of fulfillment for having done everything that could be done for the benefit of the child (Graungaard, 2007; Hastings et al., 2005; Luijkx, 2016). Research has indicated that the possible implications associated with parenting a child with PIMD are strongly associated with procedures and practices within the health-care and service systems that impact family life and create collateral stress (Geuze & Goossensen, 2019; Peer & Hillman, 2014; Woodgate et al., 2015).

The awareness of parents' high vulnerability raises imperative questions regarding their challenges and the family's quality of life (Boelsma et al., 2018; Luijkx et al., 2017, 2019). The current standards of evidence- and value-based care and participatory health perspectives underline the importance to engage in the parents' lifeworld to achieve care that will match specific needs (Brown et al., 2005; Groot et al., 2020; Misak, 2010). They highlight the relevance of research results that elaborate the parents' experiences from an insider perspective (Todres et al., 2014). Knowledge about the challenges that parents face derived from their own perspectives is crucial for providing appropriate and humane support systems that help parents maintain their wellbeing and quality of life. However, relatively little qualitative research has been conducted into the experiences of this specific group of parents (Geuze & Goossensen, 2019; Luijkx et al., 2019). This study contributed to the existing knowledge on "what it is like" to parent a child with PIMD. The aim of the present study was to contribute to in-depth understanding of the parents' essential concerns and the meaning of parenting a child with PIMD and the associated medical fragility.

The study draws from parents' narratives and focuses on particular parental experiences by examining autobiographical blogs authored by four Dutch parents. Blogging has become an increasingly popular way of sharing narratives with the outer world. These online blogs are often publicly available and represent a potentially rich source of information for learning about what parents may experience (Braun, 2017; Heilferty, 2011). The study was designed to identify the challenges within parents' daily lives. The study's aim led to the following research question: "What are day-to-day happenings and experiences of parents caring for children with PIMD?" Following on from this, the study reflects on consequences for organizing support for these parents.

## Methods

The study was conducted using a qualitative descriptive design (Sandelowski, 2000). Qualitative description is a valuable method to present the "facts" of events in the everyday language and terms of those events. In qualitative descriptive studies researchers stay close to the data and aim to convey the meaning participants give to those facts in a comprehensive and unadorned manner. This way of naturalistic inquiry comprise a good strategy to gain in-depth awareness of the matters that affected the parents (Creswell & Creswell, 2018; Sandelowski, 2000). The method used was thematic analysis as described by Riessman (2008). Understanding themes across narratives encourages thoughtfulness about ethical issues and the evaluation of common practices (Andrews et al., 2013; Riessman, 2008; Widdershoven & Smits, 1996). They consequently provide a basis for reflection on what constitute adequate services and support necessary to help parents.

## Data Collection and Sampling

This study was conducted in The Netherlands, where there are a fair number of parents who share personal experiences about parenting children with profound disabilities in online blogs. Parents write these online blogs to inform their family and friends about recent developments in their family and/ or to express personal reflections about experiences of parenting a child with PIMD. The narratives in these parents' blogs are laden with descriptions of what the parents experience and value in life and sources of important information about existential and emotional troubles in the parents' day-to-day lives (Braun, 2017; Tracy, 2020).

Criteria for eligibility and purposive sampling were used to include blogs in the research. Blogs were found through social media and the search engine Google, using the Dutch equivalents of "parents," "blog," and "disabilities." Links on selected blogs led to identification of additional blogs. Blogs had to be written in the Dutch language and with contributions that had been made for 4 years or more to cover a sufficiently long interval of time and provide a thorough comprehension of the impacts of parenting children with PIMD (Nakken & Vlaskamp, 2007; Van der Putten et al., 2017). Purposive sampling included seeking diversity in the parents' cultural, ideological and socioeconomic background and nationwide coverage (Sandelowski, 2000; Tracy, 2020). From identified blogs that met the criteria for inclusion, we selected two blogs that provided detailed and rich descriptions of everyday life (for the characteristics of the parents and their children, see Box 1; pseudonyms were used for protection of family's privacy). The available material was limited to part of the blog entries to make the data manageable (see Box 1).

**Box 1.** Characteristics of the parents and their children.

The first blog was written by Elisa and Tom, parents of Luke. Luke was affected by PIMD, including an epilepsy syndrome and chronic pulmonary infections. Within hours after birth, health problems occurred, and after a difficult period of uncertainty, it became clear that Luke had a genetic anomaly leading to disabilities. Luke died at the age of four due to complications associated with his condition. During his life span, parents committed themselves to writing a blog about their son's ups and downs. Their blog entries included writings about the experiences associated with parenting Luke and photos. Selected time period: 35 months (2 years, 11 months) starting from January 2014; total number of selected blog entries: 143 (out of  $N=252$ ) containing 37,030 words.

The second blog was written by Carmen and Aron. They care for their son Jules. Jules was struck by meningitis and encephalitis a few days after birth. A few months afterwards, he developed epilepsy. These combinations of factors led to PIMD and respiratory and gastrointestinal dysfunctions. The parents' motivation to write a blog was to raise awareness about the implications of parenting a child with PIMD and frail health. The blog entries included photographs to illustrate stories and experiences. Selected time period: 77 months (6 years, 5 months) starting from January 2011; total number of selected blog entries: 97 (out of  $N=126$ ) containing 38,676 words.

Both couples lived together and parented healthy siblings as well. They combined caring for the child with disabilities with working outside the home and/or were self-employed. The families were in touch with diverse healthcare professionals, such as pediatricians, medical specialists, paramedics and professionals working in their homes and/or at respite services.

**Ethical considerations**

The parents' blogs were publicly available on the internet. For ethical reasons and the management of copyrights, we chose to actively approach the parents who had written the blogs by phone and e-mail to ask for permission to use their life stories as research data. Information outlining the study's aim and context, including data handling for publication intent, was supplied verbally and in writing. The parents were informed that names would be changed throughout the research and that the disclosure of personal details would be limited to ensure the protection of their privacy. The four parents approved the use of quotations and signed a written informed consent form. The study was evaluated by a regional Medical Research Ethics Committee that is, Research Ethics Board, which confirmed that the Medical Research Involving Human Subject Act (in Dutch: WMO) did not apply (June 2019; reference number: WAG/mb/19/020331).

**Data Analysis**

Data analysis was performed in several stages guided by thematic analysis as described by Riessman (2008). This type of analysis examines the content ("what") narratives

communicate and identifies common thematic elements across narratives (for specifications of the study's process, see Tables 1 and 2). The data analysis was administered with the assistance of ATLAS.ti. Data management entailed intervals of reflection and open reconsideration of data analysis. Interpretation of meaning of data and the final main themes were discussed together to enhance understanding and the validity of interpretation (Braun & Clarke, 2006; Sandelowski, 2000). A senior Bachelor of Nursing student took part in the data analysis and was involved in the discussion of established themes. The student (IH) conducted data analysis with the necessary explanation but did so independently from the supervisors to enrich the interpretation of the data (see Table 1: steps 3 through 5). The interpretation of the data analysis was also discussed with the parents to add to insight and credibility (member reflections) (Tracy, 2020). A final version of the research findings was supplemented with a Dutch translation to enable the participating parents to verify the findings and translation of quotes. The parents read the study results and agreed with the interpretation of their lived experiences and final choice of themes. This was confirmed by phone and e-mail.

**Findings**

The blog entries explicated experiences about parenting children with PIMD and medical fragility. The parents wrote about tensions related to health issues associated with their child's PIMD, the consequences for daily life and their viewpoints about social interactions and professional care services. Analysis of the parents' narratives led to identifying the overarching theme of keeping balance. The parents tried to simultaneously focus on optimum wellbeing of the child they loved and cared for while at the same time aiming to preserve the family, social and working life. This meant they had to constantly adapt to dynamic day-to-day happenings and weigh up options regarding the wellbeing of child and family. Five main themes were identified after the analysis of blog entries: *Dealing with uncertainties* addressed the unpredictability present in the everyday lives of parents, *Love and loss* described the complexity of concurrently cherishing the child and grieving over various types of loss, *Struggling with time, energy and finances* detailed the imbalances and struggles related to parents' personal resources, *Feeling included in communities and society* specified social interactional implications, and *Relating to professional care services* reflected on stress and support associated with professional care delivery. Relevance for organizing support was mingled with descriptions of everyday family life and the characteristics of informal and professional care.

**"Pounding Hearts": Dealing with Uncertainties**

Striking in the context of the parents' life was the degree of unpredictability present in everyday life. In blog entries,

**Table 1.** Overview of Data Analysis Following Thematic Analysis (Riessman, 2008).

Phases of data analysis (steps 1–7)	ATLAS.ti key terms
Step 1: Reading and rereading parents' blog entries several times. Purpose: Familiarization with blog entries and tentative understanding of parents' lifeworld and stories as a whole.	—
Step 2: Transferring selected blog entries in chronological order to text documents using Microsoft Word. Result: Simplifying the reading of selected blog entries.	Create New Project
Step 3*: Reviewing and quoting text documents on significant aspects of parents' writing (chosen topics, modes of thought, concerns, emotions, frames of reference). Purpose: Identifying meaning units and creating quotes.	Creating Quotations
Step 4*: Coding identified meaning units followed by discussion in peer dialog. Purpose: Examining content of quoted text fragments.	Open Coding
Step 5*: Comparison of codes and identification of themes in blog entries followed by peer discussion. Purpose: Translating into abstraction by understanding the meaning of experiences and disturbances.	Code Manager
Step 6: Describing thematic elements across blog entries while preserving stories as a whole. Parents' quotations were used to express meaning, and descriptions were discussed. Purpose: Theorizing and describing meaning across the multiple narratives.	—
Step 7: Presenting the interpretation of the data analysis to parents to validate the understanding. Purpose: Strengthening of research findings through member reflections.	—

\*Steps 3 up to 5 were repeated by a senior Bachelor of Nursing student.

there were references to challenges related to uncertainties impacting various domains of life and making life difficult to manage. Some worries that were described related to the unpredictable allocation of care and supplies, uncertainties around future perspectives and sudden deteriorations of the health status of the children prompting the fear of losing their children. For instance, the parents encountered bureaucratic difficulties while applying for devices and adaptations required for caring for their children at home:

Last Thursday, we had an initial meeting with someone from the municipality about home modifications. This is the first step toward the actual modifications, namely, an assurance of what is possible from the side of the municipality and what personal budget we can count on. We also handed over the list of requirements, drawn up by the occupational therapist. Now we have to wait for a response. (Elisa and Tom)

The application processes often involved months of waiting without any indication of an outcome or the final distribution of supplies and arrangements. These long intervals sometimes led to extended and distressing time periods during which families lacked appropriate tools. Carmen and Aron wrote about further uncertainties caused by changing policies on financing their child's care:

With pounding hearts, we follow current political discussions on individual care budgeting. We are terrified as they debate our frail existence. The vulnerable balance we finally reached is just sufficient to survive. Emotionally. Financially.

Parents also described uncertainties associated with the search for medical diagnoses during various stages of their child's lives. Elisa and Tom were finally provided clarity on

their son's main diagnosis causing PIMD after years of testing only to be told that the diagnosis did not afford much information because the disorder was so rare. Carmen and Aron knew that their son's brain damage had been caused by a virus shortly after birth, but they went through long periods of not knowing about their son's future abilities. After a new setback related to the epilepsy that he developed, they wrote:

The doctor said the words we didn't want to hear: 'The electroencephalogram (EEG) does not look good. Jules has West syndrome, a serious epilepsy syndrome as a consequence of his brain damage.' I read some information before about the consequences on his development. An unbearable thought. How much more does he need to endure? How much longer can we keep seeing him in such discomfort?

The parents' life stories revealed concurrent uncertainties related to sudden deteriorations of their child's health status and recurring hospitalizations. Elisa and Tom explained how they were watchful for indications communicating annoyance and illness:

Our sweet little Luke is not feeling well. He never cries (because he is unable to), but yesterday and today, he cried a lot. Luke makes a very miserable sound without tears. He only does that when he is really bothered by something. He has been making that sound for two days now without apparent reason. [. . .] He even does not want to cuddle on our laps, something he normally really enjoys. What is wrong with him? We gave him paracetamol twice today, but it doesn't seem to help. We will give the emergency medication against epilepsy soon. Hopefully, that will help him. (Elisa and Tom)

The blog entries showed that watchfulness was also required during hospital stays. The parents had to await the child's



**Table 2.** Illustration of Data Analysis: Identifying Meaning Units (Coding), Clustering, and Identifying themes.

Written language	Code	Code group	Theme
"Luke had a good week. The new medicine seems to work for him. Fortunately, he does not get drowsy from it (something we were afraid of). Last week he had his vegetables a few times at the respite care facility (only 5 or 6 bites but that's a real achievement for him, so another step forwards.) His pulse is also a lot calmer now."	Awaiting the child's response to treatment.	Tense times.	Dealing with uncertainties.
"This hospital stay was a turning point. Our hope for improvement disappeared. Jules could not drink independently anymore and got a feeding tube. Half a year later we started daily intestinal flushing. The stretching of his arms and legs, spasms, became more intense. During some of the attacks Jules started to scream in panic. Especially at night. We dared to speak about not treating him no matter what, in case something would go wrong. Scary. But it felt right."	Decision making during hospitalization.	Tense times.	Dealing with uncertainties.
"I look at the cards again and realize that someday we will have to attach a fourth card to the fridge. In a week, a month, a year, 10 years, 20?"	Fear of losing the child.	Cherishing the child.	Love and loss.
"Slowly Luke starts babbling again. He probably feels a lot better now. Outside, in the pram, he seems to feel wonderful. He moves his head in all directions and talks quite loud. We love going out with him again."	Enjoying doing "normal activities."	Enjoying common family events.	Love and loss.
"We met several nurses and people in the corridors that we know from the ward where Luke usually stays during admission. Everybody knew we were related to Luke and asked about Luke. That is very nice. They really know you, you are not a number."	Nice to be recognized by professional caregivers.	Professional care delivery.	Relating to professional care services.

response to treatment and concurrently reorganize family life. Due to the many uncertainties, the parents described family life as afflicted and out of balance by the dynamic and changeable nature of daily life.

### *"At Those Moments. . .": Love and Loss*

The narratives revealed that the loving connection parents had with their children was key to committing to caring for the child with PIMD. The parents' stories highlighted the complexity of simultaneously experiencing moments of heartache related to adapting expectations and images about future family life and loving their children unconditionally. Several experiences of loss were conveyed in the parents' writings about the changed standards of normality and family life, including the anticipated loss of their children. For example, the parents were forced to increasingly adapt daily necessities to facilitate parenting a child with PIMD. The parents also described their grief over opportunities they would never have to create the kind of family life they had imagined. Parenting a child with PIMD forced the parents to take a new parental approach that involved alternative commitments compared to parenting only healthy children. Noticeable in the parents' stories was their grief about the

impossibility of getting to know the imagined child. Milestones that were late or missed and new findings about their child's condition triggered episodes of mourning in the parents' realities. The various caring roles the parents provided for their children with PIMD were often experienced at the expense of healthy siblings and vice versa, causing additional worry:

These are annoying moments. When Mike [Luke's brother] has his holidays, we actually want to do fun things with him, but that's simply not possible. We constantly have to consider time, time and time. Consequently, we have to put off fun activities and miss out on things. When Mike is in school, we can sort things out with the home care and give Mike the attention he needs, but when he has his school holiday, we need to consider bringing Luke to the respite care facility more often. (Elisa and Tom)

In multiple narratives, the relationship with the child was interweaved with the probability of losing the child at a young age. Elisa and Tom described a medical check-up that made them confront Luke's delimited life expectancy:

The orthopaedist looked at Luke's radiographs and said his back doesn't look good. His scoliosis has developed. [. . .] With the

crook of his spine, his ribcage will have difficulties expanding, which will prevent his lungs from maturing. In time, this will cause an incapacity of his lungs, and then his heart will need to work too hard, which will cause damage to his heart. However, all of this will only show up in the further future.

Associated with chances of losing their children at a younger age, the parents described compounded and mixed feelings. On the one hand, the parents pushed away the notion of the definite loss of their children, while on the other hand, they expressed ambiguous feelings about their child's hardships. Carmen reflected on this complexity by writing about her love for her child and her heartbrokenness, leading to thoughts about the relief of an ending:

Jules is quiet again. Until I hear him getting new seizures. [. . .] Every day over and over. For years. I know how tight his muscles are and how his face turns into a grimace. [. . .] Sometimes Jules cries again after an attack. With even more despair. At those moments, I think of death.

Dealing with everyday reality compelled the parents to focus on the here and now. It was valuable for the parents to spend time together as a family and to find opportunities to enhance their child's comfort. Examples of such actions included taking long walks outside and soothing the children by cuddling. The parents described these moments as being very important to retaining a love for life and to cherishing their connection with their children.

### ***"Dreaming? We Do Not Do That Anymore": Struggling with Time, Energy, and Finances***

The parents' writings revealed imbalances affecting their personal resources of available time, energy and finances. Struggles were related to the care responsibilities associated with the child's PIMD, lack of sleep and free time due to parenting commitments and the adaptations necessary for caring for children in the family environment. Regarding the impacts of parenting their son, Carmen and Aron wrote:

Caring for Jules continues day and night, 24/7. It is looking after him and nursing him and responding to a diversity of unpredictable factors. We haven't slept through the night for four years now and provide care on a daily basis for a child who is uncomfortable many times, stretches all the time, cries, screams, never laughs, is in pain way too often and is tortured by epileptic spasms many times a day. The impact of his condition is tremendous. The creative, dynamic and enterprising people of previous days have faded for the most part. His future? Our future? Totally unpredictable. Dreaming? We do not do that anymore.

The blog entries disclosed the parents' responsibilities, including providing care to children who are entirely dependent on their caretakers for washing, dressing, eating and

moving around. Their responsibilities included handling medical devices (e.g., tubes, pumps, hoists and medical oxygen delivery systems), administering medicines, tube feeding several times a day and comforting children during epileptic and/or coughing fits. The accounts expressed that care responsibilities continued most of the night, affecting parents' energy levels for years in a row. Parenting also involved complex planning duties, as the families faced frequent encounters with doctors, paramedics and representatives of professional services, which took a large amount of their available time and energy:

Today, various appointments were planned. After consultations with the hospital over several weeks, we managed to bundle the appointments into one afternoon. This is especially nice for Luke because now, he only needs to make the, for him, long ride once. (Elisa and Tom)

The parents' narratives described financial worries associated with the child's PIMD, as parents experienced growing costs while the care their children needed pushed them to reduce their working hours. The parents described struggling with maintaining the balance of caring for the child with PIMD with work and time for healthy siblings. Using forms of professional care services and respite care was described as critical to securing careful balances and for finding the opportunity to step back from daily responsibilities and recharge every now and then.

### ***"These Reactions. . .": Feeling Included in Communities and Society***

The parents' narratives described the implications of their child's disabilities for social interactions. The lived experiences disclosed issues within the public domain, within the communities to which the parents belonged and within their closer relationships with family and friends. The concerns they experienced in public places were linked with people questioning the child's abilities and quality of life and staring at the children because of their uncommon physical appearance:

At another time, I was maneuvering the pushchair through a crowd at a busy schoolyard. A man stepped aside, looked into the stroller and said 'SO!'. You feel it's an offensive reaction to Luke, and that hurts. We can imagine people reacting this way. Luke can look nice and relaxed, but he can also look a bit weird. But then say nothing! (Elisa)

Societal responses often contrasted with parents' own perspectives and warm feelings for the child with PIMD. The parents made references to challenges related to their position in their communities. These challenges included the lack of opportunity to participate in common activities due to care commitments and people's uneasiness with the parents'

context, which prevented equal and open interaction. In the blog entries, the parents described the importance of the nearness of family and friends for experiencing mutual fondness of the child with disabilities and being attuned to ambiguous feelings about important dates, such as birthdays and holidays. The parents also described the importance of practical support, such as taking healthy siblings to activities and visiting the child with PIMD during respite care. It was heartening for the parents to receive help, such as taking over caring for the child with PIMD to give the parents some time off and organizing sponsorship activities for helping the parents with the financial implications of the family situation.

### ***“I Do Not Think They Realize. . .”: Relating to Professional Care Services***

In their writings, the parents referred to interactions with medical staff and other professional caregivers. They described facing difficulties as well as experiencing support from professional care services. Difficulties were associated with the variety of healthcare professionals. The parents were dependent on the care provided by various healthcare organizations and described their frustration with explaining their child's circumstances again and again to new people. The parents also described frustrations with care deliverers failing to read medical records before meeting the child and noted a lack of professional empathy and a sense of equality in the healthcare partnership:

Elisa unexpectedly went to the hospital yesterday. The surgeon and the stoma nurse wanted to see the skin around his feeding tube; it looked and smelled pretty bad. Last Monday, one of the home care nurses emailed a picture, then they wanted to see Luke in the hospital as quickly as possible (I do not think they realize what arrangements we have to make for that). [. . .] The hospital visit was for nothing. The surgeon examined his skin briefly and had to go to the operation room, and the stoma nurse knew nothing at all. (Elisa and Tom)

The blog entries showed that parenting children with PIMD included learning to live with professional caregivers working within the parents' homes. The parents described the need for assistance and their appreciation for the support in finding out how to care for the child and/or to have time for other commitments. Sharing the house, however, regularly demanded much energy, as parents were not always able to freely choose the child's caregivers and had little family privacy. The parents' stories also revealed positive experiences with regard to professional care delivery. For instance, Carmen and Aron related a genuine engagement with a doctor with whom they discussed the dilemmas about treatment options:

We knew this conversation had to come. But still. When you hear the combination of your child's name and 'resuscitation', it

feels very unreal. We were aware Jules' life was in danger on certain days. Somehow. We felt the fear. Death was already invisibly present, like a mean shadow ready to smother the light. [. . .] 'When his situation gets worse, we need to ask ourselves how far we should go with the treatment', we heard the doctor's mouth saying a few days ago. He looked worried and talked carefully. He realized all too well these were painful words that might hit us a little less when cautiously voiced. I felt grateful for that.

The parents' lived experiences underlined the importance of professional diligence for meeting their child's complex needs, including medical decision making associated with limited life expectancy and end-of-life care. Elisa and Tom wrote about the last moments of Luke's life:

They did a lot of things so he would regain consciousness, until Elisa asked if this was of any use and also asked if Luke could sit on her lap. This was immediately done. Our little Luke passed away quietly while laying on her lap, conforming to Elisa's wish.

The parents described how they valued when professional caregivers were aligned with their input and the things they found important. They also described the value of expertise-based insights provided by professional caregivers. Additionally, the parents narrated how they valued the professional caregivers' striving to get to know their child's specifics because the child's wellbeing was at least partially dependent on professional awareness and informed decision making processes.

## **Discussion**

The present study contributed to the understanding of the meaning of parenting a child with PIMD and interrelated fragile health. The interpretation of blogs written by Dutch parents led to identification of the overarching theme of keeping balance. In their day-to-day lives, the parents constantly struggled to find ways to maintain and protect the wellbeing of their children and families. The analysis of blog entries indicated five themes connected to the experienced vulnerabilities: *dealing with uncertainties, love and loss, struggling with time, energy and finances, feeling included in communities and society* and *relating to professional care services*. The examination of the parents' insider perspective showed the complexity of the parents' striving for wellbeing at the personal and family levels. The study results suggested that external support from healthcare needs to acknowledge both practical and existential concerns to allow parents to maintain family life and prevent the total loss of energy (caregiver burnout).

Our findings resemble other studies that examined the experiences of parents caring for children with PIMD. Studies have shown that parents of children with PIMD spend significantly more time on childcare and supervision

and have far less free time than parents raising typically developing children. This was despite a substantial amount of time provided by professional support (Axelsson & Wilder, 2014; Luijckx et al., 2017). Many common family activities such as participation in leisure activities happen less frequently in families with children with PIMD (Axelsson & Wilder, 2014; Woodgate et al., 2012). Our findings indicated that the overpowering effect on available time and energy was due not only to the child's high dependency and fragile health but also to the work the parents had to do to access the necessary resources such as medical devices, suitable transportation, home modifications and respite. This corresponds with other studies that related easy access to resources to the parents' ability to "have a life" and participate in society in a way that suits their personal ambitions (Boelsma et al., 2017; Woodgate et al., 2015). This principle was also revealed in studies that examined the concept of resilience in families with children with disabilities (Breitkreuz et al., 2014; McConnell et al., 2014; Muir & Strnadová, 2014). These studies illuminated that (a) social support from extended family, friends and neighbors and (b) successful access to the resources needed were key in experiencing wellbeing and the ability to maintain daily activities (Breitkreuz et al., 2014; Muir & Strnadová, 2014). The importance of social support and a feeling of being included in communities and society was also reflected in our findings. This relates to studies that illuminated that acceptance and understanding of their situation are conditional factors for the social inclusion of families with children with disabilities and their feelings of belonging to communities and society (Boelsma et al., 2018; Woodgate et al., 2012).

The study findings may be seen in light of concepts of vulnerability and dignity (Leget, 2013; Scully, 2014). Scully (2014) stated that manifestations of vulnerability can be differentiated by inherent (ontological) and situational (contingent) vulnerabilities. The parents' narratives showed that vulnerabilities were intrinsic to the child's permanent disabilities and unpredictable health state. Analysis of the parents' perspectives, however, revealed that the greater part of the parents' challenges emerged from situational vulnerabilities linked with their sociocultural and political context. Research on thriving emphasized that humans cannot begin to do well until basic needs, such as the opportunity to grow and develop, having a sense of meaning and purpose, and the experience of encouragement, support and participation, are fulfilled (Benson & Scales, 2009; Ettinger et al., 2021). Contextualizing the challenges of the parents in this study revealed that implications of the child's PIMD prevent them from thriving and experiencing wellbeing as individuals and as a family. The identified themes accentuated that the parents of children with PIMD thrive in care systems that are more humane (holistic) and based on the recognition of the needs present in a unique family situation. Awareness of the parents' existential distress and flexible use of available ways to support and allocate resources may help parents

manage and thrive. This stance was supported by perceptions of social dignity and belonging that related inner feelings of value and worth to sociocultural and institutional practices (Delmar, 2013; Leget, 2013).

Nurses that are engaged in the support of families with children with PIMD can extend their leadership positions and help these families thrive. Attentiveness to the parents' challenges, followed by a responsibility to respond to the existence of needs, is seen as the first step to support (Tronto, 1993). Genuine attentiveness is also important in itself as it can create relationships in which parents may express their essential concerns and challenges (Baart, 2004; Iles, 2014). Nurses and other healthcare professionals are in the position to create space for such attentiveness and to foster an understanding of the factors underlying the existential disturbances and backgrounds of what parents value in life and care. Recognizing parents' unique perspectives and feelings contributes to mutual understanding and better communication. These findings resonated with studies on advance care planning in pediatrics and parents' satisfaction with family-centered care (Fahner et al., 2020; Seliner et al., 2016; Smith et al., 2015). These studies underlined the parents' need for an attitude of listening and encouragement from healthcare professionals in order to express their feelings and deeper motives and values (Fahner et al., 2020). Enabling them to actively participate in decision making on care and treatment and awareness of their expectations in the decision making processes was considered important by parents (Zaal-Schuller et al., 2016). Giving a voice to parents' individual stories can also help to construct a map for handling experienced loss and mourning related to the consequences of the child's PIMD.

### *Strengths and Limitations of the Study*

The present study applied guidance for thematic analysis to optimize methodological accuracy (Riessman, 2008). Earlier and later sections of parents' writings were kept in mind to foster connection with the full number of published blogs. The participating parents verified the interpretation of their lived experiences. The current study indicated the added value of using blogs written by parents as research data to disclose parents' perspectives (Dahlberg et al., 2008; Heilferty, 2011).

There are limitations to the study's preciseness and the specific way of interacting with the data. The study contained two (Dutch) blogs with the purpose of obtaining in-depth understanding of parents' lived experiences. The stories of different people with unique histories and particular family characteristics offer distinct experiences and important details. Examining only two blogs limits how broadly these findings may be applied (Braun, 2013; Braun, 2017; Riessman, 2008). However, blog entries involved attention to macro contexts, including prevalent sociocultural practices sensitive to, for example, power relations and



inequalities (Riessman, 2008). Therefore, the study clearly has a “sensitizing” function toward understanding the perspective of parents living in developed countries. The general nature of the research findings should be understood not as universal and factual but in a broader and existential context.

Other considerations are related to the parent’s freedom to write about topics important to them. The selected blogs indicated a freedom to speak as they pleased; however, the participating parents may have had to conform their expressions based on social and/or time pressures and linguistic norms. Consequently, there was the risk of a gap between the extent and depth of parents’ life stories (the “what”) and the manner in which their stories were formed into words (the “how”) (Freeman, 2003; Heilferty, 2011). Consequently, the parents’ narratives potentially revealed as well as concealed experiential components. This consideration also points to the importance of validation by the member reflections to ensure that the parents’ intentions were conveyed (Braun, 2017).

## Conclusion and Implications for Practice

This study reflected on the essential concerns of parents caring for children with PIMD. The findings emphasized the complexity of the parents’ pursuit of wellbeing in varied existential facets of human life. Five themes, which revealed tensions important for care professionals to consider, were identified in this study. The findings underlined that the causes of the parents’ distress concerned gaining access to the necessities for managing daily family life, handling with the experiences of loss and mourning and the inclusion and acceptance of the child with PIMD in society. The concerns had a huge impact on the parents’ emotional, psychological, spiritual and social health, that is, their mental wellbeing. An awareness of these existential concerns may inform arguments related to these parents being able to thrive and protect their vulnerable family functioning and experienced dignity. The ongoing debate on how the Convention on the Rights of Persons with Disabilities should be implemented includes a strengthened position and better quality of life for families with children with PIMD. Our findings supplemented moral considerations that should be addressed in addition to practical matters related to access to the facilities and resources needed. These considerations involved increased awareness of explicit and implicit sociocultural norms and values that impact the social inclusion of families with children with PIMD and their feelings of belonging to communities and society. Nurses, physicians, and other healthcare professionals can make a difference by being attentive to family needs and the position of parents in decision making on the comfort of a child with PIMD, including end-of-life decisions and related family needs. The study findings reflected that such an understanding of existential distress largely contributes to

family empowerment and wellbeing. In future research, parents should be asked for their ideas about creative and humane care systems that are based on the recognition of the existential distress present in everyday life. These studies may adopt parents’ insider perspective (lifeworld) as the foundation of empirical understanding. The interconnectedness and interdependence with parents’ cultural backgrounds, religious or spiritual views and the role of technology dependency in daily family life may be further explored (Ripat & Woodgate, 2011). In addition, further research should be conducted to examine gender-related factors that influence parents’ opportunities and decisions (Bostrom & Broberg, 2014). Professionals working in healthcare and/or educational settings could use the study findings for reflection and for initiatives improving family care.

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